

The Lived Experience Academy

Authors

Mr Christopher Gibbs, Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust,

Mrs Janine Smith, Lived experience research leader,

Mrs Claire Hills, Lived experience research leader,

Mr Alisdair Cameron, Recovery College Collective Limited,

Professor Toby Brandon, University of Northumbria at Newcastle,

Mr Simon Douglas, Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust,

Miss Natasha Downs, Lived experience research leader and Senior Research Assistant at Northumbria University,

Professor Charles Fernyhough, Durham University,

Dr Cathryn Meredith, University of Northumbria at Newcastle,

Mr Edward O'Malley, Gateshead Metropolitan Borough Council,

Miss Tara Scott, Lived experience research leader,

Ms Libby Walker, Lived experience research leader.

Plain Language Summary

Research Background and Aims

We wanted to understand how people with lived experience of mental health issues can lead research. So they can make decisions and shape research from start to finish, not just advise or give feedback but lead projects. We also wanted to learn what support people need to do this safely and with confidence.

Becoming a researcher usually means going to university or doing clinical training. This is not possible for everyone. We wanted to help people become research leaders, even if they have not taken those paths.

What we did

We tested ideas for a Lived Experience Academy. We worked with people with a range of experiences, university researchers, local and national organisations. Together we:

- looked at existing evidence using creative arts-based methods;
- educated people with lived experience through an accredited university programme;
- found researchers who want to work with lived experience researchers.
- learned what support people need;
- explored ways to help people develop their own research ideas;
- held a national event;
- created interactive theatre scenes based on what we found.

What we found

- People with lived experience can lead research. This brings clear benefits for research.
- People need individualised support. This includes clear communication, confidence-building and practical help with employment, benefits and wellbeing.
- Creative and arts-based methods help people engage and see things differently.
- Old ideas about who is 'in charge' still shape behaviour. This happens even when lived experience researchers hold official leadership roles.

- Lots of NHS trusts, universities, health research systems, charities and funders like the Lived Experience Academy idea.

What this means for future research and care

When people with lived experience are supported to lead research by experienced researchers, research can be more inclusive, fair and create positive change.

This could change the questions researchers ask. It could change how research happens and how services and systems change. Future research will need:

- clear structures to help people move from learning to leading;
- practical and emotional support;
- support for people with lived experience to make real decisions and be in charge – not just give people a voice;
- funding models that value lived experience leadership.

Patient and Public Involvement

People with lived experience were involved in every part of the project. They were leaders, fellow researchers, equal partners, coordinators and decision-makers. They shaped everything we did and developed the Lived Experience Academy model.

Their involvement made the research better. They challenged old ideas and created new ways of understanding data and experience. For example, using creative methods helped us understand how power shapes research.

Next steps

We want to find funding to develop the Lived Experience Academy into a national programme. This will help us:

- improve our approach to lived experience-led research;
- continue supporting lived experience researchers to develop their own projects;
- build more partnerships with NHS trusts, community organisations and research organisations;
- develop support pathways that different organisations can use.

Even though lots of organisations are interested, we have not yet found funding to continue this work.

Summary of research findings

Background

Involving people with lived experience (PWLE) in research is recognised as a general good, and some form of involvement (or PPIE) is required by research funders. This involvement brings several benefits¹, including better recruitment into research studies², greater acceptability of trial design and more relatable findings³. Co-production of research is increasingly recognised as an ideal⁴, although it is rarely achieved in practice⁵. However, despite a growing focus on what is termed 'co-production'⁶, PWLE involvement often only reaches as far as helping to set research agendas, advising on research design and giving some strategic oversight to projects⁷. All these aspects of involvement are important. However, the assumption that this represents the limit of PWLE involvement is built into most funders and research institution's approaches to PPIE.

