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Capturing impact of public and patient involvement and engagement in NIHR ARC Wessex - summary

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Summary of PPIE Impact in NIHR ARC Wessex

Patient and Public Involvement and Engagement (PPIE) has significantly shaped research across ARC Wessex projects, influencing design, methodology, recruitment, and dissemination. Public contributors prompted protocol changes, refined research questions, and improved tools, ensuring studies aligned with real-world priorities. Their input made sure more people were included, through accessible materials, diverse representation, and flexible participation options. PPIE also improved data collection by integrating lived experience and adapting digital tools for accessibility.

Public contributors co-authored papers, created lay summaries, and developed infographics, broadening dissemination and community engagement. Long-term impacts include capacity building through training initiatives like the NxtGen Researcher Programme and influencing policy and practice, such as Integrated Care Partnership strategies.

Additional benefits included confirming our research was relevant, fostering experiential learning for researchers, and informing future studies. Challenges remain in recruiting underrepresented groups, sustaining engagement, and addressing resource constraints, accessibility, and ethical complexities.

For public contributors, involvement provided validation, skill development, networking opportunities, and recognition, often leading to personal growth. Most were recruited early and reflected target populations, though diversity gaps persist. Actions to engage underserved communities included targeted outreach, flexible participation, and inclusive materials. Training varied from formal courses to informal support, with future requests focusing on research processes, advocacy, and technical skills.

We would like to give grateful thanks to all Public and Patient Involvement and Engagement contributors, ARC Wessex research teams and staff of the Southampton Centre for Research Engagement and Impact who gave their time and feedback to allow us to evaluate our approach in order to better our understanding and improve our processes for the future.

Contents

1. Introduction

Capturing the impact of patient and public involvement and engagement (PPIE) in research is essential for understanding both the positive and negative effects on contributors and on the research.

The NIHR ARC Wessex Partnership Board emphasised the importance of assessing the impact of PPIE. In response, we conducted a survey of researchers and public contributors to evaluate nature and impact of PPIE undertaken between 2019 and 2026.

2. The Impact of Patient and Public Involvement and Engagement

Patient and Public Involvement and Engagement (PPIE) has been integral across multiple ARC Wessex projects, influencing research design, implementation, and dissemination. The following examples demonstrate how PPIE contributions have led to immediate changes and sustained improvements in research relevance, inclusivity, and impact.

Influence on Research Design & Methodology

- **Protocol Changes**

The public contributor suggested including patients and caregivers in qualitative work packages, fundamentally changing the research design and aligning with stakeholder priorities.

The public contributor's review highlighted the absence of early PPIE involvement, prompting the team to add a pre-design PPIE session to capture patient concerns before co-design workshops.

- **Method Adaptation**

Feedback from PPIE sessions led to offering one-to-one interviews alongside focus groups to accommodate under-represented communities.

Public contributors advised on trauma-informed approaches for including victim/survivors in domestic abuse research, enabling their safe participation.

Public contributors informed the structure and delivery of 'Active Living Cafes' to maximise engagement.

- **Research Question Refinement**

Social workers and public collaborators shifted the focus to recruitment and retention in social care, ensuring practical relevance.

SPLW framework design was modified to integrate mental health needs based on PPIE input, addressing a critical gap in support pathways.

- **Survey & Tool Development**

Public contributors ranked treatment burden questions, resulting in a new, patient-preferred measure used in published research.

The public contributor suggested wording changes to improve clarity for nurses and carers, enhancing survey validity.

Enhancing Recruitment & Inclusivity

- **Accessible Materials**

Public contributors co-produced participant information sheets, consent forms, and easy-read versions, reducing barriers for frail older adults.

Public contributors reviewed amendments for patients lacking capacity, ensuring ethical and inclusive: Public contributors co-designed participant information sheets, consent forms, and easy-read versions, reducing barriers to participation.

