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Patient and Public Involvement Engagement and Participation (PPIEP) Strategy 2024-2026 NIHR Applied Research Collaboration Wessex

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Supported by ARC Public Involvement Forum (APIF) Wessex

Document Overview:

The purpose of this strategy

Patients and the public are at the heart of our vision to improve the health and well-being of people across Wessex. Wessex includes Dorset, Hampshire, the Isle of Wight and South Wiltshire. We need and value the voices of the communities our research serves.

The knowledge, experiences and support of patients and the public are essential to ensure that our research goals and solutions are relevant, prevent waste, and bring the greatest possible benefits to society.

This document outlines our strategy for Patient and Public Involvement Engagement and Participation (termed PPIEP) in the work of ARC Wessex.

Definitions

We recognise there are different definitions to describe involvement and engagement activities within health and social care. For the purposes of this document we will adopt the following definitions:

Patient and public involvement: research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. (NIHR INVOLVE 2017).
Engagement: where information and knowledge about research is provided and shared.
Participation: where people give formal consent and take part in a trial or study.

PPIEP: an abbreviation/acronym. Used to describe patient and public involvement engagement or participation in work and projects, or activities, trials or studies.
Public: in this strategy we use the term 'public' to describe people affected by our research who do not have a professional role in health and social care services. This may include patients, service users, survivors, carers, family members or members of the general population.

We also use the acronym **APIF**, which stands for ARC Public Involvement Forum. This is our strategic PPIEP group. It is composed of Theme Public Advisors, the PPIEP team and staff links for each research theme.

As you read this document, you may come across other terms, abbreviations and acronyms that are unfamiliar to you. We have provided brief descriptions in a glossary of terms at the end of the document.

Context and opportunities

ARC Wessex launched in October 2019. As part of our application to become an ARC, we developed an outline PPIEP strategy. CLAHRC Wessex (preceded ARC Wessex) shared our commitment to PPIEP, and the work done by the CLAHRC laid good foundations for ARC Wessex to build on and progress. We are proud of the work we have done to embed PPIEP throughout all our research activities.

This strategy, developed in wide consultation with our partners, public and stakeholders, builds on the outline PPIEP strategy from our application. It covers the extension period for ARC from October 2024 – March 2026.

Our locality, Wessex, has strengths in involvement, engagement and participation. ARC Wessex plays a leading role in connecting and collaborating in the region. We do this by sharing our knowledge, supporting and developing each other. We also work together on projects that would not be possible if we did not share the workload between us. These include developing PPIEP training and trialing approaches to improve diversity and inclusion in PPIEP.

Our partners in NHS providers (any organisation that provides NHS services), local authorities, charities and higher education institutions (e.g. Universities) have their own expertise and strengths. We are willing and committed to working together on areas of shared priority.

Our Vision

We aim to deliver high quality public involvement and engagement for health and social care. Our activities will meet the values and principles of good public involvement as outlined in the UK Standards for Public Involvement.

Our activities will occur across, and add value to, each aspect of ARC Wessex:

- At project-specific level (e.g. an ARC-funded or ARC-supported research project).
- Across each of our four research themes (Ageing & Dementia; Long Term Conditions; Healthy Communities and Workforce and Health Systems and the wider ARC programme.
- With our partners and collaborating organisations.

Our overarching aims

Aligned to the UK Standards for Public Involvement, our aims are to:

1. Listen to voices relevant to our research priorities that reflect the diversity of our local population – ensuring the underserved have a voice (UK Standard **Inclusive Opportunities**).
2. Build a culture that respects different perspectives, values contributions and supports mutually respectful and productive relationships (UK Standard **Working Together**).
3. Work with health research communities, aligned to our research themes and local needs and the public including those socially and/or geographically isolated in Wessex to deliver adequate PPIEP training, support and learning opportunities at the right time for their project/programme and/or their own development needs (UK Standard **Support and Learning**).
4. Involve the public at strategic and operational levels, ensuring best practice and supporting research transparency (UK Standard **Governance**).
5. Use innovative approaches and good communication to expand the reach of our activities, maximising impact by stimulating knowledge-of, and interest-in, our research (UK Standard **Communications**).
6. Capture, monitor and share learnings to feedback to those involved, avoid duplication, contribute to the evidence base and build our academic and applied health research capacity and capability. PPIEP (UK Standard **Impact**).

We will build on our local strengths and focus on areas where we believe we can have the greatest impact.