Aims and Objectives

Our main aims were to develop a framework for lived experience leadership in mental health research, and to trial the key elements of the Lived Experience Academy (LEA). We also sought to explore the impact of lived experience leadership on both research impact and quality, as well as on the health and wellbeing of individuals themselves. We designed this work to lay the groundwork for a future programme grant developing the LEA as a national endeavour. Through this, we sought to reframe the central question of public involvement from 'how PWLE might be supported to adapt to existing research systems', to 'how those systems need to change to embed meaningful and purposeful lived experience research leadership as foundational practice'.

At the point of funding our specific objectives included six work packages (WP):

WP1. Map existing knowledge and identify gaps in the evidence base on the impact of lived-experience-led research.

WP2. Identify an initial academy cohort and work with them to hone their research ideas.

WP3. Establish a database of established academics interested in working with LEA members to make their research ideas competitive for external funding.

WP4. Establish, through a qualitative, naturalistic enquiry led by peer researchers and community partners, the support needs of both PWLE and established researchers.

WP5. Pilot the process of developing several LEA members' research ideas to outline-application stage.

WP6. Develop a competitive programme grant bid.

Methods

While the project's main aims and objectives remained unchanged, several methodological refinements were implemented to better achieve our core goal of supporting and learning about the process of PWLE becoming leaders within research.

The most important methodological change was a project-wide pivot towards deeper co-productive principles across all work packages. This was necessary to ensure PWLE were involved as genuine partners and co-investigators. This change strengthened our ability to meet the original objective of creating an inclusive research model that puts PWLE at the heart of the research process. It also went beyond traditional models of involvement which largely confine PWLE to marginal roles and activities.

Our co-productive pivot shaped our literature review (WP1). The review focused on the quality that PPIE/Co-production adds to research, and its possible benefits for impact. Originally 915 peer reviewed papers were selected, which were narrowed down to 56, which inform this report. The PWLE working on WP1 decided to co-produce the review, using creative methods developed with our PPIE Lead (CH) and WP lead researcher (TB), including learning disabled members of a community theatre group: an approach the group called 'Papers Got Talent' after the TV talent show *Britain's Got Talent*. It involved paper selection using buzzers (live auditions), reading full papers (judge's houses) and thematic analysis. While we did not observe a measurable change in the quality of the review itself, it had a clear positive impact upon the confidence, skills and knowledge acquisition of the PWLE themselves. This is being written up separately as a paper.

All partner organisations supported the identification of our initial academy cohort (WP2) of twenty students who sat Northumbria University's 'An Introduction to Public involvement and co-production in research' education programme. This first-of-its-kind accredited education programme offers a 60-credit level four Higher Education Certificate with no academic entry requirements. It was led by TB and further developed with CG before the programme development grant application was submitted. This education programme introduces students with lived experience to concepts, activities and ethical issues of research. It aims to equip them to understand, and to be engaged and involved meaningfully in, health research. All students from the first cohort of the full programme of this course were offered the opportunity to work in our PPIE group or to apply for more formal roles, such as the two peer researcher posts.

Our PPIE group led and shaped the design and delivery of our established researcher database (WP3). This involved the academic WP lead (CF) providing the PPIE group with a design brief (including basic details of what the database needed to do), and the PPIE team then brainstorming ideas and working iteratively with the academic lead to produce a final data-capture survey. The database is now established, and academic researchers interested in becoming LEA mentors continue to be added.

WP4 was the project's qualitative research strand, using ethnographic, naturalistic inquiry. This work aimed to find out the support needs of both lived experience and established researchers and the impact this had both upon the research and the individuals involved. The whole project was the field of study. Two peer researchers, supported by WP lead (CM) used all aspects of the project as opportunities to generate knowledge. Its purpose was to study what happens when lived experience research leadership is put into practice.

The original application proposed a half-day workshop to share our learnings and engage with research system leaders and policy makers. This evolved into a full-day workshop, held on 17 October 2025, which presented questions and ideas raised by our research, and used Participatory Action Research techniques to support active engagement.