- **Language & Framing**

Public contributors suggested avoiding certain words or jargon (e.g., replacing "research" with "project") to increase engagement with the research.

- **Diverse Representation**

PPIE feedback on a prototype app led to offering eight avatar choices with varied gender and ethnic appearances, aligning with EDI principles.

Adaptations suggested by public contributors (e.g., telephone interventions) reduced digital exclusion for older adults.

The public contributor's local knowledge facilitated recruitment through dementia support groups, reducing researcher time and increasing diversity amongst participants.

Improving Data Collection & Tools

- **Flexibility in Participation**

At the suggestion of public contributors, offering a choice between interviews and focus groups improved recruitment and retention.

- **Digital Accessibility**

Public contributors trialled online surveys and eye-tracking experiments, leading to changes that reduced fatigue and improved clarity.

- **Integration of Lived Experience**

Public contributors co-facilitated workshops and focus groups, adding authenticity, lived experience and ensuring data collection remained grounded in real-world priorities.

Shaping Dissemination & Communication

- **Co-authorship and shaping dissemination**

Public contributors co-authored academic papers and lay summaries, improving clarity and accessibility.

The public contributor drafted a plain English summary for a realist synthesis review, ensuring findings were understandable for non-specialists.

The public contributor's input led to podcasts accompanying academic papers, widening reach.

A study participant wrote an anonymous blog for the toolkit website, adding a personal perspective.

Public contributors co-developed infographics, toolkits, and lay explanations of technical terms.

- **Community Engagement**

Public collaborators promoted research in local networks, improving awareness, recruitment, two-way communication. Led to events showcasing contributions and promoting recognition.

- **Strategic Partnerships**

Suggestions led to collaboration with the Royal College of Nursing and advocacy networks, amplifying dissemination and credibility.

Sustained Impact & Capacity Building

- **Training & Co-Creation**

Young people co-developed the NxtGen Researcher Programme, creating resources and shaping best practice for participatory research.

- **Long-Term Collaborations**

Public contributors became integral team members, influencing future grant applications and research agendas.

Plans to establish public contributors as University Visitors for sustained engagement.

- **Policy & Practice Influence**

Recommendations from youth-led research informed Integrated Care Partnership strategies, demonstrating real-world impact.

PPIE input on alcohol research in older adults prompted a seed funding application to tackle stigma through creative practice.

Public contributors helped interpret the findings to set priorities for work now delivered by our partners, Saints Foundation and HIOW Integrated Care Partnership, who are delivering Southampton Neighbourhood Hubs in-line with NHS 10 Year Plan Agenda (2025).

3. Additional benefits or learning

Validation and Relevance

- PPIE feedback confirmed that research approaches and findings were acceptable to lay audiences.
- Reinforced the importance and real-world relevance of research questions.
- Prevented "academic drift" by ensuring feasibility and alignment with lived experiences.

Experiential Learning for Researchers

- Increased empathy and understanding of patient challenges.

- Corrected potential biases and improved clarity for non-specialist audiences.

Impact on Future Research

- Provided insights for planning future studies and improving PPIE practices.
- Highlighted need for budgeting dedicated PPIE resources in grants.

Ethical and Practical Considerations

- Addressed concerns around AI/ML in healthcare decision-making.
- Influenced design of decision-support tools to maintain human-led processes.

4. Challenges

Recruitment Challenges

- Difficulty recruiting individuals with specific lived experiences (e.g., food aid users, heart failure patients over 65, diverse cultural backgrounds).
- Limited success in engaging people from underrepresented communities despite outreach efforts.
- Hesitancy in certain settings (e.g., primary care) to involve public contributors.

Continuity and Retention

- Public contributors withdrawing due to health issues, age-related constraints, or feeling unable to contribute meaningfully.
- Maintaining engagement over long project timelines was challenging, especially when public contributors had other commitments.

