

ARC West Public and Community Involvement, Engagement and Participation (PCIEP) Strategy 2019-2024

Introduction

NIHR Applied Research Collaboration (ARC) West is hosted by University Hospitals Bristol and Weston NHS Foundation Trust, and the partnership includes local providers of NHS services and NHS commissioners, universities, local authorities, voluntary sector and patient and user organisations, and the West of England Academic Health Science Network (AHSN).

ARC West's research focuses on four research themes: healthier childhoods, integrated and optimal care, mental health, and public health and prevention. Each theme has a Research Oversight Group (ROG), whose public contributor and stakeholder members have worked with ARC West staff to identify topics and priorities for the health and care systems and communities in the West. Each ROG has at least two public contributor members, alongside a member of the Public and Community Involvement, Engagement and Participation (PCIEP) team, who have been fully involved in identifying and agreeing top line priority topics in 2020. More information about the priorities identified is available [here](#). All nine public contributors working on the ROG's are members of the PCIEP Strategy Group which has developed this document. The Strategy Group is co-chaired by Public Contributor, Anna Ferguson-Montague and the Deputy Director, Sabi Redwood, and includes representatives from the research, communications and PCIEP teams.

The PCIEP team at ARC West is led by an Academic Lead, based at the University of the West of England (UWE), and is supported by a Public Involvement Facilitator, and a Research Fellow (Patient and Public Involvement). The team includes about a hundred public contributors working at strategic, theme and project levels, and additional capacity is provided by ARC West staff, including designated researchers to lead public involvement at a project level.

This strategy builds on the public involvement structures and approaches developed for our previous research organisation CLAHRC West (Collaboration for Leadership in Applied Health Research and Care). The first section describes the purpose of our PCIEP strategy and sets out our key aims and objectives. Section 2 provides some detail of key milestones to meet our objectives. Section 3 describes the resources and capacity available. Section 4 outlines our partners and collaborators, and Section 5 the leadership and lines of reporting. The final section describes how we will monitor, review and report on PCIEP.

Section 1: Purpose, aims and objectives

Purpose of this strategy

Our aspiration is for ARC West to become a truly joint endeavour between the public and local communities, the health and social care system, researchers and health professionals. We believe that working together is both ethically the right thing to do, and will increase the practical benefits of ARC West's health and social care research to individuals and society as a

whole. We will identify and work with key partners to further develop and implement our strategy.

Aims

1. To further develop and embed the public voice in all our projects and increase public involvement in the implementation of research findings. Public and community involvement in projects will be our main focus, with co-production, engagement and participation activities supported where appropriate.
2. To increase the diversity of the public and communities we work with, and to connect with under-served groups. This includes a commitment to challenge oppression and exploitation and to address inequalities brought about by systemic/embedded discrimination and discriminatory behaviour.
3. To develop and extend how we work with the public and communities both in terms of the depth of involvement and offering different ways of becoming involved, to remove barriers and make it as easy as possible for people to contribute.
4. To improve the reach of our communications into local and regional communities.
5. To improve capacity through a learning and development programme for public contributors, researchers, other partners and collaborators.

To underpin our five key aims we will:

- Strengthen and support the public voice in the governance structures of ARC West. This includes our PCIEP Strategy Group that oversees the annual cycle to plan, deliver, review and report our public involvement activities, and public involvement at Board and Research Theme levels. See Section 5: Leadership and lines of reporting.
- Ensure we are delivering high quality and impactful PCIEP and continue to use the UK Standards for Public Involvement to support good practice and for reflection and learning. This includes seeking ongoing feedback from public contributors and capturing examples of impact. See Section 6: Monitoring, review and reporting.

Objectives to deliver our aims

Aim 1: To further develop and embed the public voice in all our projects and increase public involvement in the implementation of research findings.

