NHS
Cumbria, Northumberland, Tyne and Wear
NHS Foundation Trust

Lived Experience Service Spotlight

Q2: July - September 2026

Launch of the Lived Experience Reference Groups

The Lived Experience Reference Groups bring together service users, carers, staff and partner organisations to share experiences, influence decisions, and help improve services across Cumbria, Northumberland, Tyne & Wear (CNTW) NHS Trust. The groups provide a safe and supportive space where people can work in partnership with staff to ensure lived experience is at the heart of service development and quality improvement. These groups will be held every 3 months and form a part of the Trust's wider Lived Experience Network (LEN). The groups plan to host smaller more focussed discussions.

There are five Lived Experience Reference Groups that people can join: Community, Inpatients, Specialist and Neurological, Children and Young People CYPS) and Secure Care. Attendees can attend as many groups as they would like – they don't have to pick just one.

The Lived Experience Reference Groups have successfully moved from development into delivery:

- **Community Lived Experience Reference Group** was held online on the 29th September.
- **Inpatient Lived Experience Reference Group** was held online on the 30th September.
- **Secure Care Lived Experience Reference Group** was held face-to-face on the 8th October.
- **Children and Young People's Services (CYPS) Lived Experience Reference Group** was held face-to-face on the 8th October.
- **Neurological and Specialist Services Lived Experience Reference Group** was held face to face on the 15th October.

"*By the second half of the meeting I was getting excited realising the potentials and impacts the reference group can make on the services. Great job from everyone in the meeting! Lots of things were clarified too! Feeling very positive about contributing to the group's work.*" **Community Lived Experience Reference Group Attendee**

"*The facilitation was excellent! And super excited about what I heard. Everything was explained so well.*" **Inpatient Lived Experience Reference Group Attendee**

The next phase focuses on evidencing impact, strengthening co-production and ensuring the voice of service users and carers directly informs service improvement and decision-making across the Trust.

If you would like more information about the Lived Experience Reference Groups, please contact *ReferenceGroup@cntw.nhs.uk* or telephone 01670 501 816.

July - September 2026

158 Fulfilled Involvement Bank Activities

- 16 Inpatients
- 44 Community
- 27 Specialist
- 65 Trustwide
- 6 Youth Involvement



447 Involvement Bank Contributors

15 Youth Bank Contributors

- 5 Inspections
- 4 Personal Stories
- 22 Staff Recruitment
- 22 Staff Training
- 102 Working Groups
- 3 Research Projects

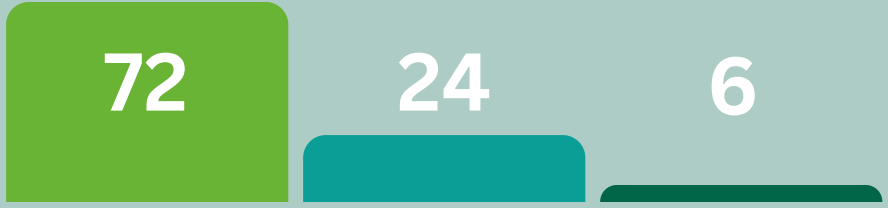


7 Carer Awareness Training sessions co-facilitated by Carers

390 Carer Cards issued



102 Peer Supporters employed in CNTW



The Together Strategy Strategic Ambition:
Workforce

Get to Know: Maisie Clark, Peer Supporter

I joined the Cumbria Adult Autism Assessment Service (CAAAS) in 2025, as its first Peer Supporter. Peer support is the last place I thought I'd ever end up. I had a rough time growing up (to put it lightly) was told I was 'too much', and I honestly thought I was broken. After struggling with compounding mental health difficulties, that no amount of therapy or medications seemed to help, I was diagnosed with ADHD in 2024 and then Autism Spectrum Disorder in 2025. Receiving a late diagnosis of neurodivergence and having experienced trauma has a profound effect on a lot of things. A big one for me was never being able to find a job that fit.

When I got the Autism diagnosis, it all clicked. I grieved the 'what if' and started learning about my authentic self. I struggled to put the mask back on - it's taken time to learn (and accept) that I don't need the mask, not when I'm in a role that values me for me. My Autism diagnosis isn't just a piece of paper; it is validation that my brain may be built different, but I'm still me. I'm not too much, or broken.