Time and Resource Constraints

- Scheduling meetings around public contributors' availability was difficult.
- Co-design and review activities required significant time, often exceeding planned schedules.
- Limited resources impacted sustained engagement and primary data collection.

Diversity of Perspectives

- Managing differing opinions among public contributors; changes had to reflect majority views.
- Some suggestions were unrealistic given budget and time constraints.

Accessibility and Communication

- Information sheets were too lengthy despite efforts to simplify language.
- Need for more accessible recruitment processes and clearer explanations of complex projects.

Structural and Process Barriers

- Delays due to hospital policy changes and slow R&D processes.
- Minimal PPIE involvement at project initiation due to setup constraints.
- Scarcity of guidance and training for co-writing papers with public contributors.

Ethical and Safety Considerations

- In projects involving sensitive topics (e.g., stalking), ethical and risk concerns prevented inclusion of certain populations.
- Lack of guidance on involving individuals with potentially harmful behaviours in research.

Representation Issues

- Some public contributors did not match the target demographic (e.g., older adults in alcohol-related studies).
- Challenges in ensuring appropriate representation for workforce-related research topics.

Key Challenges Across Projects

- Recruitment and retention remain the most significant barriers.
- Time and resource limitations affect depth and continuity of engagement.
- Inclusivity and accessibility need improvement in materials and processes.
- Ethical complexities arise in sensitive research areas.

5. Positive impact for the public contributor personally

Sense of Validation and Purpose

Public contributors expressed that being involved gave them confidence their lived experiences were valued and relevant to shaping real-world research. This validation reinforced their sense of purpose and contribution.

Skill Development and Learning

Many public contributors gained new knowledge about research processes, terminology (e.g., anticholinergic effects), and healthcare systems. Some were involved in co-authoring abstracts, developing toolkits, and even preparing for data analysis roles, which expanded their skills.

Some public contributors felt they gained insights from the research that they could incorporate into their own lives and work.

Opportunities for Collaboration and Networking

Public contributors engaged with researchers, designers, and other stakeholders, sometimes leading to new collaborations (e.g., socially engaged arts projects). They also participated in community engagement events and conferences, strengthening their professional and social networks.

Recognition, Inclusion and Impact

Public contributors were acknowledged as co-authors and invited to university roles (e.g., Visitors at the University of Southampton), which provided formal recognition and inclusion in academic spaces.

Public contributors felt empowered by seeing their input lead to tangible changes in research design, recruitment strategies, and dissemination plans. This sense of influence was personally rewarding.

Personal Reflection and Growth

Involvement prompted public contributors to reflect on their own experiences and those of others, deepening empathy and understanding of complex health and social care issues.

6. Stage the public contributor was recruited to the research project

Public contributors were generally recruited early in the research lifecycle, but with some variation across projects.

Most Common Stage

- Before or during proposal development
    - Many public contributors were involved at the idea formation, bid development, or funding application stage.
    - They helped shape research questions, design, and lay summaries.

Other Early Stages

- Prior to ethics submission
    - Public contributors reviewed protocols and advised on methodology.
- At project inception or start
    - Some were recruited as soon as the project began or within the first few months.

Ongoing Recruitment

- Throughout the study
    - New public contributors were added at different stages (e.g., before focus groups, during analysis, or dissemination planning) to bring fresh perspectives.

Overall Pattern

- Early and sustained involvement was the norm, often starting at proposal development and continuing through design, conduct, analysis, and dissemination.
- Recruitment was iterative, with additional public contributors joining at key milestones for new insights.

7. Extent to which public contributor reflects the group or population of research interest

Strong Representation in Key Areas

- Public contributors often had direct lived experience of the condition or context being studied (e.g., multiple long-term conditions, dementia care, mental health, rheumatoid arthritis, early childhood obesity).
- Some brought dual perspectives—personal experience plus professional or advocacy roles—adding depth to discussions.