Programme of activities

We have developed objectives and activities to support us to meet our aims. In many circumstances, activities will support us to meet more than one aim. For each activity, we have identified our success criteria and how we will measure and monitor success.

Resources

Our PPIEP team, in partnership with our research community (including public and researchers), will deliver the programme. This includes a Lead for PPIEP to oversee delivery. A Community Engagement Manager and Community Engagement Officer. A Communications & Partnerships Manager, Administrative Officer and two PPI Officers support them.

A dedicated PPIEP budget will support:
- expense and time reimbursement for public contributing to our work;
- training costs required to support public in their role;
- consumable and facilities costs relating to PPIEP events, including training events;
- development and testing of new initiatives.

This is in addition to PPIEP budgets set out within each research project, and academic career development awards.

Partners and collaborators

We will work closely with involvement, engagement and communications teams in our partner charities, health and care providers and higher education institutions. This will enable us to maximise opportunities, minimise duplication and create economies-of-scale.

Our public engagement activities will benefit from University of Southampton's experienced Public Engagement in Research Unit, Public Policy Unit (connects with policy advisors and central government) and LifeLab (working with young people to engage them with research).

Consolidated funding for our Lead for PPIEP facilitates strong cross-organisational working. This Lead person manages a PPIEP team working across University Hospital Southampton and other NIHR infrastructure (Southampton BRC and CRF).

Reporting and monitoring

An annual plan is written each year that covers progress against last year's objectives and the wider strategy; objectives, plans and milestones (with timescales) for the next year; plans for engaging our stakeholders; plans for dissemination and monitoring impact; cross ARC collaborations; plans for research and capacity building; leadership and management; finances progress to date and plans for the next year. The plan is developed by the Lead, with input from APIF, and approved by the ARC Director.

Progress against our milestones are reported to:

- APIF at our meetings (every two months).
- The Executive Leadership Group (every two months). Rolling theme updates (including PPIEP) are a standing item. The Lead for PPIEP provides a formal update annually and given additional time on the agenda to discuss items as required.
- The ARC Deputy Director at meetings with the PPIEP team (twice a year).
- The ARC Partnership Board (twice a year) as part of the progress reports submitted to board members.
- Clinical Commissioning Facility (CCF) via the formal annual reporting structures (once a year).

Glossary of Terms

Accessibility	Accessibility is about making sure that things can be accessed and used by as many people as possible. This includes people with impaired vision, motor difficulties, cognitive impairments, learning disabilities and deafness or impaired hearing.
APIF or Applied Research Collaboration Public Involvement Forum	APIF is our strategic PPIEP group. Its membership includes our Theme Public Advisors , staff links and PPIEP staff.
ARC-funded or ARC-supported studies	ARC-funded studies receive financial funding directly from ARC Wessex. Other studies are 'ARC-supported' – these studies do not receive any direct financial support from ARC but do receive other support, such as ARC staff providing support to the study.
ARC or Applied Research Collaboration	ARCs support applied health and care research that responds to, and meets, the needs of local populations and local health and care systems. They are funded by the NIHR. There are 15 funded across England.
ARC Partnership Board	This is a decision-making body for ARC Wessex. It meets quarterly to set priorities and directly contribute to, support delivery and monitor performance of our programme. The board membership has two public representatives.
BRC or Biomedical Research Centre	BRCs bring together academics and clinicians to translate lab-based scientific breakthroughs into potential new treatments, diagnostics and medical technologies. There are 20 NIHR funded BRCs in England. The ARC Lead for PPIPE also leads PPIEP for the Southampton BRC. Our researchers also work closely with staff in the BRC.
CCF or Clinical Commissioning Facility	They manage and administer the ARC funding scheme. We report to them annually and will have to report our progress against this strategy.
CLAHRC or Collaborations for Leadership in Applied Health Research and Care	This is the term for the organisations which preceded the ARCs. They were also funded by the NIHR and had a similar function. This funding scheme closed in Sept 2019 when the ARC scheme succeeded them.
Communications and Partnership Manager	This role has responsibility for shaping and delivering our communications, and supporting productive relationships across our partners. At the time of publishing, Jamie Stevenson fills this post.
CRF or Clinical Research Facility	CRFs are purpose built facilities in NHS hospitals where researchers can deliver early-phase and complex studies. There are 22 NIHR funded CRFs in England. The ARC Lead for PPIPE also leads PPIEP for the Southampton CRF.
Engagement	Where information and knowledge is provided and shared with the public.