Objectives:

1. Provision of advice, guidance and support to ARC West staff, public contributors and collaborators.
2. Ongoing recruitment of public contributors with relevant personal experience to work on projects, as members of advisory groups and/or in topic focused involvement groups.
3. A review of recruitment processes to encourage more diverse involvement.
4. Development of the successful public involvement structures developed in CLAHRC West. Our involvement groups have a specific function, and provide input across ARC West as needed. They currently include the:

- Plain English Panel – a group of public contributors who provide quick reviews of documents to ensure they are written in plain English. This group contributes to Aim 4, improving communications activities.
- Health Systems Panel – a group of experienced public contributors with some knowledge of the health and social care system.
- Young People’s Advisory Group – a group of children and young people with experience of offering advice and guidance on research into or about issues relevant to young people.

The Strategy Group will consider whether any additional groups are needed to support ARC West as our research develops over time.

5. We will increase public involvement in the implementation of research findings by working with the ARC West Impact Strategy Group to ensure public contributors are supported to be involved in implementation plans from the outset.

The extent and quality of project involvement will be monitored as described in Section 6, page 11 below.

Aim 2: To increase the diversity of the public and communities we work with, and to connect with under-served groups.

This includes a commitment to challenge oppression and exploitation and to address inequalities brought about by systemic/embedded discrimination and discriminatory behaviour.

Objectives:

1. Develop, implement and review a system to record the number and diversity of public contributors working with ARC West.
2. Identify and build links with people and community groups/organisations who are under-served, especially those that are important for specific research themes and projects. This includes working with existing partners and collaborators to identify relevant people and community groups/voluntary organisations/stakeholders for involvement in each ARC West project at the design stage, and through the project implementation and impact planning process. How these links will be built is described in 3.1-3.3 below.
3. Work with partners to provide guidance and training to researchers and stakeholders to develop approaches to public involvement that are appropriate for their work and are accessible to people from a wide range of social, cultural and economic backgrounds.

Aim 3: To develop and extend how we work with the public and communities both in terms of the depth of involvement and offering different ways of becoming involved, to make it as easy as possible for people to contribute.

Objectives:

1. Continue to offer online methods of involvement, including video calls, to support the involvement of those who find it hard to attend face-to-face meetings. ARC West will develop an approach to consider and address digital exclusion, for example payment for data or broadband access or IT equipment where needed if people are digitally excluded.
2. With People in Health West of England¹ (PHWE), develop accessible and user-friendly digital methods. We aim to use a digital platform to support more people to contribute without attending meetings.
3. Develop and agree an approach to working in partnership with community and voluntary organisations that supports and maintains relationships with under-served groups. This approach will include relationship building and identifying shared interests, payment for the organisation and staff time, and negotiating clear ways to work together.
4. We aspire to the principles of co-production, and will continue to support and develop our co-production approach where we can by:
 - Identifying and supporting ARC West co-production projects.
 - Providing training and resources to increase capacity in this area.
5. The benefits of using creative methods to develop strong relationships between public contributors and staff has been explored in the *How Do You Move* and *Create to Collaborate* projects. We aim to build on and share our learning from these projects on the ARC West and PHWE websites and through our PCIEP networks.
6. Extend our capacity for PCEIP by offering public contributors the opportunity to take on more responsible roles, for example developing and co-ordinating relationships with community organisations and delivering training. These extended roles will include appropriate payment and support.

Aim 4: To improve the reach of our communications into local and regional communities.

Objectives:

1. We will develop and implement a plan to extend the reach and accessibility of our advertising and communications channels for all involvement and training opportunities. Including developing networks via social media, stronger links with Healthwatch in our region and other community groups in partnership with PHWE. We want to build better links with social care and community/voluntary sector organisations. This plan will be developed alongside continuing to advertise opportunities through the PHWE regional involvement network.
2. To improve the dissemination of research findings to non-academic audiences. This will be based on Implementation and Impact Plans for each project. We will also ensure project materials aimed at people whose first language is not English will be available in the relevant language.

¹ People in Health West of England is our regional public involvement network. See Section 4 for more information.

3. To offer review of materials by the Plain English Panel to ensure information about projects and findings are written in plain English.

Aim 5: To improve capacity through a learning and development programme for public contributors, researchers, other partners and collaborators.