Partial or Indirect Representation

- A few public contributors were not exact demographic matches (e.g., retired professionals, carers instead of patients, or lacking experience in specific subgroups).
- Some projects acknowledged gaps in diversity (e.g., ethnicity, socio-economic status) and noted improvements in recruitment strategies over time.

Diversity and Inclusion Efforts

- Several studies actively sought diversity in age, gender, ethnicity, and health status.
- There was a clear commitment to INCLUDE guidance (NIHR 2022) for under-served groups, including ethnic minorities and people with SEND, neurodiversity, and care experience.

Added Value Beyond Demographic Match

- Public contributors often provided unique insights from professional expertise (e.g., social care, HR, GP experience) or community engagement, which enriched research even if not fully representative of the average participant.

8. Actions taken to engage underserved communities and/ or provide inclusive opportunities for public members in PPIE

Targeted Outreach to Underserved Communities

- Partnered with charities (e.g., Active Lives) and community leaders to reach underserved groups.
- Engaged with local community groups (e.g., Heart Health group, dementia support groups) and deprived areas (e.g., Glasgow).
- Worked with trusted intermediaries and service providers to introduce projects to victim/survivor groups.
- Advertised opportunities specifically to under-represented communities.

Representation and Diversity in PPIE Teams

- Recruited public contributors with lived experience of specific conditions (e.g., rheumatoid arthritis, inflammatory bowel disease, multiple LTCs).
- Included youth voices via LifeLab's Youth Panel and NxtGen programme.
- Ensured diversity in advisory boards (e.g., MELD-B project) and recruited members from varied ethnic and cultural backgrounds.
- Reflected on limitations (e.g., predominance of retired white males) and sought EDI expertise to address gaps.

Flexible and Accessible Participation Methods

- Offered multiple formats: online, in-person, hybrid, telephone, email, video/audio submissions.
- Scheduled meetings at varied times (daytime/evening) and convenient locations.
- Provided one-to-one sessions for those unable to join group meetings.
- Adapted communication methods (e.g., simplified email formats, printed materials, phone calls for those with memory or vision issues).

Inclusive Design of Materials and Processes

- Created accessible materials (plain language, visual clarity).
- Accepted contributions in different formats (written, audio, video).
- Removed digital barriers by meeting in-person and offering hybrid options.
- Piloted informal pre-meetings to build trust and provide background.

Building Relationships and Trust

- Personal engagement before and during projects to foster inclusion.

- Utilised professional networks and community links for recruitment.
- Empowered public contributors to choose preferred communication channels.

Continuous Improvement and Reflection

- Acknowledged challenges (e.g., limited diversity, reliance on online resources).
- Incorporated EDI considerations into analysis and reporting.
- Planned future strategies for underserved communities in next research stages.

Creative and Community-Based Engagement

- Explored collaborations with artists to amplify voices of underserved groups.
- Participated in public events (e.g., NIHR ARC Wessex showcase, Saints Foundation day) to connect with potential public contributors).
- Secured additional funding (e.g., Vivensa Foundation grant) to engage older adults and underserved communities.

9. Training or support received by the public contributor(s)

Formal Training

- Some public contributors attended CPD courses on involving people in research. E.g. NxtGen Researcher Programme (research and advocacy skills), Young Researchers' Programme (training for data collection tasks).
- Certain public contributors were given university access and resources (e.g., Visiting Fellow status at Bournemouth University).

Informal or On-the-Job Training

- Training occurred through project involvement, e.g. for Youth Panel members.
- Public contributors learned by working alongside researchers and through introductory sessions explaining project aims, methods, and expectations.
- Some public contributors gained skills during analysis workshops (e.g., qualitative analysis coding and theming).

No Formal Training, but Support Available

- Many responses indicated no structured training, but:
    - Teams were happy to explain research aspects as needed.
    - Public contributors were encouraged to ask for help and were supported during meetings.
    - Peer support was noted (e.g., learning from more experienced public contributors on the team).

