NIHR | National Institute for Health and Care Research

Learning from PPI in action:

A collection of webinars

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Contents

Introduction

Welcome to your guide to Patient and Public Involvement (PPI) in action.

This e-book, compiled from excerpts of the NIHR PPI in Action Webinar Series, offers a unique look into successful PPI within health and social care research. It showcases practical examples and valuable insights, clearly illustrating how the UK Standards for Public Involvement come to life in practice.

The webinars presented cover a diverse range of projects and approaches to PPI, as outlined below.

Co-Production in Practice – Building Relationships for Research Impact

The first webinar in the series focused on co-production for research with impact, using an example of a study aimed to understand the everyday use of restrictive practices in the care of people living with dementia during hospital admissions. The approach involved outreach and continuous engagement, working closely with organisations and individuals.

Arts were used to support involvement, especially painting, offering non-verbal routes of expression which are crucial when verbal communication is difficult. This approach yielded rich data and new understandings, providing space for people to express traumatic experiences.

The session emphasised reaching out to and meeting people where they are, rather than expecting them to come to researchers. Engaging diverse communities was discussed, highlighting the value of contributions from various backgrounds, such as the LGBTQ community. Funding for community engagement often came from a mix of NIHR grants, university funds, and other funders, with participants receiving recompense for their time. Co-production was described as fundamentally about building relationships and working in partnership, distinguishing it from mere consultation.

Engaging Policy Makers and Practitioners in Research: Lessons from the Active-6 Study

The second webinar in the series discussed PPI with policy makers and practitioners using the example of the Active-6 study, which examined the impact of COVID-19 lockdowns on children's physical activity. The study convened an online Impact Advisory Group comprised of representatives from various organisations to share project updates and emergent findings. This group played a vital role in shaping the dissemination strategy.

Collaborating with stakeholders, particularly those in data and insight roles, helped researchers understand the most useful formats for findings (e.g., slide decks, policy briefings, 1-page summaries). The Impact Group also facilitated access to channels the researchers might not have otherwise reached, including professional networks and blogs. Key learnings included the importance of building long-term relationships with stakeholders and planning for dissemination strategically from early in the project.

Voices of Experience: Involving Young People in Childhood Obesity Prevention Research

The third webinar focused on involving children and young people in an evidence synthesis project (ESCCOPE) around the prevention of childhood obesity. The involvement began during the funding application stage, with young people providing ideas on how to explore data. The Young Person's Advisory Group (YPAG) was central to this involvement, offering input from multiple perspectives to ensure research relevance to young people.

YPAG members were actively involved in developing the analytic framework and even coded interventions for a "fun factor" – a concept that originated in their meetings. They also helped interpret results, particularly when they were unexpected, reinforcing their value and ensuring they felt listened to.

Effective communication, including pre-meetings to explain terminology and materials, and using features like private chat during online sessions, was critical for supporting their meaningful participation. The shift to online working due to the pandemic also allowed the YPAG to broaden its membership and diversity. Training for coding was practical and iterative, with young people taking to the task well, though the value of rewriting complex snippets in plain language was noted for future projects. The importance of not making assumptions about how people want to be involved and offering choices was highlighted.

Driving Health Forward - Embedding Public Involvement in the SHIFT Programme

The fourth webinar presented the Structured Health Intervention for Truckers (SHIFT) programme, demonstrating how PPI was embedded from conception to implementation with heavy goods vehicle drivers. The need for this work came from drivers and industry partners observing poor health markers in this occupational group.

Pre-funding, the programme was co-created with a logistics company. Throughout the NIHR-funded period, extensive driver and industry involvement continued. Drivers informed decisions on outcome measures (e.g., opting for finger-prick blood samples over whole blood) and significantly shaped recruitment messaging and study documentation, finding the baseline health check appealing and helping build buy-in. Regular meetings were held with the PPI group to gather feedback on plans and documentation. Knowledge exchange activities included events with key industry stakeholders where findings were presented, leading to the co-development and implementation of a driver training module based on the programme.

The presentation stressed the importance of acting on PPI feedback and demonstrating that their input is valued and impactful. Challenges included building research literacy in a group new to research, addressed through early discussions and accessible communication. Dissemination methods included knowledge exchange workshops and producing infographics of findings, informed by public members.

Building Capacity and Inclusion: Insights from the SCRiPT Study on Adult Social Care Research

The fifth webinar in the series focused on inclusive involvement in Adult Social Care Research, drawing on the experiences from the SCRiPT study. This study tested ways to build research capacity in social care, including setting up research in practice teams which included people with experience of social care services.

A key aspect discussed was working with individuals with lived experience of adult social care services, addressing challenges such as recruitment, supporting contributors as peers, and navigating contested terminology around a preferred term for PPI contributors. Shaping Our Lives, a user-led organisation specialising in inclusive involvement, was a co-applicant on the SCRiPT study and led on recruiting and supporting PPI contributors. The discussion also covered challenges around research ethics and governance for nested projects within a feasibility study, training for researchers on working with public contributors, the value of managing expectations regarding the slow pace of research outcomes, and evaluating the impact of public contributors, often through informal 1-to-1 discussions and contributions to papers and meetings.

Embedding Co-design and Co-production in Practice: Learning from Refugee Mental Health Research

The sixth webinar explored embedding co-design and co-production to support refugee mental health through the Routes to Wellness project. This project utilised experience-based co-design, which is based on narrative and aims to change behaviour by crushing hierarchy and creating more egalitarian spaces that value different knowledges.

The project involved people with lived experience from the very beginning, including in setting priorities and co-producing the proposal and research questions. They also played a crucial role in co-designing the evaluation framework and were involved in data collection, analysis workshops, and developing scenarios and tools for peer support workers. Recruitment of peer support workers included individuals with lived experience sitting on the interview panel.

Key learnings included the importance of reciprocal relationships beyond just payment, recognising the potential therapeutic impact of involvement for some individuals, taking a transculturally trauma-informed approach, being consistent and reliable, and managing practicalities like timely payment. The project also highlighted the importance of not assuming vulnerability in people with forced migration experience, but rather focusing on the fragility of circumstances, and the need for slower, trauma-informed research.

Round up

Drawing these varied experiences together, this e-book offers a rich tapestry of real-world examples of PPI in action. Across the different projects, common threads emerge: the fundamental value of lived experience as expertise; the importance of building strong, often long-term, relationships; the necessity of flexible, accessible, and tailored communication and involvement methods; and the constant process of learning and adapting based on feedback and experience. The webinars highlight both the successes and the challenges, offering practical insights into aspects like ethical considerations, recruitment, support, evaluation, and dissemination.

This e-book provides valuable lessons for anyone involved in or considering PPI in health and social care research. By delving into these specific case studies, readers can gain a deeper understanding of how effective involvement works in practice, the benefits it brings to research, and the practical steps and considerations required to embed PPI meaningfully from start to finish. We hope this resource helps you on your public involvement journey.

Executive summary

This executive summary synthesises key insights from the NIHR PPI in Action Webinar Series, highlighting how patient and public involvement has been effectively integrated and delivered across a range of NIHR-funded health and social care research. The collection demonstrates diverse project approaches, providing valuable, real-world illustrations of successful PPI implementation.

The research projects presented in the series consistently demonstrated the application of the UK standards for Public Involvement in health and social care research, which provide a framework for ensuring high-quality and consistent public involvement.

UK Standards for Public Involvement in Research:

- **Communications:** This standard ensures that information is clear, timely, and relevant to all involved.
    - Projects adapted communication to suit different audiences, for instance, in Adult Social Care Research, where terminology was challenging due to differing preferences for terms like "service users" or "experts by experience". The Routes to Wellness project changed its title based on feedback from people with lived experience, reflecting sensitivity to language.
    - Visual and interactive tools were employed, such as using artworks and paintings in dementia research to support non-verbal expression for people with communication difficulties, yielding rich data on sensitive topics. The SHIFT study also used visual aids to engage stakeholders.

  - Clear and accessible information was prioritised, with the Active-6 study creating various outputs like plain English blog posts to summarise academic papers. The ESCCOPE study, involving young people, used pre-meetings and private chat functions to clarify technical language. "Driver-friendly" information sheets were developed for the SHIFT study using graphics and accessible language.

- **Working together:** This standard emphasises valuing all contributions and building mutually respectful relationships.
  - Partnership from conception was evident, with the SHIFT study demonstrating partnership from the very beginning, as it originated directly from needs identified by industry health and safety managers, and the Routes to Wellness project engaging the refugee community to understand priorities before funding.
  - Projects used various involvement structures, for instance, the Active-6 study included policy and practice colleagues as key stakeholders in both grant applications and data collection. In Adult Social Care Research, Shaping Our Lives, was a co-applicant leading on recruiting and supporting lived experience partners.
  - A key focus for researchers was fostering equitable relationships, in the dementia study they included having a carer and person with dementia as core members of the project oversight committee, ensuring their lived experience was equally valued. In Routes to Wellness, people with lived experience participated in recruitment panels and were named authors on papers, signifying equitable contributions.
  - Co-creation and adaptation were central, with the SHIFT project refining its intervention based on discussions with logistics companies. The ESCCOPE study involved young people in developing its "analytic framework" and coding interventions for a "fun factor".

- **Inclusive opportunities**: This standard focuses on ensuring accessibility for a diverse range of people.
  - Projects actively targeted diverse communities, with dementia research promoting the voices of African and African Caribbean, South Asian, and deaf people living with dementia through outreach events like art workshops, building trust over time.
  - Barriers to engagement were addressed, particularly in Adult Social Care Research, where working with specialist user-led organisations like

    Shaping Our Lives helped bridge gaps in accessing marginalised communities.

  - Support for diverse needs was provided, such as the Routes to Wellness project adopting a transculturally trauma-informed approach for people with forced migration experience, providing telephones to facilitate connection. For young people in ESCCOPE, having multiple public contributors provided peer support. The SHIFT study recognised the importance of neurodiversity and aimed to improve accessibility for future initiatives.

- **Impact**: This standard focuses on improving research through public involvement and sharing the benefits.
  - Public contributors added value in Adult Social Care Research, with their input evaluated through informal meetings and direct contributions to outputs like animations.
  - The Routes to Wellness project saw tangible outcomes such as increased social connections and reduced mental health stigma through co-designed peer support, with participants expressing personal growth.
  - The SHIFT programme demonstrated translation into practice by becoming an accredited, mandatory driver training module reaching 6,500 drivers, signifying real-world impact on industry practice.
  - Dementia research, by involving public contributors, addressed key, often "hidden aspects of care" like restrictive practices, with arts-based approaches providing deep understandings that directly influenced project reporting.
  - Involvement fostered personal growth and learning for young people in the ESCCOPE study, providing insight into research processes and developing valuable skills, leading to researchers appreciating the unique expertise public involvement brought.

- **Governance**: This standard refers to public involvement in research management, regulation, leadership, and decision-making.
  - Structured oversight was implemented, with parent members recruited to the Study Steering Committee for Active-6 and individuals with lived experience integrated into management structures for the dementia study. Shaping Our Lives, as a co-applicant in Adult Social Care

    Research, managed all involvement-related matters, including payments and support.