Objectives:

1. To provide an annual programme of free learning and development opportunities for members of the public, communities, researchers and other staff in the West of England. The programme will be delivered in partnership with PHWE, and promotion of the programme will be addressed by the communications plan described in the objectives for Aim 4. The programme will be reviewed and updated over time. It currently includes the following workshops:
 - Co-producing health and social care research
 - Digital health and use of data for public contributors
 - Enhancing facilitation skills for meetings with members of the public
 - Evidence behind the headlines
 - Introduction to involvement for researchers
 - Introduction to involvement for public contributors
 - Practical introduction to the evaluation of public involvement.
2. UWE will also support a public involvement journal club and a public involvement seminar series with 2-3 seminars per year.

Section 2: Programme of projects and activities

Milestones for delivering the PCIEP Strategy for ARC West are outlined in this section. However, given the considerable uncertainty related to the pandemic, and the ongoing impacts on public involvement and engagement activities, these commitments will be reviewed and amended regularly by the Strategy Group.

In addition to this Strategy, ARC West is developing a more detailed PCIEP work plans, linked to each Research Oversight Group and research theme. The Research Oversight Groups and PCIEP Strategy Group will ensure ongoing monitoring and review of these plans.

Short term – year 2 from April 2021 to September 2021

- Review and refresh the induction and resource pack and intranet page for staff and public contributors. (Aim 1)
- Review of initial use of Impact and Implementation Plan in 2 projects. (Aim 1)
- Target recruitment processes to improve reach to more diverse groups. (Aim 2)
- Work to identify and reach out to relevant individuals and communities as research themes and projects develop. (Aim 2)
- Develop reference document for researchers and stakeholders to develop and implement approaches to public involvement that are accessible to people from a wide range of social, cultural and economic backgrounds. Step 1: produce guidance with links to existing resources by Sept 2021. (Aim 2)
- Provide guidance to address digital exclusion. (Aim 3)

- Piloting and review of use of the online Discourse platform for 1 ARC West project – Strategy. (Aim 3)
- Recruitment of a Communications and Engagement officer with PHWE. (Section 3 and Aim 4)
- Delivery of 5 learning and development workshops. (Aim 5)
- Completing one evaluation. Potentially running a ‘Cube’ workshop with PCIEP Strategy Group. (Section 6)
- Identify and write up two examples of impact/learning. (Section 6)

Medium term – years 3 and 4 from October 2021 to September 2023

- Review use of Implementation and Impact Plans in 8 projects (4 per year), and feedback learning to staff and public contributors. (Aim 1)
- Develop and implement a system to record the number and diversity of public contributors working with ARC West. (Aim 2)
- Work to identify and reach out to relevant individuals and communities as research themes and projects develop. (Aim 2)
- Pilot use of online platform with at least two projects, and evaluation of the benefits and challenges of the platform. (Aim 3)
- Working with PHWE partners to agree an approach and develop a template/resource for working in partnership with community and voluntary organisations that supports relationships with under-served groups. (Aim 3)
- Working with PHWE to develop and deliver of training for researchers and stakeholders on diversity of approaches to public involvement. (Aim 3)
- Completion of work for *Create to Collaborate* project by November 2021 and production of findings/resources. (Aim 3)
- Identify and offer at least two extended public contributor roles. (Aim 3)
- Development and implementation of a plan to extend the reach and accessibility of advertising and communications channels. (Aim 4)
- Identify projects for dissemination of findings to non-academic audiences and pilot approaches to doing this. (Aim 4)
- Delivery of 10 learning and development workshops. (Aim 5)
- Identify a minimum of three impact/learning examples to publish each year based on national standards. (Section 6)
- Conduct/support two project evaluation processes each year, potentially including reviews of work of the public involvement panels/YPAG. (Section 6)

Long term – year 5 from October 2023 to September 2024

So by the last year of the ARC we will:

- Identify key learning from Implementation and Impact Plans for the involvement of public contributors in the implementation of research findings. (Aim 1)
- Review system recording the number and diversity of public contributors. (Aim 2)
- Review and report on links with people and community groups who are under-served. (Aim 2)