During my Autism assessment, I spoke about wishing there had been someone to talk to while on the waitlist, someone who really gets it. Peer Support was mentioned as a career possibility, as I had lots of lived experience to pull from. I researched and contacted the Lead for West Cumbria at the time, Laura Wilson. It was the scariest thing I'd ever done, however, now I get to work with the team who helped me make sense of my life - an opportunity I can't put into words. I can't thank the team enough for sitting with me as I told them my life story, and we worked together to unpick it all so the outcome was right for me.

Something I tell service users is that the assessment is not a pass or fail test. It's a collaborative process where the team gather information, have real conversations, and leave no stone unturned. CAAAS want to make sure that the service user leaves with the right outcome, at the right time, for the right reason.

I've found my tribe. I can turn my time in services on its head and support others. That's the point of Peer Support. They have experience of situations that some will only ever read about in books. I'm working with people who really 'get it'.

I've learned so much about being a Peer through the Peer Support Education Programme. I've also learned I'm braver than I ever thought I was. The main thing I'll take from my first year in post is how important it is for a team to be open to what a Peer Supporter can bring. I've had a very positive experience coming into this role, it hasn't felt just like integration, but also acceptance.
When I arrived in post, we worked together to build the Peer Support role, specific to the CAAAS. It was also said: "Peer Support is neither clinical nor administrative. Peer Support is the sincere, human middle ground that is valuable in and of itself, regardless of formal educational background. Peer Supporters qualifications come from their vast life experiences."
I never had a plan, now I'm building a career. The fact I'm here reflects on the very service I have the pleasure of now working in. I was trapped in a pit. The CAAAS helped me build a ladder. Now I have the blueprints, I can support others in building their own ladders too.

by Maisie Clark

The Together Strategy Strategic Ambition:
What's working well and why?

Triangle of Care Report 2026

The Triangle of Care report provides an assessment of how effectively the Trust is involving and supporting carers as partners in care. It highlights progress against the six key standards of the Triangle of Care, celebrating good practice while identifying areas for improvement to strengthen collaboration between staff, service users and carers. The Trust continues to make progress in embedding the Triangle of Care across services, with positive performance reported across all six standards and clear evidence of carers helping to shape service development, quality improvement and decision-making.

A particular strength has been the continued growth of lived experience involvement. The Involvement Bank has grown to 443 contributors, while carers, young carers and family members continue to influence recruitment, training, service development, working groups and quality improvement initiatives. The development of the new Care Group Reference Groups and wider Lived Experience Network is also creating more opportunities for carers to influence services closer to where care is delivered.

Carer feedback remains very positive. During 2025-2026, 1,513 carers shared their experiences through the Trust's Your Voice survey, a 25% increase on the previous year. 92% of carers reported feeling involved in care, while 90% said they felt safe using Trust services.

The expansion of dedicated carer roles has also strengthened the support available across the Trust. Carer Leads, Carer Champions, Carer Peer Supporters, Family Ambassadors, Lived Experience Leads and Involvement Facilitators are helping to ensure carers have access to information, support and opportunities to influence change. The number of Carer Peer Supporter roles has increased to 18, further enhancing peer-led support for carers.

Co-production and lived experience continue to be central to the Trust's approach. A particular highlight during 2025-2026 has been the year-long young carers campaign, with members of the Youth Involvement Bank helping to raise awareness of young carers and contributing to the development of future resources and support.

Together, these developments demonstrate the Trust's ongoing commitment to recognising carers as equal partners in care and ensuring their voices remain central to improving services and outcomes for the people we support.

Lived Experience is Shaping the Doctors of Tomorrow

Sometimes the true impact of a project becomes clear in unexpected ways. During a chance conversation at a hospital outpatient clinic, a student doctor recognised the Medical Education Simulation Programme involving Peer Supporters and described it as one of the most valuable parts of their training. It was a powerful reminder of the lasting impact lived experience can have on future healthcare professionals.

Since 2022, colleagues from the Medical Education and Development Team and the Lived Experience Service have worked together to embed lived experience within medical simulation training. What began as an innovative collaboration has grown into an established and highly valued part of the programme, supported by colleagues including Richard Lamph, Georgia Hodgson, Tyne Percival and Lewis Gardner.

Through simulation exercises, students hear directly from people with lived experience, helping them develop empathy, communication skills and a deeper understanding of person-centred care. Rather than focusing solely on diagnoses and assessments, students are encouraged to understand the individual behind the clinical presentation and build meaningful therapeutic conversations.