    - Challenges included navigating bureaucracy, with Adult Social Care Research highlighting the complexity of multi-layered ethics and governance approval systems.
    - Projects emphasised working ethically beyond formal approval, such as requiring parental consent for young people in ESCCOPE and maintaining patient confidentiality in the SHIFT study when identifying health problems.
- **Support and learning**: This standard is key to building confidence and skills for public members in research.
    - Dedicated support and resources were crucial, including PPI coordination time for ESCCOPE and additional funding for Shaping Our Lives to support experts by experience.
    - Tailored training and development were provided, such as bespoke training for social care practitioners and reflection sessions for the Routes to Wellness team and contributors. Reciprocal benefits included named authorship, job references, and work experience opportunities.
    - Building trust and relationships was consistently stressed as vital, often through long-term engagement, informal chats, empathy, and consistent presence in community environments. Regular social catch-ups helped build rapport and ensure well-being.
    - Flexibility and responsiveness to evolving needs and contributions of public contributors were recurring themes, including researchers actively meeting people in their communities rather than expecting them to come to the researchers.

In conclusion, the webinars collectively demonstrate that while adhering to the UK Standards for Public Involvement can be resource-intensive and challenging, a commitment to effective communication, genuine collaboration, inclusive opportunities, clear impact, robust governance, and continuous support and learning significantly enhances the quality, relevance, and real-world impact of research.

Chapter 1: Co-Production in Practice – Building Relationships for Research Impact

Untitled artwork reproduced with permission of study 'The use of restrictive practices in the everyday care of People Living with Dementia in hospital settings: an ethnographic study'. Materials: acrylic paint and Brusho ink - created 30 November 2022, Ruthin Craft Centre, Denbighshire, Wales. All the paintings in this series are anonymised [Ethics approval obtained from the UWL Ethics Panel on 23/11/2022]

This chapter explores the vital role of Patient and Public Involvement and co-production in conducting research with real-world impact, drawing on insights from a team focused on improving care for people living with dementia. This draws on The use of restrictive practices in the everyday care of People Living with Dementia in hospital settings: an ethnographic study (NIHR132903), carried out by the Geller Institute for Ageing and Memory, University of West London.

Why is co-production essential? Focusing on dementia care

People with dementia represent a significant hospital population, occupying between 25% and 50% of acute wards. They typically arrive for urgent, unscheduled care due to potentially preventable or treatable conditions like pneumonia or UTIs, not primarily because of their dementia. However, a hospital admission puts them at a high risk of poor care quality and experiences, which can lead to deterioration, institutionalisation, and an increased risk of death. Despite this, people with dementia are an under-researched population, and their care is often not recognised as a priority for NHS leaders, ward teams, politicians, or the public agenda.

To address this, the research team focus on specific, often hidden, aspects of care like resistance to care, continence care, and in this study, the use of restrictive practices and restraint in care. They also prioritise looking at the experiences of specific populations at high risk of poor care and outcomes, such as African and African Caribbean communities and people with dementia admitted to mental health wards who are at risk to themselves or others.

The core aim of their PPI work is to gain deeper understandings into:

- experiences and perspectives of care among people living with dementia
- values and standards of care people believe should be prioritised
- what good practice and training looks like, and the training needed to achieve it

Embracing inclusion and diversity

A key goal is to support inclusion and diversity and promote the voices of people from a wide range of cultures, religions, communities, and backgrounds. This includes specific focus on groups such as people living with young onset dementia, older people from African and African Caribbean communities, people from South Asian backgrounds, and deaf people living with dementia. Engaging diverse communities requires time and creativity. It's essential not to see engagement as merely a means to an end for research data, but as an opportunity to build genuine relationships.

Building long-term relationships and trust

A fundamental aspect of this co-production approach is the commitment to building long-term relationships with communities. This involves identifying and partnering with relevant community organisations and networks in catchment areas, supporting the work they do while also seeking engagement for research. The aim is to build trust with communities and establish collaborative relationships, moving away from a model where researchers simply show up, ask questions, and leave. It requires working together over the long term to create mutually beneficial relationships and fostering trust, so people feel comfortable sharing their experiences and stories.

Outreach and community engagement

Reaching out and meeting people where they are is central to this approach. Instead of expecting people to come to the university or research setting, researchers go out to meet them. This includes having informal meetings like tea and coffee sessions, lunches, and running inclusive events that bring people together.

Outreach has been crucial for developing grounded and mutually beneficial relationships with organisations and individuals. This often involves supporting organisations in practical ways, such as developing and delivering outreach events.

Examples of such events include collaboration in holding dementia-friendly operas, Calypso dances, afternoon tea to celebrate the Windrush generation, Christmas carol events, and art workshops. These activities are not always immediately about discussing specific research topics, especially sensitive ones like restrictive practices. Over time, through consistent outreach, trust is developed, and research discussions and involvement can emerge naturally from these relationships.

Creative approaches: the power of arts

Expressing ideas and experiences through the arts, particularly painting, has been a significant part of this PPI programme. This approach aims to provide new lines of communication and engagement, especially for people living with dementia for whom verbal communication may be difficult. Art offers an alternate route to expression, particularly for sensitive or traumatic topics that are hard to talk about.

Key aspects of using art in this work include:

- supporting people to express themselves in a way that is personal to them, without a preconceived outcome
- researchers often painting alongside participants to find non-verbal connections
- providing a balance when discussing difficult topics, as painting can introduce positive or calming elements
- creating a fluid and immersive process that accommodates symptoms like anxiety or confusion that might exclude people from standard PPI work
- allowing for both articulated thoughts and abstract expressions – a simple line or colour choice can be a valid form of expression without needing verbal explanation

While drawing on some learning from art therapy, the methodological approach is more aligned with arts-based methods. The workshops serve both PPI engagement and potentially data collection, with appropriate ethical approval. The interpretation of artwork involves careful observation of *how* people use paint and appear while working, alongside any verbal communication that occurs in the moment. This approach yields deep and rich understandings over time, particularly when working consistently with individuals. It requires giving people the space and time to express themselves.

Paintings created by participants hold significant meaning. For instance, 1 painting depicted a person's traumatic experience of being physically restrained in hospital, using colours (reds/oranges for intense feelings, blues/greens for time moved on) and shapes (a 'demon') to convey their emotions and associations, while also highlighting the positive impact of a caring professional's simple touch. Such insights directly inform research projects feeding into reports and helping researchers understand people's experiences and desires for future care.

Other creative and social activities

Beyond visual arts, the team incorporates music events into their outreach. This recognises the social isolation often experienced by people with dementia and aims to provide inclusive opportunities. Examples include dementia-friendly film events, opera performances, afternoon teas, and celebration events where music plays a central role in bringing people together and reducing isolation.

Discussions also touched upon music therapy and singing groups like "Singing for the Brain" and the "Forget Me Not Chorus". These groups offer therapeutic benefits and social connection. A key learning from experience is the importance of not making assumptions about musical preferences, ensuring variety that includes pop, rock and roll, calypso, dancehall, and other genres that resonate with diverse groups and younger people living with early onset dementia.

The partnership model: equals in research

A core principle is that PPI participants are research partners, not subjects. This is real co-production, which is distinct from consultation or simply interviewing someone for feedback. Co-production involves asking people what *they* want to research, what topics are important to *them*, and what *they* want included. This involves a relationship of equals, where lived experience is valued as much as clinical expertise.

Partners like Rosie, a carer, and Andy, living with vascular dementia, are integral to the team. Rosie chairs the project oversight and management committee, where researchers report back on their progress. This structure allows for ongoing dialogue and problem-solving, emphasising that important issues should not wait months until the next formal meeting. Andy participates in the steering group, contributing his personal experience and also acting as a voice for others with dementia through his networking.

This partnership extends to challenging researchers, ensuring they are "doing the right thing" and thinking about how the research findings will actually change things. The most rewarding and important research topics often emerge from these conversations, based on what truly matters to people, rather than researchers' initial ideas.

Navigating challenges

- **Staff and participant turnover:** Relationships are dynamic. Just as project teams may change, participants in PPI groups will also change over time due to various reasons. It is not a constant source of data but requires consistent work and effort, like any relationship.

- **Engaging diverse communities:** Finding and engaging diverse groups can be very difficult. Strategies involve outreach, creativity, building long-term relationships, and contributing to and supporting the work of relevant community organisations.

- **Working with people who find verbal communication difficult:** Specific techniques are employed to include people with dementia who may find verbal communication difficult. This includes using creative methods like art, focusing on non-verbal communication cues, engaging with their families and carers for insights, and simple acts like maintaining eye contact and gentle touch to show respect and provide comfort. Basic signals from Makaton (a language programme that uses signs, symbols, and speech to help people with learning or communication difficulties express themselves and understand others) have also been explored as a potential tool for communication.

- **Consent and boundaries:** It is crucial to recognise that everyone, regardless of condition, has the right to consent to research involvement. However, it's also important to differentiate between research participants and PPI partners. While research participants require formal consent, PPI partners involved in shaping research questions or design do not necessarily need a signed consent form for these collaborative activities. Legal and ethical considerations regarding privacy and data protection are important.

Evaluating co-production activities

Evaluation of co-production activities can move beyond standard quantitative measures. Instead of just measuring feelings before and after a session, evaluation can focus on what actually occurs during the interaction – how people engage, how they work together, and the connections that are made. Keeping open communication with organisations and individuals, maintaining fluid dialogue, and being open to honest feedback are paramount for understanding how things are going and adapting to people's changing needs.

Key learnings for effective co-production

Based on the team's experience, the fundamental takeaways are clear:

- reach out and go out to meet people - do not expect them to come to you
- invest in building long-term relationships based on trust and mutual benefit
- be creative and flexible in your approaches to support different ways of communicating and engaging people
- recognise and value the knowledge and expertise that people with lived experience bring, often far beyond their specific condition
- listen deeply to understand what truly matters to people, as this is where the most impactful research questions will emerge
- ensure inclusion and diversity are central to your efforts, actively thinking about whose voices might be missing
- view PPI partners as equals and integral parts of your research team, not as subjects or consultees

By embracing these principles, researchers can unlock the richness of lived experience, making their work more relevant, impactful, and ultimately, leading to better outcomes for the people they seek to help.

Watch the Co-Production for Research with Impact webinar.

Chapter 2: Engaging Policy Makers and Practitioners in Research: Lessons from the Active-6 Study

This chapter delves into the critical role of involving policy makers and practitioners in health research, focusing on the experiences of the Active-6 study (NIHR131847) carried out by the NHS Bristol, North Somerset and South Gloucestershire Integrated Care Board. By collaborating with these key stakeholders, the study team significantly enhanced the dissemination and impact of their findings on children's physical activity during and after the COVID-19 lockdowns.

Understanding the Active-6 Study and its goal

The Active-6 study was designed to measure the impact of the COVID-19 lockdowns on children's physical activity levels. Physical activity is essential for children's mental and physical health, yet even before the pandemic, only 41% of UK children met recommended guidelines. With schools closed and restrictions in place, researchers anticipated a potentially significant impact on these activity levels.

Leveraging existing data from a previous study of 10 and 11-year-olds in the wider Bristol area, Active-6 used this as a baseline to measure physical activity as lockdowns eased. Funded rapidly by the NIHR through a public health research fast track call in April 2020, the study collected data in 2021 (short-term impact) and 2022 (medium-term impact).

The core aim of Active-6 was to quickly collect, analyse, and use data to rapidly inform policy and practice decision-making. Recognising the potential for useful findings from this large study, collaboration with a range of policy and practice stakeholders was considered crucial throughout the project.

Patient and public involvement in Active-6

In Active-6, policy and practice colleagues were viewed as a key stakeholder or 'public' group. PPI was integrated into various aspects of the study, not just with policy and practice, but also with schools, children, and parents.

- **Grant application stage:** Input was sought from teachers, parents, and children on data collection plans. Crucially, policy and practice colleagues provided letters of support, explaining the potential usefulness of the data to their work.
- **Study oversight:** A parent member was recruited to the study Steering Committee (oversight) and another to the study Management Group (day-to-day running).
- **Data collection materials:** Children, parents, and teachers provided input on data collection materials and processes.