- Review and report on work to develop and extend how we work with public contributors including digital exclusion, benefits and challenges of community collaborations, use of digital methods. (Aim 3)
- Review of number and success of/learning from working on co-production projects. (Aim 3)
- Review outcomes and learning based on extended public contributor roles. (Aim 3)
- Review dissemination of research findings to non-academic audiences. (Aim 4)
- Review and reflection of PCIEP in governance of ARC West. (Section 5)
- Review and reflect on ARC West's approach to evaluation. (Section 6)
- Publish four more examples of impact/learning. (Section 6)
- Begin work on a public involvement plan for ARC West beyond 2024.

Section 3: Resources

In March 2021 staff resources specifically supporting PCIEP activities in ARC West are:

- 5% PCIEP Academic Lead
- 50% Public Involvement Facilitator
- 60% Research Fellow (Patient and Public Involvement)

Public involvement in ARC West is supported by about a hundred public contributors working at strategic, theme and project levels. ARC West researchers provide significant additional capacity and commitment, leading projects with an emphasis on public involvement or co-production and taking on the role of public involvement researcher lead in projects. In addition, the PHWE Administrator provides some additional capacity to the ARC West PCIEP Team.

The ARC West Communications Team also provide support for the PCIEP strategy. Communications capacity will be improved by appointing a Communications and Engagement officer with PHWE. This post will support all PHWE partners to reach out to under-served groups, support improved communications and relationship building with community organisations.

Resources to support the PCIEP Strategy include a budget to pay public contributors for work done at the recommended rate agreed by PHWE, supported by a payment policy and guidance. PHWE will follow guidance from the NIHR's Centre for Engagement and Dissemination on payment. The budget also includes resources to pay community organisations to support ARC West projects as agreed, and to address digital exclusion.

Section 4: Partners and collaborators

ARC West has 26 organisational partners, listed [here](#), and in 2020/21 has worked with public contributors and other stakeholders from the three health and care systems in our footprint to identify and agree research priorities for the four research themes.

Our key partner for public involvement is People in Health West of England (PHWE). PHWE is a network of people and organisations who work together to encourage good quality public

involvement. The network links up members of the public and staff across the West of England region, so that relevant knowledge, skills and resources are developed and shared. PHWE is a collaboration led by the University of the West of England. In early 2021 the PHWE partner organisations are:

- Bristol Health Partners (BHP) www.bristolhealthpartners.org.uk/
- NIHR Applied Research Collaboration West (ARC West) arc-w.nihr.ac.uk/patient-and-public-involvement/
- NIHR Bristol Biomedical Research Centre (BRC) www.bristolbrc.nihr.ac.uk/patients-public/
- NIHR Blood and Transplant Research Unit (BTRU) www.bristol.ac.uk/btru/work/public-patient/
- NIHR Clinical Research Network: West of England (CRN) local.nihr.ac.uk/lcrn/west-of-england/patients-carers-and-the-public/
- NIHR Health Protection Research Unit in Behavioural Science and Evaluation (HPRU) hprubse.nihr.ac.uk/public-involvement/
- University of the West of England (UWE) www.uwe.ac.uk/research and
- West of England Academic Health Science Network (WEAHSN) www.weahsn.net/our-work/involving-our-patients-and-the-public/

4.1 Community collaborations

As well as working with our main organisational partners and stakeholders in each research theme, ARC West continues to develop projects in collaboration with community organisations. Some relationships initiated in CLAHRC West have led to ongoing partnerships which have generated new projects. We will continue to develop ongoing relationships with community and voluntary sector collaborators across the lifetime of ARC West, as described in objective 3.3 above.

In CLAHRC West we developed a number of projects in partnership with community collaborators. These included: *'How Do You Move?'* with Knowle West Media Centre; *'Reducing drug use in female street sex workers'* with One25, Bristol Drugs Project and Bristol ROADS; *'Working with the Bristol Somali community to improve outcomes for children with autism'* with Autism Independence; *'Low versus high dead space syringes: user preferences and attitudes'* with Bristol Drugs Project; and *'Evaluating Hope'* a project to reduce suicide with Second Step. We have continued to work with many of these community organisations on an ongoing basis.

