



Members of the Lived Experience Academy project team are pictured with students from the Certificate in Public Involvement and Co-Production programme at Northumbria University.

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New study demonstrates an inclusive approach to leading research

People with lived experience of mental health distress will be able to take a lead on health and social care research thanks to new funding.

Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust (CNTW), a leading provider of mental health and disability services, has partnered with Northumbria University, Gateshead Council, Durham University and Newcastle-based independent mental health charity, ReCoCo, on a project

that aims to redefine the role of lived experience in health research.

Funded by the [National Institute for Health Research \(NIHR\)'s Programme Development Grant](#), the project has secured funding for 18 months and will build on previous collaborations between the partners to involve and engage people with lived experience.

Lived experience is the knowledge and understanding someone gets when they have personally lived through something. This first-hand perspective provides unique insight that can enhance the quality and relevance of research, making it more authentic and genuinely informed.

The funding will go towards the development of a Lived Experience Academy, where individuals in local communities have access to education and support to lead on their own research ideas, fostering a culture of lived experience leadership in research.

The Academy will focus on several key areas to enhance research. It will examine the impact of experience-led research, as well as the support people with lived experience require to develop their research skills. Additionally, the Academy will train traditional researchers to support people with lived experience to write and lead their own research proposals.

This includes building on a programme of study offered by Northumbria University, understood to be the only accredited programme of its kind in the UK, which provides people with lived experience the opportunity to achieve a Certificate in Public Involvement and Co-Production.

“The programme is flexible and allows people who may have valuable, lived experience to become empowered with their own research skills by studying individual modules or completing the full programme to achieve a Certificate of Higher Education,” explained [Toby Brandon, Professor in Mental Health and Disability at Northumbria University](#). “We wish to find a route to flipping the traditional narrative of who is the researcher and who is the researched. We also recognise how university education can positively shift people’s identities from say, being a patient to a student, or to a paid researcher as the result of such a programme.”

The research will investigate the barriers and challenges to lived experience-

led research and the effects of this shift in power dynamics. This novel approach could significantly influence the role of lived experience in research by ensuring people with lived experience are regarded as a fundamental workforce that can lead and shape more inclusive and effective research across the UK.

Tara Scott, a peer researcher with lived experience working on the study, said: “I’m so excited to be involved with the Lived Experience Academy, which can provide a springboard for the unheard voices in research while giving ‘real’ people a genuine opportunity to lead and design projects. My hope is not to become an academic but to know my differences, capabilities and strengths in my own experiences and to be welcomed to work alongside typically recognised researchers.”

Chris Gibbs, Research Involvement Coordinator at CNTW and a Visiting Scholar at Northumbria University, said: “As someone with lived experience of mental health challenges and neurodivergence, co-leading this study is both groundbreaking and deeply personal. The Lived Experience Academy ultimately seeks to transform health research by creating an environment where people with lived experience can empower themselves to shape and lead research. We’re studying how this shift impacts upon individuals and the research ecosystem, while exploring how different parts of the system – from NHS trusts to universities, local authorities and funders of research – can best enable and support lived experience researchers. We aim to influence a more inclusive, relevant and effective health research environment.”

Alisdair Cameron, Co-Director at [ReCoCo](#) said: “This is an exciting opportunity to form ideas about what a Lived Experience Academy might look like and do, in order to best utilise the hard-earned knowledge of those who’ve experienced mental distress. It puts the lived experience community in charge of determining ways to lead research, education, and knowledge exchange. People will move away from being the subjects of research and the recipients of services, to being researchers, leaders and change-makers.”

As well as providing opportunities for new research ideas, the Lived Experience Academy also aims to nurture talent in the lived experience community and create further opportunities for collaboration and teamwork.

Alice Wiseman, Director of Public Health for Gateshead and Newcastle, said: “The voices of people with lived experience are essential to improving public

health policy and practice. By supporting people with lived experience to lead research projects, we can also reduce the stigma around mental health in our society, which will inspire more people to be part of the life-changing projects. Many people may feel that being involved with research isn't for them, or that their voice doesn't make a real difference to policy – the Lived Experience Academy will go a long way to shift that perception and make research more accessible for our communities.”

James Duncan, Chief Executive at [CNTW](#), said: “The Lived Experience Academy is a hugely exciting development. Here in the North East and Cumbria and in CNTW, we have a wealth of experience, resources and assets in research. We also have many ways that we look to involve service users, carers and families in all that we do. But this is the first time that we have looked to develop a systematic approach to ensuring the voice of lived experience is heard and is active in the world of research. I hope and expect that this will be a real game-changer in our journey of learning, improvement and ensuring that we have the most meaningful and best offer for the people and communities we serve.”

Professor Charles Fernyhough at [Durham University](#) said: “There are still assumptions about what kinds of role people with lived experience can and cannot take on in research. We want to invert the traditional hierarchies and ensure that people with lived experience get a chance to lead their own research projects, rather than just being shuttled in and out when it suits the traditional academics.”

In time, the project team plan to develop a larger funding bid to make the Lived Experience Academy a UK-wide project. A workshop is planned for 17 October 2025 to share learning. For more details contact researchinvolvement@cntw.nhs.uk

Northumbria University is dedicated to reducing health and social inequalities, contributing to the regional and national workforce and improving social, economic and health outcomes for the most marginalised in society. Through its new Centre for Health and Social Equity, known as CHASE, researchers will be delivering world-leading health and social equity research and creating innovative, evidence-based policies and data-driven solutions to bring impactful change across the region, the UK and globally.

Press release adapted with thanks to Cumbria, Northumberland, Tyne and Wear

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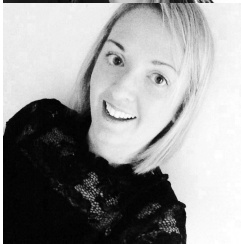


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