The Impact Advisory Group: a key mechanism for PPI

A central mechanism for engaging policy and practice colleagues was the establishment of an Impact Advisory Group (IAG).

- **Purpose:** The IAG's primary role was to provide expertise and 'on-the-ground' experience from policy and practice. They advised on data collection plans, and preliminary and final findings were shared with them rapidly to inform their decision-making.
- **Membership:** The group consisted of approximately 25 members initially, but grew over the study's course, with members joining and leaving. Members represented national, regional, and local stakeholders across various sectors related to children's physical activity. Often, those involved were people who led on data or insight within their organisations, seeing value in the study's robust and timely data. The group aimed for a good spread of organisations geographically and by focus.
- **Formation and growth:** The IAG started with existing contacts of the research team. It expanded through identifying representation gaps (e.g., reaching out to Sport Wales and connecting with Public Health Wales). This process of building foundations and relationships was lengthy but helped the findings reach a wide audience.
- **Meetings:** The IAG convened online meetings roughly every 6 months to share next steps and emergent data. While not everyone attended every meeting, turnout was sufficient for productive conversations. Virtual sharing also occurred between meetings, particularly regarding findings and dissemination.

- **Researcher perspective:** The IAG was extremely helpful for immediate feedback on whether emerging findings matched members' on-the-ground observations and for shaping the study as it progressed.
- **Member perspective (Alan Inman-Ward):** As a member from Active Gloucestershire (an 'active partnership' funded by Sport England and NHS Gloucestershire), Alan highlighted how their role involved using evidence and research to inform their work on increasing physical movement and addressing health inequalities. The Active-6 data was timely and critical, providing robust research that helped inform projects like the Active Schools framework. Alan felt included and valued, appreciating the opportunity to bring a "layman's view" and learn from the findings.

Dissemination planning with stakeholder input

Given the goal of rapid dissemination to inform policy and practice, a robust dissemination plan was essential. Involving the IAG in this process was seen as a way to strengthen both the outputs created and the methods of sharing them.

Drawing on advice from an NIHR communications planning workshop, the team mapped out stakeholders (audiences), channels (how/where to reach them), and tactics (resources/materials). Mapping this out revealed gaps in the initial plan, particularly regarding channels and the need for tailored resources for different groups (e.g., a policy briefing would not suit schools).

The IAG played a vital role in refining the dissemination plan:

- selected IAG members were consulted individually about main channels they used to find evidence and industry communications
- they advised on the best resources and formats for the data for themselves and others in their sectors
- draft dissemination plans and resources were shared with the wider IAG for feedback in meetings and virtually

This process opened up previously unknown channels and helped build buy-in, making members keen to share findings through their own networks. Alan noted the benefit of this collaborative approach in helping to influence communications and widen the reach of the findings, especially for non-academic readers.

Tailored dissemination resources

Based on IAG input, the team developed a range of tailored resources:

- **Slide deck:** Advised by members in data/insight roles as a good record and resource. It included study details, findings, and implications. The IAG provided feedback, and the final version was shared for saving in professional channels like Alan's Active Gloucestershire Insight hub.
- **Policy briefing:** Planned from the start and supported by the University of Bristol's Policy Bristol team. IAG feedback was key for highlighting policy implications and connecting findings to current agendas. Shared directly with the IAG and relevant politicians (MPs, Lords, councillors).
- **1-page Summary for club providers:** Developed after an IAG member (a local club provider) highlighted that the policy briefing was not suitable for those delivering sports opportunities. This summary focused on active club attendance findings. Drafted with input from a local provider's staff meeting to ensure appropriate language and focus, then shared with providers and schools.
- **Blog posts:** Short, plain English summaries of academic papers, often published on partner organisations' blogs (like Active Gloucestershire's "we can move" blog). This helped reach audiences who might not read academic papers.
- **Online hub:** A central location hosting all resources, with key items (policy briefing, animation) pinned at the top and folders organised by stakeholder group for easy access. Hosted by Actify (an organisation that provides a digital platform and training services to help the sport and physical activity workforce learn, share, and connect), this platform was free and sustainable as long as Actify exists.

Key learnings and reflections

- **Close working is beneficial:** Engagement throughout the project was helpful for the study and specifically for dissemination. It helped researchers understand data relevance, create appropriate resources, and collaborate on sharing through new channels.
- **Plan for dissemination early:** Strategically mapping audiences, channels, and tactics is highly beneficial and should ideally start as early as possible in a project, although it's never too late.

- **It requires significant effort:** Engaging with stakeholders and tailoring dissemination is a lot of work, requiring dedicated time and capacity, but it is worth it. The IAG relationship continued and grew in subsequent projects.
- **Nurture relationships and networks:** Regular meetings and interactions help build community and trust. People are often happy to connect and collaborate with others in the same field from different perspectives.
- **Be strategic within constraints:** Recognise limitations in time and resources and strategically choose 1 or 2 key dissemination activities aligned with main goals.
- **Experiment and iterate:** "Try a lot of things" – some approaches might not yield measurable impact (like the club provider summary), but others can open doors (like emailing the policy briefing leading to a meeting with an MP). Even less impactful efforts can build relationships and demonstrate understanding.
- **NIHR standards as guidance:** The NIHR standards prompt reflection on how to integrate public involvement. Active-6 was stronger in areas like 'Working Together' and 'Communications' than 'Inclusive Opportunities', which is acceptable; it's not necessary to cover all standards equally in every project.

Positive impact on the target group (parents and children)

While direct feedback from parents and children on the study's impact was limited, the main positive impact is hoped to be via informing policy and practice decision-making.

- The study contributed to the evidence base highlighting increasing inequalities in children's physical activity since the pandemic.
- This evidence is used by organisations working in the sector (alongside data from other sources like national surveys) to target their efforts towards those most in need.
- It is hoped that this ultimately leads to positive changes for families. For example, the data helped bolster efforts to create the Active Schools framework, which is reported to be doing well.

In conclusion, involving policy makers and practitioners as a key 'public' group in the Active-6 study, particularly through the IAG and collaborative dissemination planning, proved invaluable for ensuring the study's findings were relevant, reached the intended audiences, and could rapidly inform efforts to address the impacts of the pandemic on children's physical activity. While challenging and resource-intensive, this approach demonstrated the power of collaboration in bridging the gap between research evidence and real-world action.

Watch the PPI with Policymakers and Practitioners: The Active-6 Study webinar.

Chapter 3: Voices of Experience: Involving Young People in Childhood Obesity Prevention Research

This chapter explores the invaluable contribution of young people to an evidence synthesis project focused on preventing childhood obesity. The project, officially titled Towards optimal public health interventions for preventing obesity in children: a novel evidence synthesis (NIHR131572), was referred to by the team as 'Evidence Synthesis for Components of Childhood Obesity Prevention Effectiveness' (ESCCOPE). This NIHR-funded project was led by Professor Julian Higgins at the University of Bristol and aimed to understand which interventions are most effective for children and young people aged 5 to 18.

The ESCCOPE project at a glance

At its core, ESCCOPE was an evidence synthesis project that utilised systematic reviews. The research involved updating a previous Cochrane review to identify over 200 randomised trials examining the effects of childhood obesity prevention interventions. To interpret this extensive data, the team developed an "analytic framework" – essentially a collection of hypotheses about which intervention characteristics were likely linked to greater effects. This framework guided the coding of trials and interventions, enabling complex statistical analysis to determine which characteristics were associated with larger or smaller impacts on preventing weight gain. A secondary aim of the project was to investigate whether factors associated with inequities, such as socioeconomic status or ethnicity, influenced intervention effectiveness. The goal was to reduce existing inequities or, at the very least, ensure interventions did not exacerbate them.

Why involve children and young people?

From the outset, the project team recognised the crucial importance of involving the target demographic – children and young people. As Julian Higgins noted, these are the people who "understand what impact these interventions might have on their behaviours," which is central to the research goal. Planning for their involvement began even during the funding application phase.

Introducing the Bristol Young People's Advisory Group

Much of the young people's involvement in the ESCCOPE project was facilitated through the Bristol's Generation R Young People's Advisory Group (YPAG). YPAG is a public and patient involvement and engagement group comprising young public contributors aged 10 up to their early 20s who are interested in health and care research. Run by Lucy Condon and Eva Roberts (and formerly Mike Bell), the Bristol YPAG is part of a national initiative called the Generation R alliance, set up by the NIHR. With over 90 members, it is 1 of the larger groups in the alliance, which includes 25 YPAGs across the UK.

How young people shaped the ESCCOPE project

The involvement of children and young people in ESCCOPE was multifaceted and deeply integrated throughout the research cycle.

- **Early consultation:** An initial face-to-face meeting, fortuitously held just before the first formal lockdown, provided valuable early input. Young people shared great ideas for exploring the data and gave a "particularly strong steer about the importance of separating the primary school aged children from the secondary school aged children," which became a central element of the data analysis.
- **Membership on the project advisory group:** Maddie Coleman and Elizabeth Sheldrick were full members of the project advisory group from start to finish. This group included diverse experts, and Maddie and Elizabeth served as the "young people's experts," providing guidance and advice from their vital perspective to ensure the research was comprehensive and relevant. The support from the chair, Jeremy Grimshaw, was key to their effective participation. He held pre-meetings to go over materials and language and used the private chat function during formal meetings to check understanding, allowing the meetings to maintain necessary technicality while ensuring the young people felt included and able to contribute effectively.
- **Developing the analytic framework:** YPAG members participated in dedicated sessions to help develop the analytic framework, shaping the direction of the

study. These sessions, some involving parents for a broader family perspective, provided a platform for young people to share what they felt was important. Maddie and Elizabeth even worked with Julian Higgins beforehand to plan these sessions, offering insights from their experience of participating in research meetings to ensure the language and format were interactive and effective.

- **Coding intervention characteristics (the 'fun factor'):** A significant contribution that emerged directly from discussions with young people was the concept of the ’fun factor’ of interventions. YPAG members were involved in actually coding the interventions described in trial reports based on how fun they were. Using a questionnaire, 35 young people rated short extracts describing interventions on a 5-point scale from "really boring" to "really fun," and also rated their appeal to specific age groups. The rationale was that "who better to code whether an intervention is a fun thing to do? Well, the children and young people themselves". This 'fun factor' rating was then used in the analysis to see if interventions coded as more fun by YPAG members were more effective at preventing obesity. While this was a fantastic example of researcher responsiveness, the team learned that planning more time for this activity and potentially converting the original paper snippets into plain English beforehand would have been beneficial.
- **Interpreting results:** Maddie, Elizabeth, and other YPAG members were involved in further PPI meetings to look at the analysis results. In further dedicated sessions, the young people helped the researchers interpret what they saw, particularly when results were unexpected. This step was crucial for the young people, as they often feedback that they want to hear how their input has shaped the research, which helps them feel valued and understand their contribution.
- **Disseminating findings:** Elizabeth played a key role in sharing the study's findings at a meeting of experts, including teachers and members of the local council. She presented her role and, importantly, fed back the YPAGs understanding and interpretations of the findings, ensuring that the young people's perspectives were heard directly by key stakeholders.