WP5 focused on supporting PWLE to develop and lead on their own research grant applications. This work initially progressed well. However, when the member of our initial cohort with whom we were working secured full-time employment, progress faltered. This is a positive individual success but highlighted an inherent risk to this process. A partnership with Health Innovation North East and North Cumbria (HI-NENC), developed out of our October event, enabled us to shift our approach to developing a structured framework, adopting iterative service improvement approaches to co-produce this work.

Overall, our methods adapted to strengthen, rather than alter, the project's core mission. These changes, based on project learning, better position us for our planned programme grant application (WP6). They provide us with evidence-based insights into the impact of lived experience leadership on research quality and health outcomes, and into the support structures needed for a successful national Lived Experience Academy.

Working with people and communities

Placing PWLE at the heart of this programme ensured that engagement was meaningful and that contributors genuinely shaped the research and its outcomes. The project's leadership structure reflected this commitment, which paired two lived experience leaders with academic researchers, modelling the collaborative approach the programme aimed to explore.

To build the PPIE team, we partnered with students from the university modules, along with the Lawnmowers Research Abilities group.

PPIE was embedded throughout the Lived Experience Academy research project from the very beginning, shaping both its direction and delivery. Rather than relying on traditional, advisory-only involvement, the project developed a model that enabled contributors to participate in work packages aligned with their individual interests and skills, ensuring meaningful, purposeful and valued involvement. This was underpinned by Northumbria University's accredited education programme which provided all members of our PPIE team, and our peer researchers, with a theoretical understanding of research, public involvement and co-production. This project offered an opportunity to apply that learning into real-world practice.

A central partnership with the Lawnmowers Research Abilities group brought essential lived experience expertise from people with learning disabilities. Their participation highlighted the need for equitable support, leading the team to invest in accessible communication, preparatory sessions, regular updates, iterative learning and informal contact to enable confident and informed participation.

As the project evolved, PPIE became integrated across all work packages. PWLE worked alongside researchers to explore data, identify issues, shape interpretations and inform decisions, creating shared ownership and strengthening relationships. A key innovation was a pivot towards the use of creative, participatory methods, particularly Forum Theatre-inspired approaches, to support collective sense-making. The development and performance of these Forum Theatre scenes enabled the team to move beyond individual experiences and begin recognising wider systems, structures and influences operating within the research landscape. These themes might not have come up through traditional analysis alone.

This collaborative approach reshaped the team's understanding of co-production, demonstrating the value of involving PWLE not only in reviewing findings but in generating insight, challenging assumptions and influencing the direction of the research. The project also highlighted the structural requirements for meaningful involvement, including the need to balance embedded participation with clear oversight and coordination.

PPIE involvement also had a direct impact on the development of future work within the project. We worked with three contributors, who were not members of the PPIE team, to help them shape their own research ideas into research problem statements. This work helped to refine WP5 and led to the development and initial testing of a framework that supports PWLE to develop their own research grounded in their personal lived experience. We are continuing to support these three research ideas, linked to our database of established researchers from WP3, and have plans to further develop and validate the framework in future stages of our programme.

Throughout the project, PPIE contributors consistently showed thoughtful, careful and considered engagement. The quality of their contributions reflected the value placed upon their involvement and the genuine opportunities they created to influence the research. Rather than being consulted on decisions already made, our PPIE contributors actively shaped discussions, challenged assumptions and helped decide the direction of the work.

The project demonstrated that meaningful collaboration with PWLE is both achievable and transformative. By embedding PPIE throughout the entire research lifecycle, the programme strengthened the quality, creativity and relevance of the work. PWLE were active partners in analysis, interpretation and decision-making, developing confidence and skills as research collaborators.

PPIE shaped not only the research activities but also the culture of involvement in research. PWLE encouraged researchers to rethink traditional assumptions about participation, collaboration, and knowledge creation. Lived experience contributors played a central role in generating insight, identifying themes and influencing future research practice. Their involvement showed that co-production can lead to richer understanding and more innovative approaches to analysis.

