NIHR | Applied Research Collaboration North Thames

NIHR ARC North Thames: Public and community involvement and engagement strategy

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Contents

Glossary

AHSN: Academic Health Science Network
ARC: Applied Research Collaboration
BRC: Biomedical Research Centre.
NIHR CED: National Institute for Health Research Centre for Engagement and Dissemination
CCG: Clinical Commissioning Group
CLAHRC: Collaborations for Leadership in Applied Health Research and Care
CRN: Clinical Research Network
HEI: Higher Education Institute
ICS: Integrated care system
NCVO: National Council for Voluntary Organisations
NGO: Non-governmental organisation
NIHR: National Institute for Health Research
NIHR Schools: NIHR Schools for: Public Health Research (SPHR); Primary Care Research (SPCR); Social Care Research (SSCR)
PPI: patient and public involvement
PRU's: Policy Research Unit
RAP: Research Advisory Panel
UCLH: University College London Hospital
VDRP: Virtual Document Review Panel

Background

NIHR ARC North Thames develops innovative applied health research that meets the health and care priorities of our communities, and quickly puts findings into practice for those who need it most.

We are a partnership of leading universities, the NHS, councils, patients and the public, communities, charities and industry who share a commitment to improving health and social care services, and people's health.

The six million inhabitants in our ARC region comprise an ethnically diverse population living in inner city, urban and rural communities across London, Bedfordshire, Essex and Hertfordshire. The neighbourhoods we cover range from the sixth most affluent to the third most deprived in England.

We seek to contribute to improved health and social care services that meet the complex needs of our region.

This document outlines the public and community involvement and engagement strategy for NIHR ARC North Thames for the period 2021-2024.

Definitions

We use the following definitions from INVOLVE for 'public', 'involvement', 'engagement' and 'participation'. For 'community', we defined this according to feedback from our PPI strategy development workshops:

Community: a group of people with a shared characteristic, which could be geographical, residential or virtual, identity or needs-based, based on profession or life position for example parent, elderly, or a common interest.

Engagement: where information and knowledge about research is provided and disseminated.

Participation: taking part in a research study, for example being recruited to take part in a clinical trial or another kind of research study, joining in a focus group or completing a questionnaire.

PPI: patient and public involvement.

Public: this includes members of the general public, patients and potential patients, service users, survivors, carers and family members.

Public involvement in research: where members of the public are actively involved in research projects and in research organisations. Research is carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them.

Approach to strategy development and management plan

Our PPI strategy was co-produced with public representatives from our patient panels (Research Advisory Panel - RAP, Virtual Document Review Panel – VDRP), researchers (including ARC director, ARC Academy director, professors, Theme leads, senior research fellows, PhD students) and PPI leads from the ARC North Thames region.

A series of strategy development workshops were held in 2020 and 2021, where mixed groups of the above personnel shaped draft objectives, debated, and discussed methods to deliver these. As well as the workshops, the opportunity to give input via email was also provided. By consulting widely across the ARC, we have developed a strategy that has wide applicability and acceptability, which can have a real impact on delivery of our aims.

Our objectives are guided by the themes which emerged from our consultation sessions. We have drawn upon the UK standards for public involvement as a flexible framework for reporting the consultation session outcomes and framing our objectives. Our PPI activities align with NIHR's strategic review of public involvement in research: Going the Extra Mile.

Our strategy is intended to be flexible and able to accommodate evolving practices in the field of PPI and the dynamic nature of engagement work. Therefore, we shall conduct reviews annually (in line with our reporting timelines) and reflect the changes. A subset of strategy development workshop participants, including public representatives, will be invited to contribute to the annual PPI strategy review.

Our vision for public involvement

We believe in active and meaningful involvement and engagement of communities and the public in our region, and beyond, in our work. By creating and nurturing relationships between the public and our researchers, our research will be of direct relevance and importance to those we represent, and have a real impact on improving the health of our population.

We foster an environment where involving the public in every aspect of our research, from inception to dissemination, is considered standard practice. We embrace and pursue an ethos of inclusion, equality, diversity and respect in our work.