Reflections and key lessons for PPI

The team and young people reflected on the process, highlighting several key lessons for effective PPI with children and young people:

- **Communication is paramount: consistent communication** is essential to ensure public contributors feel included and part of the team. While emails and messages are quick, occasional meetings are also good for catching up.
- **Provide dedicated support:** Having a dedicated contact person (like Lucy or Mike) acts as a main point of contact, offering support, answering questions, and providing a "friendly face". Pre- and post-meeting catch-ups also help build relationships and comfort.
- **Involve more than 1 contributor:** Having multiple young people involved together significantly boosts confidence and provides peer support. Larger groups (e.g., 5 or 6) offer even better peer support, broader input, and continuity if individual members need to step away.
- **Secure dedicated resources:** The success of PPI in this project was strongly linked to having dedicated people (facilitators like Lucy and Mike) and access to the YPAG resource. It is vital to budget properly for public involvement, including reimbursement, pre-meeting time, travel, accessibility needs, and training, trying to anticipate various eventualities. Do not underestimate the time and resource needed from the research team as well.
- **Show appreciation and value:** Public contributors need to know their input is "crucial" and not just a "tick box". Ensuring they feel appreciated, and their opinions are valued increases engagement. Saying thank you and providing appropriate reimbursement is important. The Bristol YPAG pays young contributors the NIHR recommended rate, typically via BACS transfer, which is generally preferred over vouchers. Offering other forms of support, like references for university applications or training, can also be valuable.
- **Make it fun and interactive:** Incorporating fun and interactive elements is essential for engaging young people. This could involve using colourful materials, pictures, simple language, quizzes, game formats, or 'what if' scenarios in meetings and briefing materials.
- **Be flexible and responsive:** Researchers should be open to taking on board what public contributors suggest and be flexible and responsive to changing plans as needed. The fun factor' coding is a prime example of this responsiveness.

- **Avoid assumptions:** It is important not to make assumptions about what people will say or how they want to be involved; instead, ask them directly and present different options.
- **PPI can convert sceptics:** Julian Higgins, initially somewhat sceptical about PPI in evidence synthesis, was "absolutely bowled over" by the genuine meaningfulness of the young people's involvement. He now sees it as essential in projects where the public brings a specific "expertise that you might not have," such as understanding the target population's behaviours and perspectives on interventions.

Practical considerations for YPAG engagement

The discussion also touched on several practical aspects of working with YPAGs:

- **Diversity and recruitment:** While the Bristol YPAG was not always diverse, significant work has been done to increase representation. Strategies include going out to communities, speaking at schools and community groups, and having young people themselves present about their involvement. Moving online during the pandemic also helped broaden membership.
- **Managing group size:** Although the Bristol YPAG has over 90 members, it's rare for them all to be involved in one activity. Opportunities are offered via a mailing list, and members volunteer, typically resulting in smaller, more manageable session groups (e.g., 6 to 8 people) where individual voices can be better heard.
- **Balancing conflicting opinions:** While not a major issue in the ESCCOPE project's specific meetings, the YPAG has a group agreement emphasising respect, allowing everyone a chance to speak, and commenting on ideas rather than individuals. Reiterating the value of each young person's expert opinion is key.
- **Age and experience for formal meetings:** For more formal research meetings, experience in PPI is as important as age. While younger teens (around 15+) can cope, prior experience in other YPAG activities helped Maddie and Elizabeth participate effectively in the advisory group. It is crucial to assess individual readiness and provide tailored support. Creating separate peer group discussions that feed into formal meetings can also be helpful.
- **Ethical working practices:** While public involvement is not research *on* participants and does not technically require formal ethical approval, it is essential to work ethically. This includes using application forms, obtaining

parental consent (especially for younger members or sensitive topics), providing introductory sessions, and ensuring parents are kept informed.

- **PPI input versus primary data:** A key distinction is whether you are working with people to improve the research process (PPI) or doing research *about* people (collecting primary data from participants).

Conclusion

The ESCCOPE project stands as a powerful example of how involving children and young people as genuine partners can enrich health research. Their contributions, from shaping analysis plans and coding interventions to interpreting results and disseminating findings, were integral to the project's success. The reflections from the research team and the young contributors themselves offer valuable lessons on the practicalities and profound impact of effective PPI, particularly when researchers are flexible, responsive, well-resourced, and truly value the unique expertise young people bring.

Watch the Involving Children and Young People in an Evidence Synthesis Around Prevention of Childhood Obesity webinar.

Chapter 4: Driving Health Forward - Embedding Public Involvement in the SHIFT Programme

This chapter explores the Structured Health Intervention for Truckers (SHIFT) programme (15/190/42), an NIHR study led by Loughborough University. The research initiative focused on improving the health and well-being of heavy goods vehicle (HGV) drivers in the UK. It delves into how PPI was not merely an add-on, but a foundational and continuous element embedded from the programme's conception through to its implementation.

Understanding the challenge: the health inequalities faced by HGV drivers

HGV drivers are recognised as an essential occupational group in the UK, contributing significantly to the logistics sector. However, their profession poses unique and substantial health risks. Due to the nature of their job, drivers face numerous health-related challenges, including prolonged periods of sitting, limited opportunities for physical activity, limited access to healthy food options, and the isolated nature of their work. Tight delivery schedules often lead to high levels of stress and anxiety. Furthermore, factors like traffic conditions can result in low levels of job control, contributing to poor mental health and well-being. Many drivers work shifts, often at night, leading to restricted and disturbed sleep.

Cumulatively, these factors promote unhealthy lifestyle behaviours, leading to HGV drivers experiencing higher rates of chronic diseases, higher rates of obesity prevalence, and reduced life expectancies compared to other occupational groups. Worryingly, evidence suggests that drivers with obesity are twice as likely to be involved in an accident as those of a healthy weight, impacting road safety for everyone. This paints a clear picture of a population with a significant need for health support.

While significant investment is made in ensuring the health and safety of the vehicles themselves (with rigorous checks before every shift), drivers' health tends to be overlooked. This can leave drivers feeling undervalued and unappreciated, further affecting their mental health and well-being.

The genesis of SHIFT: an industry-identified need

The idea for the SHIFT programme did not originate solely within academia; it was identified by health and safety managers within a logistics operator in 2013. They approached Loughborough University colleagues, expressing concern about their drivers' health and seeking help, as their previous attempts to improve health had been unsuccessful. This direct approach from individuals working within the industry kick-started the entire programme of research. This origin story underscores why embedding public involvement throughout the project was considered so important – the very idea came *from* the public, specifically those working in the logistics and transport industry.

Early phase work leading to the development of the SHIFT intervention and the subsequent NIHR grant application was conducted in close collaboration with this local logistics company. This involved a PhD student conducting a surveillance study to understand drivers' health profiles and behaviours. A Knowledge Transfer Partnership allowed a postdoc researcher to be embedded part-time within the company, gaining first-hand experience of the challenges drivers face daily. This embedded approach included ride-along interviews with drivers across the country to observe and understand their experiences. Information gathered from studies, informal conversations with health and safety teams and drivers, allowed the researchers to co-create a potential intervention designed to help drivers adopt healthier behaviours within the constraints of their job. A pilot study with 57 drivers then tested this initial intervention, showing potential, particularly for increasing activity levels. Based on these findings and further conversations with drivers and company management, the SHIFT programme was refined before seeking formal funding.

An All-Party Parliamentary Group report published around the time of grant planning in 2015 also highlighted concerns for UK HGV drivers' health and called for the industry to do more, providing crucial evidence of a recognised need for this work when applying for NIHR funding.

What is SHIFT? The intervention components

SHIFT is a multi-component, theory-driven health behaviour programme, aimed at promoting positive changes in physical activity, diet, and sitting time among HGV drivers. A core component is a 6-hour structured, interactive health education session. This session was adapted from diabetes prevention education, developed by Leicester Diabetes Centre (University Hospitals of Leicester NHS Trust) used by the NHS but was specifically tailored for drivers. The content and tailoring were informed by the early research understanding the unique challenges and barriers drivers face. The intervention also included other components, such as providing equipment for activities in the cab and offering a Fitbit (fitness tracker) and health coach support.

Embedding public involvement: a continuous journey

The success of SHIFT is intrinsically linked to its embedded PPI journey. This involvement was extensive and continuous, particularly engaging drivers and the industry.

- **Involving stakeholders in grant planning:** Beyond the initial logistics partner, early engagement included the Chartered Institute of Logistics and Transport (CILT), the professional body for individuals and organisations involved in goods and people movement and their associated supply chains. A contact there became an ambassador for the work, helping to find further industry partners by highlighting the project in their newsletter. This quickly led to DHL, a global logistics company, approaching the team, ultimately partnering for the main trial. Multiple meetings and presentations were held with DHL's senior leadership team to explain the project, potential benefits, and discuss feasibility. DHL provided company-level driver data, which was vital for informing the trial's power calculation. Crucially, PPI input from DHL led to significant refinements in the proposed SHIFT intervention and outcome measures for the larger trial. For example, a component offering free fruit was dropped as it was not feasible across all DHL sites. Outcome measures were adapted from whole blood samples to fingerprint blood sampling due to logistical challenges and DHL's feedback that the former might deter driver participation.
- **Continued involvement during the funded trial (2017 to 2021):** Throughout the NIHR-funded period, public engagement was maintained. DHL contacts significantly informed the recruitment messaging and study documentation. Highlighting the value of the comprehensive health check offered (estimated at £300 privately) was a key message suggested by DHL, which proved highly effective, leading to an over-recruitment of drivers.
- **Building trust with drivers:** A key aspect was building trust with the drivers themselves, who might be apprehensive about health checks impacting their licenses and livelihoods. The research team spent time at transport sites *before* recruitment (’lobby days’) to answer questions, reassure drivers of their independence from the company (often wearing branded Loughborough University kit), and build rapport. This time spent listening and chatting to drivers, showing empathy for their challenges, was crucial in gaining their trust and getting them on board.
- **PPI group and feedback:** The study had a dedicated PPI group, formed specifically for this project, initially recruited through word of mouth, contacts, and via the NIHR Leicester Biomedical Research Centre PPI lead. While reflecting the predominantly white male demographic of the HGV population, efforts were made to include diversity where possible, such as piloting

intervention components with a female independent driver. This group had regular meetings to review plans, discuss progress, and provide input on all study documentation to ensure it was easily understood and accessible for drivers.

- **Piloting and engagement activities:** Health assessments and education sessions were piloted with independent drivers and the DHL senior health and safety team to get feedback and buy-in. The research team also attended DHL well-being conferences with stands showcasing aspects of the intervention and offering health checks.
- **Partnership with Unite the Union:** Developing a strong relationship with Unite the Union, a trade union for the drivers, was another significant success in public engagement. Building trust took time, demonstrating that the research team's interest was purely driver health promotion, independent of operators. The union has since been extremely supportive, inviting presentations at their conferences and advocating for drivers to participate in the research.

Trial findings

The main trial, a cluster RCT involving 25 transport sites and 382 drivers (reflecting the HGV demographic), faced challenges, including participant and site drop-out. Despite a reduced sample at the 6-month follow-up (206 drivers), the programme appeared effective. Relative to the control group, SHIFT drivers accumulated over 1,000 more steps per day across working days and non-workdays and reduced their sitting time at 6 months. A process evaluation showed widespread support for converting the programme into a driver training module.