All members of the PPIE team informed and shaped the project's outcomes and the emerging model for a future Lived Experience Academy. Without their involvement, the pilot would not have embodied its core principles. The research is stronger, more creative and more relevant because of the meaningful engagement of patients, service users, carers, and the public.

Research Inclusion

Mental health was our primary 'disease burden' and we included a broad range of diverse experiences.

Throughout this research, and with students on the university modules, we worked with a range of people who are often, but not exclusively, associated with mental health services. This included people with mental health distress, homelessness, those previously in the criminal justice system and people with addictions and learning disabilities. These are all communities routinely excluded from research, either as participants or researchers⁷.

Through our partner organisations – Gateshead's NIHR Health Determinants Research Collaboration (HDRC), Newcastle's Recovery College Collective (ReCoCo), CNTW (Mental Health NHS Foundation Trust) and academic partners in local universities – we recruited a group of diverse people to define, test and refine the key structures of the LEA.

The learning from this programme has underscored the importance of embedding inclusion as a foundational principle both within research and within our Lived

Experience Academy model. While we successfully engaged a range of people, the learning has highlighted the structural and personal barriers that continue to limit participation for many communities. These barriers include limited access to education or employment, lack of confidence or familiarity with research environments, and practical constraints such as financial insecurity, caring responsibilities or health-related challenges. Addressing these is essential for the future success of our programme of work in contributing towards widening participation and supporting lived experience leadership within research.

To support this inclusion, we incorporate structured support pathways designed to enable safe and sustainable participation in future plans. This pathway will provide practical work and benefit support as well as tailored continuous personal development and wellbeing support.

Findings

Two peer researchers were recruited from our initial cohort of lived experience researchers (LERs). This naturalistic inquiry revealed crucial insights regarding our support model. One peer researcher transitioned successfully and produced innovative arts-based outputs, while the other experienced difficulties with emotional strain and adjusting to their role. They moved to a more structured role in other parts of the project, before needing to step away completely. This highlighted the need to develop individualised support approaches within the Lived Experience Academy model.

The Lived Experience Academy model is different from co-production. It focuses on sharing authority as well as power and influence. Our learning led us to an important observation with regards to how authority and power differ from each other. Authority is a position of accountability and comes with decision-making expectations – for example, being named principal investigator or managing a research budget. Power enables people to influence how things are done, regardless of formal title or role. In our project, we found that people in roles of authority sometimes felt disempowered by traditional hierarchies outside the project. Others felt unable to use their power or leadership, because they felt their role was to have stepped back and let others lead. This matters for our lived experience leadership model because much existing co-production practice shares power without sharing authority. The Programme Development Grant's 'Developing Innovative, Inclusive and Diverse Public Partnerships' 2023 call enabled us to position PWLE to not only shape research decisions, but – for example as Principal Investigator – hold decision-making rights and be accountable for budgets.

The PPIE Lead and Project Co-ordinator for this programme both completed the Northumbria University education programme, an experience that motivated them to step into research leadership, use their expertise in new ways and build new skills.

Their enthusiasm for the Lived Experience Academy led them to take on leadership roles within the project and explore a new professional pathway. From these modules, which formed WP2, we recruited the PPIE Lead, and our Project Co-ordinator progressed to this leadership role after first being a member of the PPIE team. Their knowledge and real-world experience have strengthened both the project itself and the learning generated, building their fresh perspectives and valuable insights into the support need requirements and our understanding of what it means to be a lived experience research leader.

Our co-produced event was shaped around creative methods and engaged diverse delegates nationally including representatives from national charities, PWLE, academic and systems leaders. The event featured expert panels of LERs and funding / policy making representatives, exercises such as an art gallery walk, group level assessment, the 'river of research': an exercise mapping public involvement through the research lifecycle, plus a keynote address from Dame Chi Owurah MP. The event was attended by 67 people, with some travelling from London, Manchester and Glasgow. The learning from the day both enhanced our learning within the project and established partnerships to support the expansion of our work into future phases.