We believe involvement of the public across a diverse range of backgrounds and experiences improves the quality and reach of our research, ensures it is grounded in the realities of residents in our region and increases our accountability to the population we serve. It will help us deliver our aims of improving health services and reducing health inequalities, as well as further empowering our community to question, appraise and seek to be more involved in research undertaken to improve the services they (their families and communities) use.

Learning from, and building on, the experiences and learning gained from CLAHRC North Thames, we will explore creative and innovative means of involving and engaging the public in our research. Comprehensive and inclusive public involvement opportunities will enable the public to be embedded in our organisation. Wide-ranging, relevant and accessible engagement with our communities will increase understanding, and equitable engagement with our research.

Objectives

Objective 1: Involvement and Inclusive Opportunities

We will offer inclusive opportunities for patient, public and community representatives, in our research by:

- Offering a range of involvement opportunities, to ensure our research continues to be supported by people who represent the health and care needs of our area through:
    - Widening existing, successful ARC North Thames PPI structures by expanding membership of our RAP and VDRP, and exploring potential PPI collaborations with research infrastructures in our region including AHSN, BRC, PRUs, NIHR Schools.
- Increasing diversity of our public representatives to mirror our broad population range by:
    - Identifying areas of under representation through mapping techniques.
    - Championing equality, diversity, inclusion and respect in our work through flexible and accessible adaptations of our participation, engagement and involvement processes.
    - Using a range of inclusive methods and technologies to increase public engagement in our research.
- Strategically increasing our community engagement by:
    - Maintaining and further developing partnership networks who have pre-established relationships with specific communities, particularly those who have been under-represented in research participation and PPI opportunities.
    - Proactively addressing areas of under representation within our local communities.
    - Ensuring we build a programme of place-based public engagement work, which is relevant to the different communities and areas in our region.

Objective 2: Support, Learning and Working Well Together

We will support and promote public and community involvement and engagement by:

- Continuing to provide dedicated public involvement and engagement resources, including experienced personnel and realistic budgets.
- Providing and promoting training opportunities for:
    - Public representatives to build knowledge, skills and confidence, without undermining their ‘expert by experience’ status.

    - Researchers to build capability and confidence in involving the public in their research.
- Continuing to flexibly address practical requirements and arrangements for PPI recognition and community collaboration.

Objective 3. Communications
We will ensure accessible, regular and appropriate communication formulated in consultation with public representatives, communities and researchers within our region by:

- Developing clear and inclusive communication plans, which are regularly updated.
- Increasing the facilitation of clear communication pathways between public contributors and researchers to regularly highlight updates, concerns and contributions.
- Widening the range of communication methods and formats that reflect different accessibility and engagement needs of our region.
- Regularly reviewing processes and language we use in line with wider discussions about inclusivity and ensuring this is reflected in our communications.

Objective 4. Impact
We will capture and disseminate results and impacts of public involvement and embed learning for constant improvement by:

- Co-developing and piloting how best to ensure impact is recorded and measured appropriately.
- Developing a repository of PPI impact.
- Ensuring comprehensive feedback cycles between our public contributors and researchers to capture the impact of public involvement on our research, as well as the nature and experience of that involvement.
- Sharing and celebrating examples of PPI best practice and its value to research, internally, regionally and with ARCs nationally.

Objective 5: Governance
We will establish the ARC as an organisation that involves the public as standard procedure by:

- Maintaining a seat on the ARC Management Board for public representatives and developing the role of public representatives in each research Theme.
- Establishing a PPI Advisory Group (facilitated by PPI lead, including PPI representatives, an Academic PPI advisor, and ARC researchers) for annual review of strategy, and to ensure best practice and filtration of best PPI practices across the organisation.
- Monitoring and reviewing PPI plans and processes annually with PPI members via consultation.