- **Knowledge translation and implementation involvement (2022 to 2024):** Following the funded trial, PPI continued to inform the translation of SHIFT into practice:
    - **Consultation events:** A public event held at Loughborough University presented trial findings and ideas for converting SHIFT into a driver training module (Continuous Professional Competency or CPC module). This event gathered relevant stakeholders, including drivers, union representatives, transport managers, and trainers. The audience was asked about their support for a SHIFT CPC module, with 100% indicating their support. Feedback was also gathered on key aspects to include.
    - **Co-creation and implementation:** This consultation led to a partnership with Wincanton, whose Senior Health and Safety Director saw merit in SHIFT. Over 2 years (2022 to 2024), the Loughborough University and Leicester Diabetes Centre team worked closely with Wincanton driver trainers and drivers through co-creation workshops to adapt the SHIFT education session content into a driver training module. Based on industry feedback that a full 7-hour compulsory module was not feasible alongside other training, a new, shorter, bite-sized version

  called "Short SHIFT" was developed. This industry-led idea allows companies to embed awareness-raising health content into mandatory training. Both the 7-hour SHIFT CPC module and the Short SHIFT component have been accredited by the Driver and Vehicle Standards Agency. Leicester Diabetes Centre staff trained 65 Wincanton driver trainers to deliver Short SHIFT as part of their mandatory training cycle, meaning all 6,500 Wincanton drivers have now experienced Short SHIFT. The 7-hour module is offered optionally; 7 driver trainers were trained to deliver this.
  - **Informal dissemination:** PPI members were informally involved in knowledge translation. An independent driver with a strong social media following helped disseminate bite-sized messages about the study findings. The Unite the Union contact was instrumental in encouraging drivers and union reps to attend dissemination events. The union continues to invite the team to present at conferences, providing a valuable platform for ongoing dissemination and feedback. An infographic summarising the main findings was also developed and shared, informed by feedback from drivers and managers.

Key lessons learned from PPI

- **Building trust is paramount:** The single biggest take-home message is the importance of building trust with the target group and industry colleagues. This takes significant time and sustained effort.
- **Listening and responding:** Actively listening to partners and PPI members, acting on their feedback, and demonstrating that their input has been valued and used is crucial for building faith and showing they have a real impact.
  Accessibility and reassurance: Being accessible to speak with and ensuring all study documentation is understandable and readable is vital. With drivers, specific reassurance is needed regarding data sharing and researcher independence to alleviate concerns about job security.
- **Long-term relationships:** Building long-term relationships with key stakeholders, like unions and companies, is highly beneficial.

In conclusion: The SHIFT programme demonstrates how deeply embedding public involvement from the outset and maintaining it throughout the research and implementation journey is vital for developing effective, acceptable, and sustainable interventions for specific populations facing health inequalities. By listening to drivers and industry partners, the research team was able to co-create solutions that address real-world challenges and have a genuine chance of improving the health and well-being of this essential occupational group.

Watch the Structured Health Intervention for Truckers (SHIFT) – Embedding PPI from Programme Conception to Implementation webinar.

Chapter 5: Building Capacity and Inclusion: Insights from the SCRiPT Study on Adult Social Care Research

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Inclusive involvement is now widely seen as crucial in research, yet its implementation in Adult Social Care presents unique challenges and opportunities. This chapter draws on insights from the SCRiPT study (NIHR131100), which was led by the University of Hertfordshire. The study focused on building research capacity in social care, highlighting the complexities and strategies for achieving meaningful and inclusive public involvement.

The SCRiPT Study: Enhancing research capacity in adult social care and social work in the East of England: testing the feasibility of Social Care Research in Practice Teams

The SCRiPT study aimed to test ways to build research capacity in adult social care. 1 primary method involved setting up 4 research in practice teams around priority topic areas, operating within a Communities of Practice framework - where groups of people with a common concern or passion learn how to do it better as they interact regularly. These teams were funded for 2 years and typically included a social care practitioner lead, additional practitioners, and crucially, experts by experience – up to 3 per team. Each team designed and conducted a small research study. Topics explored included discharge to assess, occupational therapy reablement services, occupational therapy in Learning Disability Services, and the ethics of technology-enabled care data sharing. An overall evaluation of the process was also conducted.

Partnership for inclusion: the role of Shaping Our Lives

A key aspect of the SCRIPT study's approach to involvement was the partnership with Shaping Our Lives. Shaping Our Lives was a co-applicant on the study and took a lead role in recruiting and supporting the experts by experience. They specialise in the inclusive involvement of people from marginalised communities, particularly those facing intersectional barriers, disabled people, service users, and people with lived experience. Securing additional funding expanded Shaping Our Lives' role in the project.

Shaping Our Lives managed various aspects of involvement, acting as a driving force on matters like payments, expenses, ensuring access and support requirements were met, and guiding participation. They appreciated the flexibility afforded by their university partners, which allowed them to adapt their approach as the project progressed.

Navigating the landscape: challenges in inclusive involvement

Implementing inclusive involvement in social care research presented several significant challenges:

- **Terminology:** The language used in social care is important but complex. Terms like 'service users', 'people who draw on social care services', and 'experts by experience' are contested, and there is not 1 universally accepted term for people involved in social care research. In the SCRiPT study, there were strong opinions both supporting and opposing the use of these terms, reflecting the complexity and sensitivity of identity in this context. In reporting on the study, the team adopted the term ‘experts by experience’ (EbE) - this is still common terminology that refers to people who have personal experience of using or caring for someone who has used social care services. However, it is still important to acknowledge there is no 1 term that can be agreed upon.

- **Recruitment and access:** There is no readily available source for accessing people who draw on social care provision, unlike the health sector which has patient forums and staff familiar with recruiting patients. This makes finding people with both the capacity to be involved and direct experience of specific research topics a real challenge.

- **Diverse and marginalised communities:** Social care is means-tested, meaning people using these services are often lesser-heard voices who may have less confidence or be unaccustomed to being heard. They are likely to come from complex, marginalised, and diverse communities and face multiple inequalities, presenting barriers to accessing them for research involvement. Meaningful and diverse engagement is resource-intensive, slow, and requires time and money.

- **Building trust:** The slow nature of engagement is partly due to the need to build trust. People who need or draw on social care services might have perceptions or fears of mainstream social care services as discriminatory or unsafe, leading to a reluctance to engage in research related to them.

- **Changing roles for staff:** Social care staff are often not used to working with people who draw on social care services as peers, who are giving advice and contributing to research, rather than being supported as clients. This presented a steep learning curve for practitioners.
- **Ethics and governance:** This proved to be a minefield. Clarity on required approvals was difficult, and local authorities often did not understand or respond to HRA processes like the NHS (lacking Research and Development offices). This necessitated additional local authority and Association of Directors of Adult Social Services approvals, creating multiple layers, bureaucracy, repetition, and significant delays, particularly in recruiting experts by experience. Navigating this process was also challenging for the social care practitioners new to research.

Furthermore, recruiting experts by experience into the Communities of Practice teams sometimes happened later in the project timeline. This required careful planning to ensure they were introduced naturally and felt their experience was relevant, enabling them to contribute as partners rather than just people whose services were being addressed.

Strategies for success: overcoming barriers and building trust

The SCRIPT study team and Shaping Our Lives implemented several strategies to navigate these challenges:

- **Partnering with specialists:** Working with organisations like Shaping Our Lives, who specialise in inclusive involvement, was incredibly valuable.
- **Targeted recruitment:** Shaping Our Lives focused on collaborating with research leads to align recruitment with needs and expectations and identify individuals with complementary lived experience. They leveraged their own networks and used a community champion model, tapping into existing local community organisations with pre-existing networks. They kept momentum during the recruitment process to find suitable participants.
- **Integrating late joiners:** To address experts by experience joining teams later, meetings were organised and facilitated between the leads and participants to clarify expectations for both sides. This focused on what involvement organisers should do to meet access/support requirements and address barriers, not just what contributors should do.
- **Training and support:** Workshops and training sessions were held for research leads on how to work effectively with experts by experience, especially for those with no prior experience. Social care practitioners also received a

bespoke training package at the start of their involvement, covering involving members of the public, and participated in external fellowship training.

- **Ongoing support structure:** Shaping Our Lives provided overarching steering and management for all involvement aspects. They conducted informal 1-to-1 meetings with both research leads and experts by experience throughout the study. These sessions were not initially planned but proved valuable for capturing feedback, identifying remaining barriers, and finding ways to support empowerment.
- **Representation in core team:** Having direct involvement and representation of lived experience, through Shaping Our Lives, as part of the core project team was pivotal. This ensured involvement was planned, valued, and placed at the heart of the project to better understand social care and build research capacity.
- **Building rapport and trust:** Simple but effective practices, such as having a few minutes for a social catch-up at the start and end of meetings and checking on well-being, helped build rapport and create a safe environment where people felt comfortable speaking. This fostered trust.

The voice of experience: contributions and impact

The involvement of experts by experience was seen as adding huge value and helping to create capacity for further involvement. Teams were productive and completed studies, with ongoing impact.

Hameed, who prefers his role to be described as a ‘lived experience partner’, shared his perspective. He was initially intrigued by the study and felt he had much to offer, drawing on his background as a carer and service user. He said he really enjoyed being involved, learning and sharing, feeling that "as much as I gave, I got back". He took what he learned into other projects, connecting insights across different areas.

Despite initial challenges building online rapport, Hameed found ways for meaningful connections with the research lead. He felt his passion for equity, diversity, and inclusion was recognised. Having other public involvement members brought different, valuable perspectives, illustrating how different viewpoints could all be "right" and leading to stronger engagement. Hameed felt the project did a "great job" keeping them engaged.

A highlight for Hameed was his involvement in producing an animation, which he described as 1 of his "favourite parts" and gave him a "sense of self-esteem and confidence boost". He contributed significantly, ensuring it reflected the realistic experiences of patients and carers discharged from hospital.

Informal 1-to-1 meetings indicated that experts by experience felt their involvement "really mattered" to what the research teams were trying to achieve. Observations of team meetings aimed to understand dynamics and power dynamics between lived experience partners and practitioners.

The impact of public contributors was formally evaluated, led by Shaping Our Lives. This evaluation drew on the informal 1-to-1 feedback and reflections shared by experts by experience at various project meetings and conferences. A paper focusing on the experts by experience perspectives from the study is currently being written, co-authored by an expert by experience.

Managing expectations about the research process timeline was important, as the social care practitioners, also new to research, were themselves surprised by how long it took. Discussions about this did occur within the teams. Hameed's experience highlighted the importance of checking on participants' well-being and ensuring they felt supported and informed about outcomes at the project's conclusion. He described his journey as a "a long, happy journey" due to the support received.

Reflections and looking forward

The SCRIPT study provided a valuable, albeit steep, learning curve for everyone involved. It reinforced the understanding that meaningful public involvement in social care research is not simply "doing more of the same" as in other fields like health. It requires dedicated effort to reach diverse communities, aligning involvement with the goal of reducing inequalities. While challenges like ethics/governance bureaucracy and recruitment persist, the positive outcomes, ongoing impact, and continued appetite for capacity building and networking demonstrate the potential when inclusive involvement is strategically supported and valued. The lessons learned regarding terminology, recruitment strategies, ongoing support, and building trust are critical for future endeavours in this vital area of research.

Watch the Inclusive Involvement in Adult Social Care Research webinar.

Chapter 6: Embedding Co-design and Co-production in Practice: Learning from Refugee Mental Health Research

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Effective PPI is increasingly recognised as vital in health research. Going beyond consultation, co-design and co-production involve actively working in partnership with those affected by the research topic to shape the research process and outcomes. This chapter explores the principles and practical application of embedding co-design and co-production, drawing on insights from the Routes to Wellness project (NIHR134589) led by the University of Plymouth.

The Routes to Wellness Project: a case study

The Routes to Wellness project is an NIHR funded programme of research focused on developing, designing, and testing a peer support model for refugees in the community to improve their mental wellbeing. This project is a mixed method study over 3 phases. A key aspect of its methodology has been the use of Experience-Based Co-design (EBCD).