Community collaborators working with ARC West include:

- In work to encourage physical activity we are working with the charity Active Gloucestershire. ARC West is evaluating a programme of activities called 'We Can Move', a whole system approach that brings together public, private, voluntary and community organisations to develop a shared understanding of what causes physical inactivity. Following on from this, we are working with a community building initiative in Gloucester to help increase people's opportunities for physical activity.
- The *'Syrian mental health assessment and migration study'* continues to work with refugees and city councils in the ARC West area. Unseen is a charity that support survivors of modern slavery and human trafficking and our *'Unseen'* project is

evaluating the impact of provision of mobile technology on survivors' mental well-being, health, access to services and social connections, in collaboration with BT.

- 'Bridging Gaps' was initiated by a group of Bristol women with multiple traumas and complex needs to improve access to primary health care for women experiences issues includes addiction, homelessness, mental health, sex work, domestic and sexual violence, and poverty. This project is in partnership with One25.
- In the Healthier Childhoods theme the 'Create to Collaborate' project is working with Off the Record which is a mental health social movement by and for young people aged 11-25 living in Bristol and South Gloucestershire.
- In the Public Health and Prevention Theme:
 - we are working in partnership with Bristol Drugs Project on experiences of people who inject drugs during the pandemic, and with Turning Point, a social enterprise providing drug and alcohol support, on how the pandemic has affected people in rural villages or towns in Somerset and Wiltshire who take opiate substitutes.
 - the 'Create to Collaborate' project is working with Knowle West Media Centre community organisation and a participatory artist to facilitate creative workshops with local communities to discuss what can be done to tackle air pollution.
 - the 'Common Ambition Bristol' project addresses HIV stigma and testing in partnership with African/Caribbean communities. This project is led by Brigstowe, a Bristol-based charity for people living with HIV, in partnership with African Voices Forum, Unity Sexual Health, Bristol City Council and Fast Track Cities Bristol. Researchers from ARC West and the NIHR Health Protection Research Unit in Behavioural Science and Evaluation at the University of Bristol will work in collaboration with community members to evaluate the project.

Additional projects working with community collaborators will be added as our Integrated and Optimal Care and Mental Health research themes develop.

4.2 Regional and national activities and partnerships

The PCIEP team continue to contribute to the national across ARC Public Involvement Community, and has offered colleagues two workshops on the evaluation of involvement and co-production since October 2019. Alongside other ARC's, ARC West is supporting the new national ARC Public Involvement Community chair role. The team play an active role in a local involvement network in Bristol, as well as leading PHWE. The PCIEP team are developing relationships with the new NIHR Centre for Engagement and Dissemination and hope to establish ways to receive and provide regular updates, potentially with annual meetings with the Centre to share information and good practice.

ARC West leads on national ARC communications, hosting the ARC National Communications Manager. This role co-ordinates national cross-ARC communications, working with the 15 regional ARCs to ensure there is effective and linked up communication and promotion of leading applied research. This includes developing content and materials on

key research themes, coordinating national coverage of ARC work and ensuring content adheres to the NIHR's brand guidelines.

ARC West is leading the across-ARC collaboration on digital health and the PCIEP Academic Lead is supervising the cross-cutting theme on public involvement in this initiative. The Academic Lead is a co-applicant on an ESRC funded project led by NWC ARC 'Exploring remote working practices for patient public involvement and engagement (PPIE) in health and social care research – Responding to Covid-19'. ARC West is collaborating on national study led by University College London to understand long COVID. The study will include Bristol's Children of the 90s health study, based at the University of Bristol and NIHR ARC West Director, Professor John Macleod, is a lead collaborator. The PCIEP Academic Lead is supervising the public involvement, and the project is funded by a £9.6 million NIHR-UKRI grant.