A successful application for an uncosted 6-month extension (31 December 2025 to 30 June 2026) allowed us to build this further. Led by our PPIE Lead (CH) and working in partnership with The Lawnmowers Theatre Company, the extension allowed us to develop a unique Forum Theatre production drawing on the project findings, depicting what it is like to be a PWLE stepping into a leadership role within research. Using creative and participatory methods, the group transformed project data into scripted performance material that explored barriers, power dynamics, and inclusion within research practice.

A core objective of this project was to pilot a process supporting a person with lived experience to become a LER, developing their research idea into a clear research problem statement. Although we were able to work with one individual, they gained full time employment and exited the project. We tried to engage with other graduates and current students on the university programme. However, those who were interested in leading research lacked both the confidence in and understanding of the process and commitment involved. It became clear that to properly support LERs, we needed a clear framework and a better understanding of the practical barriers and support needs. Our extended period provided us with the opportunity to work with three LERs, each now matched with an established researcher to develop their research idea further. This has directly informed the infrastructure and support systems the Lived Experience Academy will need to support people through the transition from education to research leadership.

We used our extension period to develop and pilot a framework to support PWLE to understand, and guide them through, the process of developing a research idea. This framework is unique because it targets PWLE who are living in the community, rather than those linked to institutions or organisations, a group that has previously been underserved in this area. This framework is ready for validation within our intended subsequent programme grant. We are supporting three PWLE to develop their own research ideas, linking them with academic mentors through our established researcher database. This work has further underlined the importance of understanding the specific support mechanisms and frameworks PWLE need to develop, progress and sustain their involvement as non-established researchers. These implementation experiences have generated specific evidence-based recommendations including developing multi-modal entry points, integrating emotional labour awareness, embedding arts-based methods as legitimate research tools, and designing personalised pathways through training and research roles.

With regards to terminology, within our project we distinguished co-production from PPIE and other collaborative research methodologies such as Participatory Action Research, co-design, emancipatory research, user-led research and citizen science. Generally, these approaches are defined as research which is conducted 'by' or 'with' people with lived experience, in contrast to the more hierarchical research traditions within the biomedical and psy-sciences, which historically have tended to treat people as an object of study. Co-production itself has become a frequently aspired-to framework for this shift, with the NIHR shared commitment to public involvement describing power sharing as one of its central principles. Literature describes that, even within successful co-production projects, power sharing is the ceiling PWLE struggle to move beyond, where PWLE are included and supported to shape and lead on components of research, but ultimate authority is unavailable. Our work has actively worked to push against these accepted norms.

The project has also generated wider outcomes beyond its original objectives. This includes ongoing pilots with Newcastle's NIHR Regional Support Service (RSS); the adoption of the Lived Experience Academy into NIHR research grant applications and the AHRC creative industries clusters bid; regional funding from research infrastructures and regional academic partners for the education programme at Northumbria University; and three fundable LER-led research projects that we continue to support, as well as further PWLE who are interested in engaging with us. We have found consistent interest and enthusiasm to engage with us in our programme of work, across NHS trusts, universities, research infrastructure organisations, local authorities, the voluntary and charity sector and research funders. Despite this, we have so far struggled to identify a funding stream that is a direct fit for taking this programme of work to the next stage.

Conclusions and Discussion

This programme of work has demonstrated that the Lived Experience Academy approach is possible, that lived experience leadership can be embedded within health research, and that PWLE can take on genuine leadership, including lead and co-investigator roles.

We have developed a rich insight into how people work together, how team dynamics evolve and how assumptions about responsibility and accountability form and persist. By creating space for lived experience leadership, our intention throughout has not been to replace established researchers but to build an environment in which unestablished public LERs and traditional academics can work side by side, sharing authority, responsibility, and influence.