The project was a very big collaborative effort, involving exciting and engaging contributions from a range of different higher education institutions across the UK, really important non-governmental organisations working with refugees, and significantly, people with lived experience. Early conversations began in 2017 with community members to understand priority areas for refugee and asylum seekers. The project was funded in early 2021 and 2022. The team feels they successfully applied for funding and are addressing a real community need precisely because the prioritisation came from the community themselves.

Why co-design and co-production? The power of EBCD

EBCD was chosen for the Routes to Wellness project because it matched the principles by which the team wanted to work. EBCD typically improves existing services, but here it was applied to a completely novel space to develop something new.

The methodology relies on participatory, equitable relationships to achieve meaningful change based on people's experiences. By taking service users' experiences and understanding the nature of the problem through narrative, researchers can derive really important stories which can drive through the change or development sought. It has a transformative element, is based on equity and values of equity across everybody, and because it is based on narrative data, it has the catalyst potential to really change the mindsets, behaviours, and thinking of people involved in service delivery. The team felt it matched their principles and aims. A stringent adherence to steps is important, paying particular attention to the context. Most importantly, EBCD is based on narrative and is about changing behaviour. Because it is based on equity, it allows for working in a way that crushes the hierarchy and creates a more egalitarian space, valuing the different knowledges that space can surface. Patients, carers and the public were involved from the start at all stages of the project.

The project was guided by key principles, including:

- **Personhood:** Recognising people's strengths and capabilities. This was core to the peer support model and all engagement.
- **Sharing power:** Viewing societies as storehouses of capabilities and resources and trying to share and distribute power in all activities.
- **Person-centred care:** Seen as a way of being, existential, requiring constant reflection.
- **Social capital:** Recognising its essential role for health and well-being, involving being socially connected, valued, listened to, and having purposeful roles.
- **Trust and trustworthiness:** Underpinning and enacted throughout the whole programme. Building trust began 6 months before data collection.
- **Sensitivity to circumstances:** Recognising structural pressures, differing cognitive resources, relational understanding, and social norms due to varied backgrounds. Ethical guidelines were developed recognising challenges like

legal precariousness and power imbalances. It was crucial not to assume vulnerability but to recognise that circumstances are fragile, not the person.

Co-production in action: phases of the Routes to Wellness Project

The Routes to Wellness project systematically embedded co-design and co-production across its phases:

- **Phase 1: data collection (discovery)**
    - Gathered information on how people expressed and experienced mental distress.
    - Used 1-to-1 interviews and focus groups with refugees/asylum seekers and service providers.
    - Identified "touch points" specific moments or interactions that were identified as causing strong emotional responses for refugees and asylum seekers in relation to their mental distress.
- **Phase 2: co-design**
    - A series of workshops were held, bringing together academics, people with lived experience, and service providers.
    - Public contributors reviewed Phase 1 data in presentation formats (text cards, images) and helped establish a common language.
    - Workshops explored decision-making around accessing services. Creative activities like "if, then because" scenarios were used in workshops to explore decision-making around accessing mental health services. This creative activity involved participants articulating a situation ("if"), their response to it ("then"), and the underlying reasons or feelings behind that response ("because"). This method helped to uncover the nuanced emotional and practical factors influencing individuals' choices in seeking support.
    - Participants discussed how a peer support worker could help and defined their characteristics.
    - The research team created scenarios (vignettes) from touch points, which team members and volunteers acted out. Public contributors watched and acted as "directors," intervening to guide how a peer support worker should and should not act.

    - Participants helped define requirements for becoming a peer support worker, including training, legality, experience, qualities, supervision, and mentoring needs.
    - The team developed an app prototype based on workshop findings about needed tools and toolkits, aiming to support peer support workers with easy access to services and information.
    - Evaluation methods for the peer support worker's work were co-designed. Contributors reviewed existing questionnaires and provided feedback on language and modality.
- **Phase 3: implementation and feasibility test**
    - The project recruited 6 peer support workers. Crucially, a person with lived experience sat on the interview panel, and volunteers with lived experience observed candidate interactions as part of the selection process.
    - The peer support model was implemented, and referrals were received.
    - A mixed method evaluation framework is being used, including qualitative conversations and measures translated into different languages.
    - Initial findings show positive impacts, such as increased social connections, reduced stigma of discussing mental health, reduced perception of isolation, and appropriate use of services. A public contributor shared how being part of the project helped them feel empowered to talk about their pain and problems.

Demonstrated impact and contribution

Co-production had tangible impacts on the project:

- **Changing the project name:** Initially titled ’forced to flee,’ the name was changed to routes to wellness based on feedback from an asylum seeker volunteer who felt ’forced’ was uncomfortable and preferred something more positive and empowering.
- **Logo design:** A volunteer from the project's art club designed the logo. The artwork used to symbolise the project was created in an early creative workshop with refugees and asylum seekers. The picture represents hope, integration, post-traumatic resilience, and the journey to safety, symbolising the complexity of loss and growth.

- **Shaping peer support worker intervention and training:** Public contributors helped develop the model of peer support and the training for peer support workers.
- **Guiding peer support worker recruitment:** Lived experience was integral to defining job descriptions and sitting on interview panels. The requirement for peer support workers to have lived experience came directly from early engagement and the co-production group, as people wanted support from those who understood their experiences and with whom they could build trust.
- **Developing resources:** Informal conversations, visits, and workshops led to the development of guidelines for working with interpreters and peer support worker training open to the public – activities not planned in the initial project proposal, but which emerged through contributions.
- **Translating concepts:** A peer researcher played a key role in engagement and in translating academic language into language that is easily understood and digestible for participants.

Lessons learned and practical considerations

Working through this project illuminated key lessons for effective co-production:

- **Reciprocal relationships:** Beyond fair payment, it's vital to find other ways to value people's time and give back. Examples included offering named authorship on papers, spending time on co-researchers' own projects, and offering job references.
- **Therapeutic potential:** Co-production research can be therapeutic for some participants, providing space for their words and a method of release through helping others and making change. To demonstrate this, public contributors made an impact film to communicate this.
- **Trans-culturally trauma-informed approach:** This is important for any population. Key aspects include:
    - discussing expectations from the beginning so people can make informed choices
    - thinking about how best to work with interpreters
    - discussing means of support if material is distressing, perhaps using briefing/debriefing setups
    - being consistent and reliable

    - openly talking about how personal cultural interpretations and experiences might shape the research

- **Practical tips:** Organising payment *before* work starts or immediately after meetings is valued. Being flexible around participants' availability and times is helpful. Saving participants' time on administrative tasks they do not value is appreciated. Paying for *all* time spent on the project, not just direct meetings, is important. The overall theme is finding ways to value their time as much as your own.

The project team also acknowledged challenges such as different temporalities between institutions and services, sustaining regular involvement, and communicating research and data effectively. Organising engagement activities like celebration events injected energy and joy. Adequate resources and funding are essential, particularly for paying for contributions and childcare.

Finally, a key learning was that doing trauma-informed work takes time. There is a real importance to doing slower research when working with people who have experienced trauma.

Conclusion

The Routes to Wellness project demonstrates how embedding co-design and co-production, particularly using Experience-Based Co-design, can lead to research that is more relevant, acceptable, and impactful, especially when working with diverse and potentially vulnerable communities like refugees. By valuing lived experience as equitable knowledge, fostering reciprocal relationships, and adopting trauma-informed and flexible approaches, researchers can create genuinely collaborative projects that not only develop needed interventions but also empower participants and drive meaningful change.

Watch the Embedding Co-design and Co-production for Refugees Mental Health webinar.

Chapter 7: Key takeaways

This chapter consolidates the pivotal insights shared during the NIHR PPI in Action webinar series, presented through the lens of the UK Standards for Public Involvement in Research. Together, they offer a practical, experience-based roadmap to high-quality, inclusive, and effective public involvement in research.

Our takeaways and practices are not exhaustive, nor are they intended to be prescriptive. Rather, they are pointers and examples of how the UK Standards for Public Involvement can find expression in research practice.

1. Communications

Standard: Use plain language for well-timed and relevant communications, as part of involvement plans and activities.

Takeaways and practices:

- **Develop a communications plan for involvement activities:** Undertake a communications plan, mapping out your audiences, channels and tactics. The Active-6 study developed a communications plan based on the "stakeholders or audiences, channels and tactics" model from NIHR Applied Research Collaboration (ARC) West, an organisation that conducts applied health research in collaboration with healthcare partners, patients, and the public to improve health and care services. The plan helped them to strategically map out who they wanted to reach, how to reach them, and what resources to create, helping them identify groups they were "missing" and appropriate communication tactics.

- **Communicate clearly and consistently:** Use plain language and accessible materials, especially when working with young people or non-academic audiences. Consistent communication through various channels (emails, messages, informal chats) is important to keep everyone informed and feeling part of the team. Make communication materials engaging and accessible. Visual and interactive methods—such as paintings in dementia research—supported non-verbal communication.

- **Tailor communication and utilise varied channels**: Adapt communication methods and materials (e.g., graphics, non-verbal approaches like arts, interactive methods like quizzes) to suit diverse audiences and preferences, including terminology. Use varied channels (e.g., blogs, chat functions in pre-meetings) to ensure ongoing, accessible communication that keeps contributors informed and feeling integrated, as exemplified by Active-6/ESCCOPE using diverse digital methods.

- **Adopt structured and informal feedback loops:** Offer, gather, act on and share feedback with the public. The SCRiPT study proactively introduced "informal 1-to-1 meetings" with research leads and experts by experience throughout the study to "capture feedback and reflections". This process directly helped identify and address "barriers to inclusion" and empowered contributors, making them feel their involvement "really mattered". Hameed, a lived experience partner, highlighted the value of regular "social catch ups" that fostered a safe environment for speaking up.

- **Plan for dissemination early and strategically:** Map out how to share findings from the start and identify stakeholders, communication channels and tailored resources. Co-create dissemination tools with contributors to ensure relevance. In SHIFT, involvement helped shape a training programme that reached thousands of drivers.

- **Share learning and impact:** Actively and widely share your public involvement learning and achievements through diverse channels, including integrating insights into publications, directly communicating with communities, utilising digital platforms, engaging in broader advocacy, and fostering internal learning. The Active-6 Study published a study synopsis which includes dedicated sections on PPI and their Impact Advisory Group. They created a central online hub for all resources, including a policy briefing and a short animation summarising findings, with folders tailored for different stakeholder groups. Links to all their papers were also provided.

2. Working together

Standard: Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

Takeaways and practices:

- **Clearly define purpose, roles, and expectations:** Jointly establish and record the core purpose of public involvement from the project's outset (e.g., responding to an industry-identified need like in SHIFT), and ensure all parties have a shared, transparent understanding of their specific roles, responsibilities, and the precise nature of their involvement (e.g., clarifying "collaboration" versus "co-production" as Active-6 did), to build a foundation for effective and well-managed partnerships.

- **Cultivate trusting, long-term relationships and safe spaces:** Prioritise building deep, sustained relationships with public involvement groups, ideally before specific research tasks begin. Dedicate time for informal engagement (e.g., casual chats, regular check-ins) to foster psychological safety and mutual trust, which is critical for open communication and sustained, meaningful involvement. In the dementia research project, "long-term relationships and consistency in working with individuals" were highlighted as crucial for fostering trust and deeper engagement.
- **Explore diverse and flexible ways of working together:** Be prepared to explore different ways of collaborating. Moving past a “1-size-fits-all” approach allows for more inclusive and effective partnerships. The SCRIPT study exemplified this by integrating "experts by experience" as peers directly within their "Research in Practice" teams, going beyond standard advisory groups.
- **Ensure accessible, responsive and action-oriented communication:** Effective collaboration hinges on communication that is not only clear but also adaptable and leads to tangible changes in the research process. In the ESCCOPE study, young people were involved from the very beginning in shaping the research direction. During sessions to develop the analytic framework, the young people emphasised that interventions needed to be "fun". This direct feedback led the research team to incorporate a novel "fun factor" into their data analysis, with 35 young people rating extracts from previous papers on how fun and appealing interventions would be. This illustrates responsive communication by integrating their lived experience into the core methodology, and action-oriented communication by enabling them to actively participate in the coding process, fundamentally shaping the

research interpretation, and showing how their input "helped the researchers and their projects."