Delivery plan

Objective 1: Involvement and Inclusive Opportunities

We will offer inclusive opportunities for public representatives, including community representatives, in our research by:

- Offering a range of involvement opportunities, to ensure our research continues to be supported by people who represent the health and care needs of our area through:
  - Widening existing, successful ARC North Thames PPI structures by expanding membership of our RAP and VDRP and exploring potential PPI collaborations with research infrastructures in our region including AHSN, BRC, PRUs, NIHR Schools.
- Increasing diversity of our public representatives to mirror our broad population range by:
  - Identifying areas of under representation through mapping techniques.
  - Championing equality, diversity, inclusion and respect in our work through flexible and accessible adaptations of our participation, engagement and involvement processes.
  - Using a range of inclusive methods and technologies to increase public engagement in our research.
- Strategically increasing our community engagement by:
  - Maintaining and further developing partnership networks who have pre-established relationships with specific communities, particularly those who have been under-represented in research participation and PPI opportunities.
  - Proactively addressing areas of under representation within our local communities.
  - Ensuring we build a programme of place-based public engagement work, which is relevant to the different communities and areas in our region.

Action	**Timeframe** **short/medium/long term**	**Measures of success**
1.1 Provide inclusive, impactful opportunities for the public to be involved in our work Continue to offer: a formal seat on the ARC Management Board; membership of our two influential patient panels; representation in each Theme; membership of individual study steering groups; active involvement in co-design and co-delivery of research studies; active involvement in co-design and co-delivery of ARC Academy training courses; communication and dissemination of ARC research which could include co-authoring publications, presenting research at conferences. Provide flexible and varied routes to involvement, which could include enable meetings to be attended in-person, by video platform, by telephone or other accessibility adaptations to enable wide participation. Create opportunities to engage the public to share their ideas to identify priority areas and shape future research. Explore new opportunities to involve the public in research. These may arise through collaboration with other research infrastructures in our region where we have existing relationships (AHSN, BRC, CRN, PRUs, NIHR Schools); collaboration with other ARCs nationally (building on previous PPI collaborations with Peninsular, East Midlands, North West London and South London ARCs, and our strategic tri-ARC partnership with Peninsular and Yorkshire and Humber ARCs).	Short	Documented examples of public involvement in all levels of the ARC
1.2a Expand membership of our public representative panels to increase capacity and diversity **Existing panels: Research Advisory Panel (RAP)**: Researchers present to the RAP new ideas for research, grant proposals, progress with existing studies, specific issues in studies that need public input, plans for dissemination.	Medium	Expanded membership of panels, reflecting diversity of our region and

Virtual Document Review Panel (VDRP): Researchers send public facing documents and grant proposals to the VDRP for review and written feedback. Expand membership of our panels to increase capacity, diversity and representation of specific groups identified in strategy development workshops to include younger people, people from under-represented minority ethnic groups, social care experience, specific conditions, particular regions and backgrounds. Map current membership and use targeted communications to attract people from under-represented groups or areas identified. Connect with existing networks and organisations who represent particular groups or areas not already engaged. Advertise opportunities through NIHR People in Research, CHAIN network, Healthwatch, CCG patient groups, specific condition/interest groups, professional membership organisations, charities and NGOs, utilising images that reflect the demographic of the North Thames area. Develop a database of specialist public members who can provide in-depth insight into a study. Develop thumbnail profiles of existing RAP and VDRP members to show diversity of backgrounds and experiences to aid recruitment. Provide support for new panel members, which could include an induction package and guidance notes, Code of Conduct and outline of responsibilities. Work/engage with National Voices to promote PPI activities and recruitment opportunities more broadly.		to include representatives of community groups.
Participate in public engagement events in the region engage more widely through open days at partner organisations, science fairs, volunteering forums.	Medium	Creation of yearly event plan Attendance and monitoring of most suitable events
1.2b Increase engagement with community groups and representatives		
Build a programme of place-based community engagement work, which is relevant to the different communities and areas in our region by expanding membership of our panels to involve community groups and representatives. These may include but are not limited to, residential or local community groups, groups with a shared interest, identity or need, faith groups, youth/student groups, carers support groups and professional groups. Build on links with community groups already involved in our work for instance Care City, McPin Foundation, LGBTQ+ community. Explore use of corporate incentive/giving back schemes (this may also help us engage with commuters). Use trusted local advocates to reach groups less likely to engage with institutional structures. These may include minority communities, lower income groups, mental health service users. Recruit, train and engage with community ambassadors who can act as a liaison with under-represented communities. Target community leads at strategic level, link to people who bring together smaller voluntary and community organisations. This could include organisations such as Citizens UK, NCVO or existing charity PPI/public groups, Mind, Diabetes UK, Alzheimer's Society's service user review panels. Work with local authority partners and ICSs who have developed residents' campaigns or facilitated neighbourhood groups.	Medium	Network of links to relevant community group established