We have found that established research team dynamics persist regardless of who formally holds a position of authority. People naturally defer to perceived authority and can feel disempowered even when nominally holding a leadership role. This has been observed as a pattern across our project, leading to discussions around whether deep-rooted hierarchical assumptions may persevere unconsciously in people as individuals. A person in a lived experience leadership role may believe that their decisions need validation from an established academic researcher. An academic may feel disempowered to make decisions because they do not see themselves, within the context of the project, as a PWLE. This paradox has been observed at all levels of the project.

Another observation was an imbalance when PWLE progressed into new roles of responsibility. This often required them to work outside their comfort zone, with steep learning curves and making significant adjustments. In contrast, researchers accustomed to authority roles in research largely remain within the comfort of their established status, continuing to work in familiar and secure ways and ceding authority to others. PWLE require space, time and support to develop their skills and confidence.

We conclude that, whatever an individual's background, and given enough time, resources and underpinning skills, anybody is capable of leading a research project successfully. However, inbuilt, and possibly unconscious, tendencies to follow existing hierarchical and power structures mean people still experience disempowerment and disconnection. This is not a failure. Indeed it is evidence that the LEA framework enables research to be successfully delivered to the same standard even with PWLE sitting in roles of authority.

In future phases of our programme we will focus on developing support and training within our Lived Experience Academy that directly addresses these observations. This will involve supporting lived experience research leaders to build their confidence. This will help them to recognise the skills, knowledge and experience they bring, supporting them to feel secure in their role and hold that role with the

same legitimacy as anyone else on the research team. Likewise, we will need to work with established researchers to support them to accept LERs as equal partners whilst validating their own skills and knowledge as researchers.

This approach can, however, unsettle expectations and affect confidence, particularly when people are asked to work in new ways. We learned that while some people thrive with open-ended, creative approaches, others need clearer foundations and more structured guidance. The “blank page” can be empowering for some and overwhelming for others. Embedding co-production throughout the project has been rewarding but also challenging, and it highlighted the need for a bespoke support pathway within the Lived Experience Academy. This pathway must be flexible, personalised and responsive to the varying needs of the research team as they navigate new roles and ways of working. Where the LEA approach is possible, and every PWLE is potentially able to take on a leadership position, this does not mean every PWLE is interested in, or wants to move into, a leadership role, and the model needs to accommodate that too.

Where our programme was seeking to develop the foundations for a framework and explore the barriers, challenges and enablers, the naturalistic inquiry in WP4 highlighted specific gaps in the support available within our own work. LERs, especially those working outside their comfort zone, needed greater levels of communication and support to ensure everyone was included equitably. Recommendations from this work call for guaranteed welfare support, clarity on employment rights, effective working practices that prevent exclusion from communications or decision making and clear independent channels for LERs to raise concerns early.

These findings have formed core foundations of our LEA framework. There is a need for a robust structured pathway that allows PWLE to enter a research project at a level that feels manageable, with clearly defined stages of increasing involvement, responsibility and authority, and with genuine exit points at each stage so that stepping back or stepping off at any point is possible without unforeseen consequences, financial penalty or sense of failure. Such a pathway can prepare LERs for the challenges of lived experience leadership rather than reacting to problems as they emerge. With all of this in mind, we need to ensure that these structures and support pathways embedded within the LEA are practical, adoptable and suitable for NHS trusts as well as academic and infrastructure institutions. Strengthening skills, building confidence and offering adaptable support will be essential to enabling LERs and other team members to thrive, and ensuring that collaborative research can be sustained and scaled. We must ensure this is achievable, realistic and sustainable, grounded in the expectations and conditions of real-world practice and focusing on what matters: wellbeing, relationships, governance and whether lived experience knowledge is genuinely shaping the field.

This work has involved directly questioning widely accepted, established and embedded processes and systems. It has forced people to question and challenge identities and roles built into them. Agreeing a term that best describes / defines the role of lived experience leaders in research proved a challenge. 'Expert by experience' was found empowering by some, and the exact opposite for others. We settled on 'lived experience research leaders', accepting that each individual project should define its own terminology. In the same way, it is important to remember that PWLE are motivated to engage in different types of activities, just as researchers find their own specialities.