- **Embed lived experience directly in core teams:** Aim to make individuals with lived experience integral members of your core project teams and steering committees, ensuring their involvement is deeply embedded throughout the research process rather than being an add-on. In SCRIPT, "experts by experience" were full peers within dedicated, funded research teams. These teams, funded for 2 years, included a lead social care practitioner, additional practitioners, and up to 3 experts by experience per team, who designed and conducted research studies. This kind of deep integration, where individuals with lived experience become integral members of project teams and steering committees, truly embeds their involvement throughout the research, rather than just adding it on.
- **Value lived experience as expertise:** Recognise the deep insight and knowledge that public contributors bring. Their input can provide key insights that researchers might not have, shaping the research questions, methods and interpretation of findings. This should be valued. For example, public contributors were co-authors and decision-makers in multiple studies, including Routes to Wellness and Active-6.

3. Inclusive opportunities

Standard: Public involvement partnerships are accessible and include a range of people and groups, as informed by community and research needs.

Takeaways and practices:

- **Proactively engage and target recruitment:** Instead of expecting contributors to come to you, actively go out and meet people in familiar community settings to build rapport. Collaborate with local organisations and community champions and leverage existing networks and infrastructure to identify and reach diverse individuals with relevant lived experiences. The SHIFT Programme partnered with the Chartered Institute of Logistics and Transport and Unite the Union, who actively promoted the research and involvement opportunities through their existing networks and newsletters. This leveraged trusted channels where their target public (HGV drivers) were already present.
- **Involve patients and the public from the earliest stages:** Prioritise relationship-building and early, sensitive engagement; this ensures that voices of those most impacted are integrated from inception, leading to more meaningful and

impactful research outcomes. For dementia care research, long-term relationships were established with carers and people living with dementia, some extending over a decade before the specific project. The focus was on building trust and mutually beneficial relationships through outreach events, rather than immediately discussing sensitive topics. Andy, a person living with dementia, highlighted the steering group relationship as 1 of equals.

- **Address barriers to involvement:** Identify and address barriers such as payment for time or accessible meeting locations to ensure inclusive public participation. The Young People’s Advisory Group in the ESCCOPE study didn’t wait for young people to come to them; they actively went out to communities, spoke at schools, and engaged with young persons' groups. This proactive outreach helped break down geographical and social barriers. Furthermore, the study implemented several key strategies: they held pre-meetings to clarify complex information, used a private chat function for immediate questions, provided a dedicated support contact, and ensured proper budgeting for PPI, including reimbursement to compensate young people for their time and contributions.
- **Tailor communication approaches for specific groups:** Communication must be tailored to the diverse needs, motivations and interests of different people and groups. The Routes to Wellness project adopted highly accessible and engaging methods, such as presenting data on cards with both text and images. They also utilised creative activities and acted out scenarios (vignettes), with participants actively guiding the interactions to help understand complex areas like decision-making and ideal peer support worker characteristics. They developed a guideline for working with interpreters, demonstrating a commitment to overcoming language barriers.
- **Ensure fair and transparent partnering processes:** Ensure that your processes for involving the public are fair and transparent and be mindful that you have diverse experiences and characteristics included. The ESCCOPE study ensured fair and transparent partnering processes by deeply valuing the diverse expertise of its Young People's Advisory Group from the outset, treating them as "young people's experts" who influenced study design, analysis, and interpretation, and fostering an inclusive environment through structured support, clear communication, and active community outreach to recruit a representative membership.
- **Avoid assumptions and offer choice and flexibility:** Ask people how they want to be involved, and provide flexible options tailored to their preferences. The Dementia Care research team emphasised the importance of working with

people in "different ways," being creative and flexible, and developing approaches that supported various forms of communication, such as art workshops for non-verbal expression. Their PPI advisory group structure was designed with flexibility in mind, explicitly allowing members to "come in and go out of these groups as they wish and contribute what they can," with no rigid or lifelong commitment. This removes a significant barrier to sustained engagement. Furthermore, their outreach activities were varied, including diverse cultural and artistic events like opera, Calypso dances, and art workshops, specifically designed to appeal to a wide range of interests and backgrounds.

4. Impact

Standard: Seek improvement by identifying and sharing the difference that public involvement makes to research.

Takeaways and practices:

- **Involve the public in impact assessment design:** Involve public contributors in deciding what the assessment of impact should focus on and the approach to take. This ensures that evaluation measures are relevant, meaningful and capture the real-world benefits from the perspectives of those most affected. In the Routes to Wellness project an evaluation framework was actively co-designed with people with lived experience. This collaborative approach ensured that the assessment focused on understanding the benefits for refugees and asylum seekers in a way that was both trauma-informed and sensitive.
- **Be clear about what impacts you are assessing and what data you will collect:** Define the intended impacts for assessment and proactively plan for the specific data collection methods to measure them. In the SHIFT programme for truckers, the foundational need for the research was initially identified by health and safety managers within a logistics company, highlighting a clear, industry-driven purpose. The primary concern was the poor health profile of drivers, which directly informed the development of the intervention. To assess the impact, baseline data on drivers' health, including obesity and other relevant health markers, was systematically collected. This direct link between an identified need, the intervention, and the specific data collected demonstrates a clear approach to understanding impact.

- **Assess how well or otherwise patient and public involvement plans and activities are working:** This allows teams to understand what's working well, identify challenges, and adapt and improve their approaches for more impactful engagement. The SCRiPT study involved informal 1-to-1 meetings with both research leads and "experts by experience." These confidential conversations were invaluable for gathering direct feedback and personal reflections on the project and the involvement experience itself. Additionally, observing team meetings allowed for broader reflection on the dynamics between lived experience partners and practitioners. In the dementia research project, regular (sometimes monthly) meetings of the PPI advisory group served as an ongoing forum for reflection. These meetings fostered "conversations around research, where contributions were appreciated." This project also underscored the importance of long-term relationships and constant communication as integral means of continuous reflection and learning.
- **Act on learning and benefits from public involvement:** Always ensure that changes, benefits, and learning derived from public involvement are consistently acted upon. This responsiveness is imperative for maximising the impact of public contributions and fostering continuous improvement within your research project. Do not just collect feedback; *use* it to refine your methods, adapt your language, and even reshape your project's outputs. The SHIFT programme for truckers made refinements to the intervention based on DHL's input, such as removing free fruit provision and changing outcome measures from whole blood samples to fingerprint blood sampling to improve feasibility and recruitment. The feedback that drivers would value a comprehensive health check influenced recruitment messaging. Most significantly, the programme was converted into a driver training module, with a shorter "short shift" session also developed, all based on industry-led ideas and co-creation workshops. This has led to the compulsory inclusion of "short shift" in Wincanton's mandatory driver training, directly translating research into practice.
- **Strategically demonstrate and disseminate impact to diverse audiences:** Beyond identifying and assessing impact, it is key to actively and strategically demonstrate what has been achieved and disseminate these impacts to various stakeholders in formats and through channels most relevant to them; for example, Alan Inman-Ward, from Active Gloucestershire and a member of the Active-6 study's Impact Advisory Group, played a key role in advising the research team on how to tailor outputs and access appropriate channels, leading to the creation of specific slide decks, policy briefings, 1-page

summaries for club providers, and plain English blog posts published on their 'We Can Move' blog, significantly enhancing the study's reach and impact on policy and practice decision-making.

- **Acknowledge positive personal and emotional benefits:** Acknowledge and seek to understand the positive personal and emotional impacts public involvement can have on individuals, such as increased confidence, a sense of purpose, or even a therapeutic effect, as observed in the Routes to Wellness project where debriefing and a supportive environment led to beneficial emotional outcomes for contributors. Foster Reciprocal Learning and Benefits: Consider the impacts on public contributors. Public involvement can lead to public contributors gaining practical skills, confidence, and career benefits (e.g., co-authorship, references, work experience), as exemplified by the Active-6 study where their involvement led to these tangible personal and professional advantages.

5. Governance

Standard: Involve the public in research management, regulation, leadership and decision making.

Takeaways and practices:

- **Ensure public voices are heard, valued and respected in decision-making:** It is paramount to actively ensure public voices are heard, valued, and respected in all decision-making processes. This goes beyond mere consultation; it is about embedding public perspectives into the very fabric of your research governance. In the SCRiPT study, experts by experience were co-applicants in the study design and led recruitment and support for lived experience partners. Social care practitioners found it "really valuable" to work with experts by experience as peers. Shaping Our Lives played a central role, ensuring involvement was "not only taken into consideration and planned, but really valued and put at the heart of the project". Informal 1-to-1 meetings captured feedback and addressed barriers, with participants reporting their involvement "really mattered.”

- **Continuously monitor and review public involvement plans:** It is essential that public involvement plans are in place, regularly monitored, reviewed, and reported on to ensure their effectiveness and responsiveness (see Impact standard). This continuous oversight allows for adaptation and ensures that public contributions are genuinely integrated and impactful.

The Active-6 study strategically built PPI into all aspects of the study from the outset. They established an Impact Advisory Group (IAG) that met every 6 months. These regular meetings served as a formal mechanism to share progress and preliminary data related to public involvement.
Furthermore, Active-6 demonstrated meticulous planning and review by creating a detailed communications plan that was then refined with direct input from the IAG. This shows a commitment to iterative improvement.

- **Ensure visible and accountable public involvement leadership:** It is crucial that there is visible and accountable responsibility for public involvement throughout the organisation. This ensures that public involvement is not an add-on but an integral and governed part of research. Accountability is clearly shown through specific individuals or organisations taking ownership. For example, Shaping Our Lives served as a dedicated co-applicant for the SCRiPT study, Lucy Condon facilitated the YPAG, and Megan Wyatt acted as a specific lead for PPI programmes in the dementia research. These named roles ensure someone is directly responsible for overseeing and championing public involvement.

- **Have public contributors on research oversight/governance committees/groups:** Beyond dedicated roles, public members themselves were integrated directly into the decision-making and oversight bodies. This includes:
  A carer chairing the project oversight committee in dementia research.
  Parents being part of the steering and management groups in the Active-6 study and 2 public members serving on the independent trial steering committee in the SHIFT programme.

- **Allocate realistic resources for meaningful public involvement:** Always ensure realistic and dedicated resources (money, staff time, and support services) are allocated for public involvement from the outset. Recognise that meaningful engagement is resource-intensive and requires time and financial commitment, including fair payment, addressing access needs, and supporting contributor development. ESCCOPE specifically underlined the importance of "budgeting properly" and not underestimating resource needs. They had dedicated PPI coordination time allocated from the Applied Research Collaboration and paid young contributors the NIHR recommended rate. The Routes to Wellness budget not only covered contributor payments but also essential childcare and extensive translation services. They specifically noted that "doing trauma-informed work takes time," and offered flexible payment methods, acknowledging the specific needs of their contributors.

- **Protect personal information in public involvement:** Always ensure privacy protection is a cornerstone of your public involvement efforts. Building trust and ensuring ethical engagement hinges on demonstrating that personal information is collected and used responsibly. In the SHIFT study, trust was paramount. The research team explicitly assured drivers that "No data will be shared" with their employers and wore branded clothing to emphasise their independence. When health issues were identified, standardised referral letters were provided directly to the driver, with no information shared with the employer, reinforcing privacy and trust.