Michelle Farr (Research Fellow) is collaborating with Josephine Ocloo (ARC S London Diversity and Inclusion Lead), Peter Beresford (E of E ARC) and Oli Williams on two edited books on Covid and Co-production. <https://policy.bristoluniversitypress.co.uk/covid-19-and-coproduction-in-health-and-social-care> and <https://policy.bristoluniversitypress.co.uk/covid-19-and-coproduction-in-health-and-social-care-1>

Section 5: Leadership and lines of reporting

We aim to strengthen the public voice in the governance of ARC West and work through an annual cycle to plan, deliver, review and report our work as follows.

Involvement in development of research ideas and priorities

1. In Years 1 and 2, 2019-21, ARC West has worked with public contributors to develop research priorities and ideas within each research theme. This included having two or three public contributors with relevant experience, alongside PCIEP team members and other stakeholders, on each theme's Research Oversight Group. This group of public contributors also took part in the Research Advisory Panel which reviewed and ranked potential priorities and ideas across all four themes. This has provided a strong public voice in these activities, despite the challenges of Covid-19. In addition, the *Create to Collaborate* project is developing and running two workshops with under-served groups in the Healthier Childhoods and Public Health and Prevention research themes.
2. Following the prioritisation process, our public contributors will continue to work on the Research Oversight Groups, and with the PCIEP team, to build on and further develop public involvement plans for each research theme. These plans will include consideration of which additional individuals or groups should be involved in the design, development, conduct and implementation of research in the prioritised areas of work. Public involvement activities will be monitored, reviewed, and updated within the Oversight Groups and with support from the PCIEP Strategy Group and staff team where necessary.

Leadership for public involvement

3. Ongoing support for a strong public voice in governance at ARC West includes:
 - Increasing the number of public contributors on the Board to two, alongside the PCIEP Academic Lead
 - The PCIEP Strategy Group oversees the development, monitoring and delivery of this Strategy and associated work plans, in collaboration with the Research Oversight Groups. Our PCIEP Strategy Group is co-chaired by the Deputy Director and a public contributor. Members include our Project and Communications Managers, researchers, public contributors and members of the PCIEP team, with links to each Research Oversight Group. The Group will meet a minimum of three times a year.
 - Ongoing public contributor membership (two or three per theme) alongside PCIEP team members of Research Oversight Groups.
 - Two public contributors from the Strategy Group and members of the PCIEP staff team are also members of the People in Health West of England Operational Group, our regional public involvement network to ensure that PHWE supports the work of ARC West and to support a regional approach to public involvement.

Staff leadership for involvement includes the Deputy Director and the PCIEP Academic Lead. Periodically a member of the PCIEP team attends the ARC West Operations Group to review and report on PCIEP activities. Both PCIEP team members, ARC West staff and researchers, and public contributors work together across strategic, research theme, and project levels to ensure that activities are co-ordinated and reviewed as necessary. The PCIEP team contribute to the ARC West Impact Strategy Group and to the ARC West Communications and Impact Group to ensure that PCIEP is linked up with communications and implementation at a strategic level with the aim to increase the overall impact of our research.

Section 6: Monitoring, review and reporting

We will ensure we are delivering quality PCIEP by:

1. Recording and monitoring our activities in projects.
2. Identifying examples of impact and where learning about public and community involvement could be shared. Case studies, blogs, or films will be produced to communicate information and shared on the ARC West and PHWE websites.
3. Support researchers to evaluate their public involvement practice in identified projects:

This support includes:

- Providing training on the evaluation of public involvement
- Identifying projects for evaluation of activities with the ROG's and Strategy Group, including examples of impact and learning.
- Running reflective activities with a research project team, for example, by using the activity and impact log, or running a face to face or online 'Cube' [workshop](#).
- Seeking questionnaire-based feedback from project teams.

4. We will continue to use the UK Standards for Public Involvement to guide good practice and for reflection and learning about the quality of PCIEP activities.
5. We will review and report our activities in projects in regular meetings between PCIEP Team members and the Project Manager, in the Research Oversight Groups, in the PCIEP Strategy Group, and to NIHR in our Annual Reports.

ARC West PCIEP Strategy Group, March 2021