Equality impact assessments	The equality impact assessment is a systematic and evidence-based tool, which enables us to consider the likely impact of work on different groups of people. They help ensure that activities do not discriminate against anyone and that, where possible, we promote equality of opportunity.

Executive Leadership Group	This group operationalises strategy, policy and the research programme. The group is led by the ARC Director; the Lead for PPIEP and Communications and the Partnership Manager are members.
Higher Education Institutes	This term describes any institution that provides education post-secondary education level, for example Universities.
INCLUDE guidance	This guidance provides a suggested framework of questions to guide the deliberations of funders, researchers and delivery teams as they design and assess clinical research proposals to improve inclusion of under-served groups in clinical research. Read more.
INVOLVE	INVOLVE was a national coordinating centre for public involvement in health and care. It was funded by the National Institute for Health Research between 1996-2020. A new Centre for Engagement and Dissemination aims to build on the work of INVOLVE.
Lead for PPI/E	This role has responsibility for shaping and delivering our PPIEP strategy. They also lead PPIEP for other NIHR organisations. At the time of publishing, Caroline Barker fills this post.
Lifelab	A unique, state-of-the-art teaching laboratory dedicated to improving adolescent health by giving school students opportunities to learn first-hand the science behind the health messages.
Logic modelling and theory of change	A theory of change is a description of why a particular way of working will be effective, showing how change happens in the short, medium and long term to achieve its intended impact. Logic models are a way to graphically represent this theory. Our Lead for PPI/E supervises a PhD student who has developed a PPIEP planning and impact tool, underpinned by the theory of change and a logic model. We aim to use this to capture impacts of the ARC PPIEP programme.
Microsoft Accessibility Checker	A free tool available in Office 365. It finds most accessibility issues and explains why each might be a potential problem for someone with a disability. It also offers suggestions on how to resolve each issue. Read more.
NHS providers	This term describes any organisation that provides NHS services. This includes hospitals, community trusts, GP services, pharmacies and clinical commissioning groups.
NIHR or National Institute for Health Research	The National Institute for Health Research is funded by the Department of Health and Social Care. It funds health and care research, providing the people, facilities and technology for research to thrive.
Patient and public involvement	Research carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. Members of the public can be involved at all stages of a research project and across all levels of research organisations.

Theme Public Advisors	Our Theme Public Advisors are members of the public. They have a strategic role in our organisation. This includes working closely with the leadership of one of our research themes and with our PPIEP team. We try to have two Theme Public Advisors per research theme.
PPI Officer	Our PPI Officer is a member of staff dedicated to supporting good PPIEP. At the time of publishing, Katherine Baker fills this post.
PPI/E	An acronym for patient and public involvement and engagement. Used to describe work and projects which connect or encompass both activities.
Population risk stratification and intervention to prevent childhood obesity	This project aims to test the feasibility and acceptability of a childhood obesity prediction tool and online platform for health visitors to use when supporting families to lead healthier life styles. The involvement work will focus on working with the underserved, such as those from deprived or ethnic minority groups, who are most at risk of childhood obesity.
Public Engagement in Research Unit	This unit exists to inspire and support high quality public engagement with research across all disciplines at the University of Southampton.
Public Policy Unit	This unit, at the University of Southampton, helps researchers connect with policymakers to better support evidence-based policymaking.
Socioeconomic status	This term describes an individual's or family's economic and social position. It is a predictor of outcomes across the life span.
Staff links	Each theme has a nominated PPIEP staff link. This is a member of their research team. They are members of our strategic PPIEP group, APIF.
Sure Start	Sure Start is a government area-based initiative that was founded with the aim of 'giving children the best possible start in life' through improvement of childcare, early education, health and family support.
Training Needs Analysis	This is a process to determine all the training that needs to be completed (and when) to allow someone to complete their job as effectively as possible, as well as progress and grow.
UK Standards for Public Involvement	The standards are a framework for what good public involvement in research looks like. They provide clear, concise statements of effective public involvement against which improvement can be assessed. They were developed as a partnership of organisations across the UK, including the NIHR. Read more.

Underserved	Underserved is the term we have chosen to use to describe people who are less well included in research. We prefer this term because it highlights that the research community needs to provide a better service for these individuals. It is important to recognise that underserved groups are context-specific. There is no single, simple definition to describe all underserved groups. The INCLUDE guidance provides more information about what an underserved group is – read here.
Wessex	Wessex is the region covering Dorset, Hampshire, the Isle of Wight and South Wiltshire.