6. Support and learning

Standard: Offer and promote support and learning opportunities that build confidence and skills for public involvement in research.

Takeaways and practices:

- **Offer a range of support to address identified needs and foster research literacy:** Effective support goes beyond a single intervention; it can involve tailored training, clear guidelines, and flexible resources that respond to the unique needs of all individuals engaged in public involvement. Simplify complex research concepts (e.g., RCTs) and maintain continuous communication to foster research literacy, ensuring contributors have opportunities to learn, grow and fully engage with the project.
  It is not just public contributors who might need some training and support. The SCRiPT study provided comprehensive support for their research teams through bespoke training packages at the outset of their involvement. These packages specifically covered how to effectively involve members of the public in research. Beyond initial training, they also created guidelines and resources designed to establish and promote inclusive working practices for all involved, fostering a supportive and understanding environment.

- **Offer emotional and relational support:** Providing emotional and relational support is paramount in public involvement, fostering trust, ensuring psychological safety, and enabling genuine contributions, especially when dealing with sensitive topics. The Routes to Wellness project emphasised continuous reflection sessions and handled potentially distressing material with sensitivity, providing debriefing setups. For some public contributors, the involvement itself was found to be "therapeutic," showcasing the positive emotional impact of a supportive environment.

- **Dedicate resources for learning and development for all:** Allocate specific, designated resources, such as PPI Leads, focussed on overseeing and facilitating involvement to support the continuous learning and development of public contributors, researchers, and staff. This includes funding for training, workshops, and opportunities for experiential learning, ensuring everyone involved has the skills and knowledge needed for effective and meaningful public involvement. For Public Contributors Dementia Care went beyond mere data collection, utilising outreach activities like dementia-friendly operas and art workshops as genuine avenues for engagement and skill development for people involved in research. This demonstrates a creative approach to resourcing learning that is embedded within the involvement activities themselves.
  For researchers and staff, the SHIFT programme strategically invested in staff development. Their initial knowledge transfer partnership funded a postdoc embedded within the logistics company, allowing for deep, experiential learning about the challenges faced by HGV drivers. Later SHIFT's investment in training 65 Wincanton driver trainers to deliver the 'short shift' module showcases a significant, tangible effort to build capacity and expertise among staff directly involved in the intervention.

- **Ensure clear information and support channels:** Strive to make information and support channels clear and accessible to the public regarding involvement opportunities. This ensures potential contributors know where to find relevant details and assistance. The SHIFT study utilised accessible communication by using a text messaging service for ongoing contact and to answer driver questions, offering a direct and convenient support channel.

- **Foster a culture of continuous learning:** Embrace "learning by doing" by continually adapting your public involvement approaches based on real-time feedback and engagement. Build on successful strategies and proactively share these learnings across the project team and with the wider community to refine and improve future practices.
  The examples provided, particularly in the context of SHIFT's approach to information dissemination and support, inherently demonstrate "learning by doing." When projects actively engage with and adapt to public needs (like using text messaging for drivers), they are implicitly learning about effective

communication and support strategies. This ongoing process of trying, refining, and then sharing what works is fundamental to building better public involvement practices.

- **Properly budget and recognise contributions:** Allocate dedicated time and resources, including funding for payments (covering time, access needs, and contributor development), and offer meaningful recognition such as co-authorship, references, or experience, ensuring all contributions are valued and compensated. Contributors in projects like Active-6 and Routes to Wellness were recognised through co-authorship on publications, receiving references, and gaining valuable work experience, directly influencing study design and outcomes.

Conclusion

The NIHR PPI in Action webinar series offers powerful, real-world insights into how the UK Standards for Public Involvement can be effectively implemented. These integrated takeaways show that impactful involvement is:

- strategic and flexible
- built on strong, trusting relationships
- rooted in genuine partnership
- supported with appropriate resources
- always inclusive, ethical, and meaningful

By embedding these practices, researchers can foster co-produced research that truly reflects the diversity, complexity, and expertise of the communities they aim to serve - highlighting the complex yet rewarding nature of inclusive public involvement. These lessons underscore the multifaceted aspects of effective PPI and co-production, emphasising the need for strategic planning, flexible approaches, dedicated resources, genuine partnership, strong relationships, clear communication, and a deep appreciation for the unique expertise that public partners bring to the research process.

Acknowledgements and resources

The UK Standards for Public Involvement

Chapter 1 - Co-production for Research with Impact

Webinar presenters from The Geller Institute of Ageing and Memory, University of West London:

- Dr Katie Featherstone
- Dr Andy Woodhead
- Dr Megan Wyatt
- Dr Rosie Tope
- Dr Shadreck Mwale

Learn more about this project:

- Understanding the everyday use of restrictive practices in the care of people living with dementia during a hospital admission: reducing inappropriate use, identifying good practice and alternative approaches to reduce risk and improve care on NIHR Funding and Awards
- Follow GIAM on LinkedIn

We would like to acknowledge and thank the person living with dementia who created the beautiful artwork used for this chapter, and for their contribution to the wider PPIE programme of work as part of study NIHR132903 'Understanding the everyday use of restrictive practices in the care of people living with dementia during a hospital admission: reducing inappropriate use, identifying good practice and alternative approaches to reduce risk and improve care'. We also acknowledge Dr Megan Wyatt in her role as lead artist-researcher, supporting both the development of the research and the creative process with the artists. This is part of a wider programme of PPIE outreach and community engagement to support the involvement of people living with dementia and their family carers in priority setting and involvement in research carried out by the Geller Institute of Ageing and Memory, University of West London.

Chapter 2 – PPI with Policymakers and Practitioners: The Active – 6 Study

Webinar presenters:

- Danielle House - University of Bristol
- Alan Inman-Ward - Age UK Gloucestershire

The Active-6 study team:

- Prof. Russ Jago – Principal Investigator
- Dr Ruth Salway
- Dr Robert Walker
- Kate Sansum
- Dr Katie Breheny
- Dr Lydia Emm-Collison
- Dr Joanna G Williams
- Sarah Churchward
- Professor Frank de Vocht
- Professor William Hollingworth

Learn more about this project:

- Assessing the impact of COVID-19 on the physical activity of Year 6 children and their parents: Identifying scalable actions to mitigate adverse impacts and provide rapid evidence to policy makers (ACTIVE-6) on NIHR Funding and Awards

Resources:

- all Active-6 resources including animation, policy briefing and papers
- Active-6 synopsis, including details of the whole study, a section on PPI and IAG

Chapter 3 – Involving Children and Young People in an Evidence Synthesis around Prevention of Childhood Obesity

Webinar presenters:

- Professor Julian Higgins - Chief Investigator University of Bristol
- Lucy Condon – PPIE Facilitator University of Bristol
- Elizabeth Sheldrick – Young People's Advisory Group (YPAG) Member
- Maddie Coleman – Young People's Advisory Group (YPAG) Member

Learn more about this project:

- Towards optimal public health interventions for preventing obesity in children: a novel evidence synthesis on NIHR Funding and Awards
- Bristol's Young People's Advisory Group

Chapter 4 – The Structured Health Intervention for Truckers (SHIFT) – Embedding PPIE from Conception to Implementation

Webinar presenter:

- Professor Stacy Clemes - School of Sport, Exercise and Health Sciences, Loughborough University

Learn more about this project:

- A cluster randomised controlled trial to investigate the effectiveness and cost-effectiveness of a Structured Health Intervention for Truckers (The SHIFT Study) on NIHR Funding and Awards
- The Structured Health Intervention For Truckers (SHIFT) web page

SHIFT Co-Is and lead researchers:

- Prof Stacy A Clemes (PI), Loughborough University
- Dr James King, Loughborough University
- Dr Veronica Varela-Mato, Loughborough University
- Dr Yu-Ling Chen, Loughborough University
- Prof Charlotte L Edwardson, University of Leicester
- Prof Laura J Gray, University of Leicester
- Dr Amber Guest, Loughborough University
- Mrs Vicki Johnson, University Hospitals of Leicester NHS Trust
- Prof Fehmidah Munir, Loughborough University
- Prof Gerry Richardson, University of York
- Dr Katharina Ruettger, Loughborough University
- Dr Mohsen Sayyah, Loughborough University
- Dr Aron Sherry, Loughborough University
- Prof Thomas Yates, University of Leicester

All organisations on the SHIFT programme:

- Loughborough University
- Leicester Diabetes Centre
- University Hospitals of Leicester NHS Trust
- University of Leicester
- DHL
- Wincanton
- University of York
- National Institute for Health and Care Research
- NIHR Leicester Biomedical Research Centre
- The Colt Foundation

Chapter 5 – Inclusive Involvement in Adult Social Care Research

Webinar presenters:

- Professor Kathryn Almack – Chief Investigator University of Hertfordshire
- Hameed Khan – Expert by Experience
- Sam Prowse - Hertfordshire County Council Expert by Experience
- Ana-Maria Bilciu – Shaping Our Lives

Learn more about this project:

- Enhancing research capacity in adult social care in the East of England: testing the feasibility of research in practice teams (The SCRiPT Study on NIHR Funding and Awards
- SCRiPT Study website
- Shaping Our Lives website

Study team:

- Kathryn Almack (University of Hertfordshire/Applied Research Collaboration)
- Jenni Lynch (University of Hertfordshire)
- Eneida Mioshi (University of East Anglia/Applied Research Collaboration)
- Marina Buswell (University of Hertfordshire)
- Teresa Tinworth (University of Hertfordshire)
- John Woolham (University of Hertfordshire)
- Brian Littlechild (University of Hertfordshire)
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- Julia Warrner (University of Hertfordshire)
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- Catherine Greenlaw (Hertfordshire County Council)
- Becki Meakin (Shaping Our Lives
- Ana-Maria Bilciu (Shaping Our Lives)

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- Toby Connell (Norfolk County Council); Lucinda Fisher (Norfolk County Council); Wendy Hull (Hertfordshire County Council); Georgina Jones (Norfolk County Council); Ellie Phillips (Norfolk County Council); Kamil Khan (Expert by Experience); Hameed Khan (Expert by Experience)
- Tom Swinson (Hertfordshire County Council); Kerry McNamara (Hertfordshire County Council); Sam Prowse (Hertfordshire County Council; Expert by Experience); Gavin Howcroft (Hertfordshire County Council; Expert by Experience); Beth White (Expert by Experience).
- Sophie Tooke (Norfolk County Council); Rebecca Harris (Norfolk County Council); Kirsty Johnson (Norfolk County Council); Tamsin Leah (Norfolk County Council); Joanna Ward (Cambridgeshire County Council); Jeremy Dearling (Expert by Experience); Lynda Hesketh (Expert by Experience)

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Chapter 6 – Embedding Co-design and Co-production to Support Refugees Mental Health

Webinar presenters:

- Dr Helen Lloyd - Principal Investigator University of Plymouth
- Dr Hoayda Darkal - Research Fellow University of Plymouth
- Dr Wen-Yu Wu - Research Fellow University of Plymouth
- Megan Stuart-Richards – Trainee Clinical Psychologist University of Plymouth
- Shahla Bahmanyar - PPI Participant
- Gunel Ismikhanova - PPI Participant
- Amany Mkayies - PPI Participant

Learn more about this project:

- Routes to Wellness: Co-designing peer support for refugee and asylum seekers on NIHR Funding and Awards
- Routes to Wellness web page

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For enquiries relating to this e-book, the webinar series, or future events, please contact:

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