The literature review provides reasonable evidence that public involvement and co-production can increase both the quality of research and its potential for positive impact. If we consider epistemic justice to be an overriding driver in both quality and impact, then a stronger argument in support is easily made. Further work into the personal impact of public involvement and co-production within mental health research would be useful.

We are proud to report that we have engaged a wide range of partners throughout this work, including Rotherham, Doncaster and South Humber NHS Foundation Trust (RDaSH), Job Centre Plus, several universities (Northumbria, Sheffield Hallam, Sheffield, Glasgow, Edinburgh, Manchester), major research infrastructures (RSS, PSRC, CRDC, BRC), local authorities (HDRC, Newcastle, Gateshead, Sheffield, Lancaster), VCSE and charity sector organisations (MQ, Mind) and funders (Wellcome, UKRI, NIHR). They have all shown great enthusiasm, recognise the genuine potential of the Lived Experience Academy and want to be a part of its future.

However, even with this breadth of support, we have not yet identified a funding stream that is a direct fit to continue the Lived Experience Academy research programme.

We would recommend more research funding targeted at understanding the impact of lived experience research leadership on research quality and the impact being involved in research has on the health of individuals and their communities. In the spirit of our October 2027 workshop, we also recommend an annual event that brings together the wider research community to continue this conversation.

Data sharing statement

See link [\[https://www.nihr.ac.uk/documents/nihr-position-on-the-sharing-of-research-data/12253\]](https://www.nihr.ac.uk/documents/nihr-position-on-the-sharing-of-research-data/12253) for the NIHR position on the sharing of research data. The NIHR strongly supports the sharing of data in the most appropriate way, to help deliver research that maximises benefits to patients and the wider public, the health and care system and which contributes to economic growth in the UK. All requests for data should be directed to the award holder and managed by the award holder.

Disclaimer

This project is funded by the National Institute for Health and Care Research (NIHR) under its Programme Grants for Applied Research Programme (Grant Reference Number NIHR207098). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

This project was carried out between July 2024 and June 2026. This final report has not been peer-reviewed. The report was examined by the Programme at the time of submission to assess completeness against the stated aims. These reports do not undergo a peer review process.

References

1. Lonbay SP, Brandon T, O'Driscoll S. Making a difference for the future: the views of Educators by experience about their involvement in social work education. *Social Work Education*. 2023;0(0):1–16.
2. Greenhalgh T, Hinton L, Finlay T, Macfarlane A, Fahy N, Clyde B, et al. Frameworks for supporting patient and public involvement in research: Systematic review and co-design pilot. *Health Expect*. 2019;22(4):785–801.
3. Crocker JC, Ricci-Cabello I, Parker A, Hirst JA, Chant A, Petit-Zeman S, et al. Impact of patient and public involvement on enrolment and retention in clinical trials: Systematic review and meta-analysis. *BMJ*. 2018;363:k4738.
4. NIHR. Briefing notes for researchers - public involvement in NHS, health and social care research [Internet]. 2016 [cited 2023 Oct 16]. Available from: <https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371>
5. Tembo D, Morrow E, Worswick L, Lennard D. Is co-production just a pipe dream for applied health research commissioning? An exploratory literature review. *Frontiers in Sociology* [Internet]. 2019 [cited 2023 Oct 24];4. Available from: <https://www.frontiersin.org/articles/10.3389/fsoc.2019.00050>
6. NIHR Involve. Guidance on co-producing a research project [Internet]. 2019. Available from: https://www.invo.org.uk/wp-content/uploads/2019/04/Copro_Guidance_Feb19.pdf
7. Hutchinson A, Lovell A. Participatory action research: Moving beyond the mental health “service user” identity. *J Psychiatr Ment Health Nurs*. 2013;20(7):641–9.