"It has been an absolute pleasure working with everyone and we always receive really positive feedback from the students on the session and the involvement of those with lived experience." **Richard Lamph, Simulation and Education Development Lead**

"Many students have shared directly with me how valuable it has been to hear a real-life perspective on what it can feel like to be in that situation." **Georgia Hodgson, Peer Support Supervisor**

"It's never about criticism. It's about watching, listening and feeding back in the right way to perhaps make someone think a little differently." **Lewis Gardner, Peer Support Supervisor**

Looking ahead, the partnership is set to expand further. With Pears Cumbria School of Medicine beginning in January, there are plans to explore additional opportunities for Peer Supporters to contribute to new simulation programmes, student feedback sessions and wider medical education initiatives.

By building on the strong foundations established over the past four years, the programme will continue to ensure lived experience remains at the heart of learning, helping to shape future doctors who are not only clinically skilled, but compassionate, reflective and committed to person-centred care.

The Together Strategy Strategic Ambition:
Communication

Launch of the Perinatal Carers Group



My name is Claire, and both Hannah and I work as Peer Supporters within the Perinatal Community Mental Health Team. We are passionate about using our lived experience to support people during their perinatal journey and help ensure their voices are heard.

A gap in the service was identified, and together with my colleagues, we were determined to help address this. Drawing on our own lived experiences, we reflected on how we would have liked our partners to have been supported throughout our perinatal journeys.

We both recognised that our babies' fathers did not always feel entitled to support as carers. Their focus was often on the support needs of the mother, and they did not always recognise the impact that caring responsibilities and the perinatal experience could have on their own wellbeing. We wanted to help change this for other families by developing a dedicated space where fathers, partners, and carers could feel valued, included, and supported during what can be a challenging and emotional time.

As someone with lived experience of being a carer myself, I used my own experiences to consider what a safe, welcoming, and supportive environment could look like and how this could be translated into a meaningful group. Hannah and I undertook extensive research into similar groups both within the Trust and across the wider community to understand what worked well and to identify opportunities for improvement. We explored the evidence highlighting the vital role fathers play in infant development and family wellbeing and drew heavily on the lived experiences of fathers through networking with local and national fathers' groups.

We also engaged with the CNTW Involvement Bank to gather views from carers and worked closely with the Lived Experience Service to develop group materials, including information presentations, and to consider the practicalities of setting up and delivering the group. It was important to us that the group was co-produced wherever possible, and we actively sought feedback from individuals within and beyond the Involvement Bank. We believed that those who are currently living, or have previously lived, these experiences were best placed to tell us what support would be most beneficial.

Through this collaborative approach, we successfully launched the carers' group in September. Feedback from attendees has been overwhelmingly positive, with carers reporting that they value having a dedicated space to share experiences, receive support, and connect with others in similar situations. We remain committed to increasing engagement and expanding access to ensure that as many carers as possible within our service are able to benefit from this support.

by Claire Collier

The Together Strategy Strategic Ambition:
Leadership

Co-Producing Training to Improve Understanding of Eating Disorders



My name is Rebekah, and I am a Peer Supporter within the Community and Adolescent Eating Disorders Service (CAEDS). I have worked within the service for the past two years, using my lived experience to support others in their recovery journey from an eating disorder.

Through my role, I identified a gap in understanding around the relationship between trauma and eating disorders. I developed the idea of creating training for CNTW to help drive positive change by promoting trauma-informed practice, challenging stereotypes, and equipping staff with the knowledge and understanding needed to provide compassionate, effective care.

So, I partnered with the Involvement Bank to create a working group that involves people with lived experience of eating disorders, to share what they would like CNTW to know.

As a Peer Supporter, I have found my experience of completing and leading an activity request through the Involvement Bank to be incredibly positive and rewarding. The process was easy to get involved in and provided a fantastic opportunity to share ideas and contribute towards making meaningful changes within the Trust.

A particular highlight for me was being the lead for an activity that focused on developing training aimed at creating positive change within the NHS. Having the opportunity to take a leadership role allowed me to use my lived experience in a meaningful way and demonstrate how service users and carers can play an active part in improving services. It was empowering to know that the training we are hoping to develop can help influence practice and improve experiences for others.