Engage with existing PPI resources in ARC HEIs, including UCL's Creating Connections networking events which brings together UCL staff and students with London's wider community and voluntary sectors, QMUL's Centre for Public Engagement, UCL's Co-Production Collective, LSHTM's Public Engagement resources, City's Community Engagement Committee. Use existing resources to inform approach for example NIHR resource for community engagement and the Centre for BME Health's 'Increasing participation of Black Asian and Minority Ethnic (BAME) groups in health and social care' research toolkit.		
1.3 Identify and plan how to address potential barriers to involvement These could include physical, mental, cultural, sensory, logistical, digital barriers for specific groups or areas in our region. Consult relevant expertise where needed and available to develop methods to address these. Offer range of involvement opportunities that vary in, length of time required to participate; amount of preparatory work required; time of day/day of the week; mode of engagement for example via digital platforms, in-person meetings, post/telephone; location (if in-person); methods used could include innovative means such as photovoice technology or graphic illustrators to capture input. Ensure accessible languages and communication methods used to take account of minority languages, British Sign Language, visual impairments, learning disability and wider accessibility issues, (current PPI Lead has experience in engaging people with sight loss, deafness, mental health difficulties and learning disabilities within research). Schedule involvement opportunities in advance to ensure we can accommodate needs of participants and make appropriate arrangements for example a signer. Be particularly aware of digital exclusion that may have become exacerbated by pandemic lockdown and ensure other channels for involvement and engagement are available. However, for some groups, those who find traveling difficult, or who have accessibility issues or caring responsibilities, we found the use of digital platforms during the Covid-19 pandemic enhanced their ability to take part in involvement opportunities. Co-develop shared understanding of roles, responsibilities and expectations of PPI through consultation.	Short	Potential barriers to involvement identified. Identify appropriate methods that take into account identified barriers, so they are no longer an obstacle.

Objective 2: Support, Learning and Working Well Together

We will support and promote public and community involvement and engagement by:

- Continuing to provide dedicated public involvement and engagement resources, including experienced personnel and realistic budgets.
- Providing and promoting training opportunities for:
  - Public representatives to build knowledge, skills and confidence, without undermining their ‘expert by experience’ status.
  - Researchers to build capability and confidence in involving the public in their research.
- Continuing to flexibly address practical requirements and arrangements for PPI recognition and community collaboration.

Action	**Timeframe** **short/medium/long term**	**Measures of success**
2.1 Support Learning:		
Provide PPI guidance documents for researchers including what to consider when utilising PPI in studies, flow chart of how and when researchers could include PPI, and useful resources such as toolkits and jargon busters, for researchers to use during the entire research life cycle.	Short	Creation of PPI guidance diagram and useful resources document
Offer PPI ‘clinics’ for researchers to meet with PPI Lead and a PPI representative to discuss their project and how to address any engagement challenges.		
Co-design and co-deliver training courses for public representatives to build capability and confidence to facilitate full involvement and engagement in research, keeping their unique perspective and experience in mind.	Medium	Increased and diverse course availability for researchers and public representatives
With the ARC North Thames Academy, co-design and co-deliver training courses for researchers (including PhD students, Early Career Researchers and experienced researchers) to increase awareness, knowledge and confidence in involving the public in their research.		
Continue our RAP panel buddying scheme, where long-standing public representatives provide peer support to incoming public representative member.		
Signpost to existing training resources from other PPI providers in region for example UCLPartners, UCLH BRC, NIHR CED, through PPI page on ARC North Thames website and regular communication. These may include training courses, online resources and reading materials.		
2.2 Support recognition and collaboration:		
Review and update existing reimbursement policy to ensure fair, transparent reimbursement for PPI, based on best practice guidance (NIHR/CED) which will be reviewed annually.	Short	Creation and use of reimbursement policy
Offer range of reimbursement methods, which could include cash, vouchers, charity donation, training.		