Training Not Required

- Public contributors were often experienced in PPIE, so no additional training was deemed necessary.
- Involvement was primarily strategic or high-level review, where methodological induction was not needed.

Unclear or Not Remembered

- Several responses stated "Not sure" or couldn't recall specific training at early project stages.

10. Requests for future training or support

Understanding Research Processes and Governance

- Desire for a broader understanding of the research cycle, including thematic analysis, writing up papers, and the overall process rather than just participation.
- Interest in advanced research governance and ethical considerations for future phases.

Skills for Dissemination and Advocacy

- Training in dissemination and support for writing dissemination pieces (e.g., posters, reports, papers).
- Co-writing reports/papers and understanding how to be properly involved in writing up.
- Training in advocacy to co-present findings and influence policy.

Data Literacy and Interpretation

- Training on interpreting graphs and regression models, especially for predictive modelling and “big data” studies.
- Understanding concepts like effect sizes, precision, and calibration.

Technical and Digital Skills

- Requests for computer training to reduce reliance on family support.

Sustained Engagement and Co-production

- Need for flexible arrangements and adequate compensation to enable deeper involvement.
- Training to sustain high-level contributions beyond design phase, including implementation strategies and research-to-practice pathways.

Youth and Community Engagement

- Young public contributors need structured support for translating research results into dissemination formats (already addressed by expanding NxtGen sessions).
- Interest in community researcher training for future involvement.

Open Requests

- Some public contributors expressed no specific training needs currently but want to be informed about opportunities and reimbursement.

11. Recording of contributions and impact of the public contributor

Meeting-Based Documentation

- **Minutes and Notes**: Many responses mention recording contributions in meeting minutes, notes, or action points following PPIE meetings.
- **Audio/Video Recording**: Some projects routinely recorded meetings for reference.
- **Attendance Logs**: Public contributors' presence at meetings and workshops was logged.

Formal Logs and Toolkits

- **Public Involvement Logs**: Several teams used structured logs (e.g., People in Health West of England template) to systematically document involvement and impact.
- **Impact Logs**: Specific logs were kept for recording changes influenced by PPIE input.
- **Toolkits**: Eg. PIRIT for comprehensive documentation.

Informal Records

- **Emails and Written Feedback**: Contributions were often captured through email exchanges or informal notes, especially during proposal development.
- **Reflection Logs**: Both participants and research teams kept reflective journals documenting engagement and contributions.

Embedded in Research Outputs

- **Protocol and Manuscripts**: PPIE impact was reported in research protocols, systematic review manuscripts, and publications using frameworks like GRIPP2 for transparency.
- **Policy Recommendations and Reports**: Co-created outputs (e.g., policy recommendations, action plans) were published with public contributors as co-authors.
- **Dissemination Materials**: Posters, presentations, and seminars documented PPIE contributions.

Version Control and Methodological Evidence

- **Tracked Changes**: Projects saved versions of documents (e.g., methodology sections, interview guides) before and after PPIE input to show impact.
- **Auditable Evidence**: Adjustments to research questions and tools were stored as permanent records.

Limited or No Recording

- **Minimal Documentation**: A few responses noted little or no systematic recording, often due to early project phases or resource constraints.
- **Future Plans**: Some teams acknowledged gaps and proposed improvements (e.g., “You said, we did” approach, retrospective logs).

Reporting and Dissemination

- **Internal Reporting**: Impact summaries were shared with project teams and stakeholders.
- **External Dissemination**: Contributions were highlighted in presentations, seminars, and governance group discussions.

12. Conclusion

This work to capture the impact of patient and public involvement and engagement on the ARC research programme identified both strengths and areas for improvement. Building on this understanding and embedding a reflective approach as standard practice going forward will ensure that PPIE is measurable, effective, and beneficial for all across Wessex.

For further information on this report, contact ARC Wessex at arcwessex@soton.ac.uk.