One of the greatest strengths of the Involvement Bank is being surrounded by people who are passionate about change. Many of the people involved have had similar experiences, creating a supportive environment where individuals feel understood and less alone. There is something incredibly powerful about bringing together people with lived experience who are committed to improving services for future patients and service users.

The Involvement Bank is also a vital platform for ensuring that people have the opportunity to have their voices heard. It helps individuals recognise that their views, experiences, and ideas are valuable and that they can make a genuine difference. When you have been poorly, it can often feel like you have lost part of yourself, your confidence, and your sense of worth. Being involved in opportunities such as these helps people rediscover their value and reminds them that they still have an important contribution to make.

The skills and experience gained through involvement activities are invaluable. Opportunities to use Microsoft Teams, work collaboratively as part of a team, contribute to interview panels,

lead projects, and provide feedback all help people build confidence and develop skills that can support a return to employment or further personal development.

I would also like to recognise Andy Fox, who has been vital in supporting me throughout this activity request. He has been incredibly kind, supportive, and helpful at every stage. His encouragement, guidance, and belief in the value of lived experience has helped me feel confident in taking on a leading role and sharing my ideas.

Overall, I believe the Involvement Bank is an invaluable resource. It empowers people to use their lived experience to influence meaningful change within the NHS, provides opportunities for people to have their voices heard, helps individuals rebuild confidence and self-worth, and equips them with valuable skills for the future. Most importantly, it reminds people that their experiences matter, their voices deserve to be heard, and that they have the power to make a real difference.

by Rebekah Woolmer



The Together Strategy Strategic Ambition:
Recruitment and Selection

Associate Director for Learning Disability Services Recruitment

Sally Vine has recently been recruited as the new Associate Director of Learning Disability and Autism Clinical Business Unit. As part of the recruitment process for this role, an Involvement Bank Contributor participated in the interview panel alongside the Specialist Care's Group Director and Group Nurse Director. The interviews took place at Northgate Hospital in Morpeth.

The Involvement Bank Contributor actively took part in the panel, asking two questions to the candidates and contributing to discussions throughout the interview process. They were fully involved in assessing candidates, and worked alongside staff members to select the successful interviewee. The recruitment decision was made collaboratively which demonstrates a strong team approach and the value of the contributions of lived experience within the process.

"I was able to ask the candidate 2 questions and was involved in the discussions regarding the candidate's interview. I also chose, along with Andy and Elaine, the candidate for the position. It was a team effort choosing the candidate." **Involvement Bank Contributor**

The involvement of the Contributor ensured that the perspective of people with lived experience was represented within the recruitment process and supported a collaborative approach to selecting a senior leader for the new Clinical Business Unit.

"Having someone with lived experience involved in the recruitment process was invaluable. Their perspective helped ensure we considered not only the skills and experience of candidates, but also how they would engage with and make a difference to the people who use our services."
Andy McMinn, Group Director of Specialist Care Group

The Together Strategy Strategic Ambition:

Training

Leadership Training: Lived Experience Reference Group Chairs and Co-Chairs



The recently launched Lived Experience Reference Groups took an important step forward with the delivery of Session 1 of the new Chair and Co-Chair Leadership Development Programme.

Developed to support the newly appointed Chairs and Co-Chairs, the programme aims to build confidence, develop leadership skills and provide practical tools to help ensure lived experience remains at the heart of service development and decision-making across the Trust.

The session brought together Chairs and Co-Chairs from across the Lived Experience Reference Groups to explore their new roles, share experiences and develop a collective understanding of what effective lived experience leadership looks like. Discussions focused on role expectations, boundaries and accountability, facilitating inclusive discussions, managing difficult conversations and maintaining personal wellbeing while undertaking leadership responsibilities.

Participants worked together to create a group agreement based on respect, inclusion, psychological safety and equal opportunities to contribute. The session also explored the qualities of effective Chairs and the vital role that Lived Experience Reference Groups will play in ensuring the voices of service users, carers and families influence service improvement, quality assurance and strategic decision-making.

A particularly strong theme emerging from the day was the value of peer support and networking. Participants expressed a desire to build stronger relationships with fellow Chairs and Co-Chairs across the Lived Experience Reference Groups, creating opportunities to share learning, exchange ideas and support one another in their leadership journeys.

Feedback from the attendees was extremely positive, with participants describing the session as engaging, informative and supportive. Many highlighted the value of meeting others in similar roles and having the opportunity to discuss both their aspirations and concerns in a safe and welcoming environment.