Objective 3. Communications

We will ensure accessible, regular and appropriate communication formulated in consultation with public representatives, communities and researchers within our region by:

- Developing clear and inclusive communication plans, which are regularly updated.
- Increasing the facilitation of clear communication pathways between public contributors and researchers to regularly highlight updates, concerns and contributions.
- Widening the range of communication methods and formats that reflect different accessibility and engagement needs of our region.
- Regularly reviewing processes and language we use in line with wider discussions about inclusivity and ensuring this is reflected in our communications.

Action	**Timeframe** **short/medium/long term**	**Measures of success**
3.1 External, accessible communications		
Develop communication plan with ARC communications lead to best reflect our region, considering but not limited to British Sign Language, visual impairments, learning disability. To be reviewed annually.	Medium	Creation of communication plan
Create a dedicated PPI page on the ARC North Thames website that adheres to the NIHR Accessibility Statement. This will include information in accessible language about PPI for public representatives and researchers, opportunities to engage with our research, news highlights, diverse impact stories and learning tools. We will include an accessibility statement, and opportunity for the public to provide feedback so we are continually improving and widening accessibility.	Short	Creation of accessible PPI webpage.
Embrace digital technology to widen access and engagement to involve public and community such as social media, online video/audio meeting software, photovoice technology, as well as more traditional methods like regional press and radio.	Medium	Offering a wider range of accessible communication methods with before and after snapshot.
Develop a range of communication and engagement resources that speak to different needs and audiences. For example, using animation, video, and audio formats to engage people with different accessibility needs - this could include people with learning disabilities, people for whom English is not their first language and those who may struggle with written content.		
Use existing networks such as the RAP, VDRP, ARC academy alumni network and early career network to disseminate involvement opportunities, PPI experiences, and findings of our research.	Short-medium	PPI opportunities linked within other organisations, for example through social media shares and announcements, url links placed on partner websites, and republished blog pieces.
Conduct additional and ongoing PPI needs assessments in terms of communication and wider accessibility support needs.		
3.2 Internal communications See objective 4.3		

Objective 4. Impact

We will capture and disseminate results and impacts of public involvement and embed learning for constant improvement by:

- Co-developing and piloting how best to ensure impact is recorded and measured appropriately.
- Developing a repository of PPI impact.
- Ensuring comprehensive feedback cycles between our public contributors and researchers to capture the impact of public involvement on our research, as well as the nature and experience of that involvement.
- Sharing and celebrating examples of PPI best practice and its value to research, internally, regionally and with ARCs nationally.

Action	**Timeframe** **short/medium/long term**	**Measures of success**
4.1 Capturing impact Investigate how best to record the impact of PPI, in collaboration with public representatives and the PPI Steering Committee. Pilot co-developed methods. Activities that could inform this include: - Development of pre- and post-questionnaires for researchers to capture impact of involvement on research. - Recording experiences of public representatives involved in research projects and their input. - Capturing PPI input into activities such as governance, themes meetings, research studies and training courses, and public engagement activities.	Short	Co-development and piloting of process for capturing impact.
4.2 Sharing impact Develop case studies of best practice showing the impact of PPI at all stages of research (from development of the research question through to the dissemination processes). Celebrate best practice in various formats such as written case studies, videos (please see below), 'you said we did' posters to include input given and the impact it had, ARC North Thames newsletter. Share with ARCs nationally via ARC PPI leads group (PIC), and with regional PPI colleagues. Host celebratory events for individual projects that maximise input of PPI including the public representatives and external partners. Conduct short video 'interviews' (with captioning) as well as FAQs from research teams and PPI representatives, for dissemination via our website and for use in our co-produced bespoke training for health and care staff (in partnership with ARC North Thames Academy).	Long	Creation and dissemination of case studies
4.3 Internal communications Refine existing feedback processes to enhance communication between public contributors and researchers. Support feedback cycles between public panels and researchers to report impacts of public input, how it shaped/changed research projects or research documentation, and how input was applied in practice. Where not possible to act on suggestions from public, explain why for instance through a lessons log. Offer an assessment from the PPI perspective of their experience of being involved. For example: CHIME (Connectedness, Hope, Identity, Meaning and Empowerment) and The Lundy model have been used within other organisations as evaluative tools for impact and engagement. Develop training as a result of learning from feedback cycles to embed new ways of working where needed.	Short Long	Create a PPI feedback document for researchers to complete indicating how PPI has impacted their research. Develop PPI perspective assessments of impact drawn from evidence based, person-centred evaluative tools.

Objective 5: Governance

We will establish the ARC as an organisation that involves the public as standard procedure by:

- Maintaining a seat on the ARC Management Board for public representatives and developing the role of public representatives in each research Theme.
- Establishing a PPI Steering Group (facilitated by PPI lead, including PPI representatives, an Academic PPI advisor, and ARC researchers) for annual review of strategy, and to ensure best practice and filtration of best PPI practices across the organisation.
- Monitoring and reviewing PPI plans and processes annually with PPI members via consultation.

Action	**Timeframe** **short/medium/long term**	**Measures of success**
5.1 Maintain public representation in governance structures Maintain formal PPI seat on ARC Management Board, and inclusion of PPI as standard agenda item. Maintain public representation on ARC Themes.	Short	Public representatives regularly attend meetings and provide public voice for Board and Themes.
5.2 Establish PPI Steering committee and process of annual cycle of review of strategy Agree plans for improvements or changes, and for delivery of PPI for forthcoming period. Ensure GDPR embedded in plans. Create forum for wider group of PPI representatives to input to strategy delivery plans.	Short	Steering committee in place, regular reviews underway, changes incorporated into strategy.

PPI Infrastructure

Our operational PPI resources comprise a dedicated ARC PPI lead (0.5fte) and co-funded PPI coordinator (0.5fte, to be appointed), with additional support from the ARC Senior Communications Officer, Programme Manager, Project Manager and Administrator.

The PPI lead is a member of the ARC Management Board, the main decision-making and accountable body for our ARC, and PPI is a standing item on the Board meeting agenda. There is also a seat on our Management Board for public representatives, and currently four public representatives rotate attendance at Board meetings. This ensures PPI activity, progress and problems are reported to our highest governance structure both directly via public representatives themselves, and also through the PPI lead.

The ARC PPI lead will facilitate a PPI steering committee (objective 5.2), comprising an academic PPI advisor (currently a deputy Theme lead), PPI representatives from our panels, ARC researchers and ARC Programme Manager/Project Manager, who will regularly review the strategy and oversee its delivery.

Our existing public involvement panels, which we will build on, consist of: our Research Advisory Panel (RAP), who give advice and guidance to researchers on new ideas for research, grant proposals, progress with existing studies, specific issues in studies that need public input and plans for dissemination; and our Virtual Document Review Panel (VDRP) who provide a correspondence service to review and provide written feedback and input to public facing documents and grant proposals.

Acknowledgements and authorship

PPI strategy development workshop participants

We would like express our thanks and acknowledgment for all 37 participants (initials included) who attend four workshops to co-produce our PPI strategy, they span a range of backgrounds including: public representatives from our patient panels (RAP and VDRP; SB, KW, NR, SB, JM, KB, RM, FT, SS, VR and SS); researchers from all levels, including ARC director, ARC Academy director, professors, Theme leads, senior research fellows and PhD students; and PPI leads from across ARC North Thames (DM, KA, RR, AH, TO, RT, DS, NP, SE, PF, PC, IS, EP, EW, KN, AH, TJ, TM, FS, AH, DL, OM, JB, TW, SM and PL).

Authorship

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