"I absolutely loved the training and getting to talk to everyone." **CYPS Lived Experience Reference Group Chair**

The programme will continue with a second session focused on co-production in practice, shared power, influencing decision-making, constructive challenge and recognising tokenism. Together, these sessions are helping to equip Chairs and Co-Chairs with the skills, confidence and support required to lead the newly formed Lived Experience Reference Groups and ensure lived experience continues to drive meaningful change across the Trust.

Developing Knowledge, Confidence, and Connection through Peer Support



Earlier this year Peer Supporters from across the Trust have taken part in the 12 week Peer Support Education Programme (PSEP), a comprehensive development programme designed to strengthen knowledge, skills, and confidence in delivering high-quality peer support.

The programme brings together Peer Supporters with lived experience who are passionate about supporting others through sharing hope, understanding, and connection. Each week focuses on a different module, providing opportunities for learning, reflection, discussion, and personal growth.

Through a combination of learning, discussion, shared experiences, and reflection, participants developed both their understanding of peer support and their confidence in applying these principles within their roles.

A highlight of the programme was the Celebration Day held on 16 July 2026, which provided an opportunity for Peer Supporters to come together and share their experiences of the programme. Participants were invited to co-produce and share, reflecting on their journeys throughout the 12 weeks. The presentations showcased personal stories of growth, learning, challenge, resilience, and achievement. What made the day particularly special was the authenticity and passion with which people spoke about their experiences.

Peer Supporters demonstrated the impact that the programme had on both their personal development and their practice. Many participants reflected on:

- Increased confidence in their peer support role.
- A deeper understanding of boundaries and relationship-building.
- Greater awareness of neurodiversity and different lived experiences.
- Enhanced communication and reflective practice skills.
- Feeling more connected to other Peer Supporters across the organisation.
- A stronger sense of identity and purpose within their role.

The Celebration Day was a powerful reminder of the value that lived experience brings to services, teams, and the people we support. The willingness of participants to share their journeys created an atmosphere of openness, learning, and mutual encouragement.

The involvement and support of Peer Support Supervisors throughout the programme also played an important role, offering guidance, encouragement, and space for reflection as participants progressed through their learning. The Peer Support Education Programme continues to demonstrate the Trust's commitment to investing in Peer Support and recognising the unique contribution that lived experience brings to services.

Congratulations to everyone who completed the programme. Your commitment, courage, and willingness to learn and share your experiences have made this year's programme a tremendous success. Together, you have shown the transformative power of peer support, creating hope, connection, and opportunities for growth for yourselves and those you support.

"Every story shared, every connection made, and every lesson learned strengthens the future of peer support." **Lindsay Hamburg, Lived Experience Lead**

The Together Strategy Strategic Ambition:

Service Design and Delivery

Launch of the TOC Dashboard

The Lived Experience Service is pleased to announce the launch of the new Triangle of Care (ToC) Dashboard, designed to strengthen how we involve and support carers across the Trust.

The Dashboard provides teams with a clear and accessible way to review their progress against the Triangle of Care standards. Using a simple Red, Amber, Green (RAG) rating system, the Dashboard offers an at-a-glance overview of each service's position while also capturing key developments, challenges and priorities for improvement.

The Dashboard is now regularly referenced within Triangle of Care meetings, Carer Champion meetings and Quality and Performance Forums, supporting meaningful conversations about how carers are identified, involved, and supported within services.

Over recent months, teams have engaged positively with the new process. Ongoing guidance, demonstration sessions, and supporting resources continue to be available to help staff make the most of the Dashboard.

Going forward, the Dashboard will play a key role in informing Trust-wide reporting, monitoring progress against Triangle of Care standards and supporting our continued commitment to working in partnership with carers.

The Lived Experience Service would like to thank colleagues for their ongoing engagement and contributions.

If you feel that your team would benefit from a Triangle of Care Dashboard demonstration, please email LivedExperience@cntw.nhs.uk.

Get Involved

If you are interested in joining the Involvement Bank, please complete an expression of interest form by visiting:

www.cntw.nhs.uk/involvement

Alternatively, scan the QR code to complete an online form.

Staff members wishing to make an involvement request can visit the Involvement Service section of the intranet, or alternatively email **Involvement@cntw.nhs.uk** to request an involvement request template.