

Lived Experience Service Spotlight

Q3: October - December 2025

Changes to the Service User and Carer Reference Group

The Service User and Carer Reference Group (SUCRG) meets six times per year with approximately 200 people in attendance. The group meets face to face, with membership consisting of service users, carers, staff, and third sector organisations, providing an opportunity for service users and carers in the North-East and North Cumbria to use their own lived experience to influence change within the Trust.

The continual success of the SUCRG is something to celebrate, however this success also brings with it a number of challenges. Finding a suitable venue for the group has become increasingly challenging, and ensuring every voice is heard within such a sizeable group brings additional considerations.

To address these challenges, and after careful consideration, the SUCRG is to be restructured into smaller 'Lived Experience Networks' (LEN's). Each Care Group; Inpatients, Community, and Specialist, will have it's own Lived Experience Network. The LEN's will enable smaller groups of people to come together to influence change, ensuring everyone is meaningfully involved and that every voice is heard. By focussing the LEN's on Care Group issues, each LEN will be able to explore in greater depth the issues that are of importance to them and, together, explore how we can make CNTW the best it can be.

2025

**Service User and Carer
Reference Group**

2026

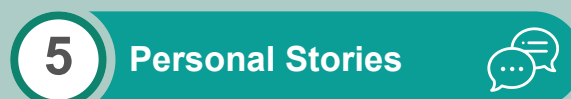
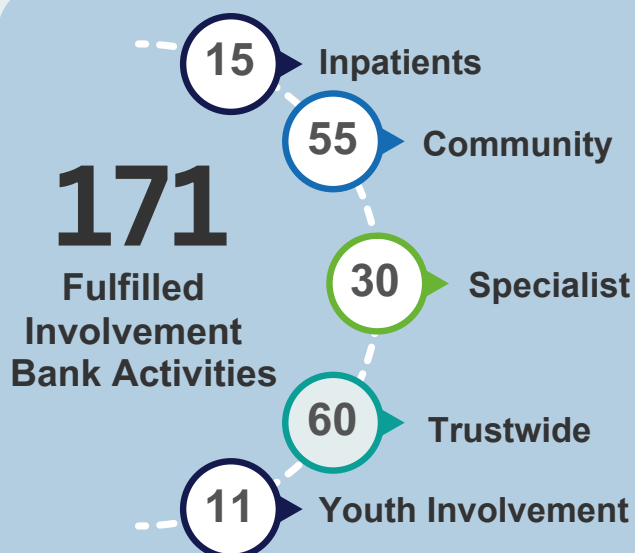
Inpatients LEN

Community LEN

Specialist LEN

The last Service User and Carer Reference Group collectively will take place on 26th February 2026. We look forward to revisiting some of the achievements the Reference Group has supported over the years. We welcome peoples thoughts on the restructure of the Service User and Carer Reference Group into smaller the Lived Experience Networks, to ensure your voices are heard and acted upon.

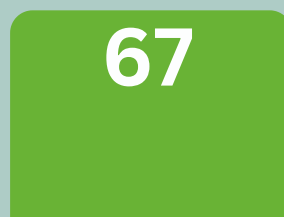
Service User and Carer Involvement in Q3



15
Carer Awareness
Training sessions
delivered



97
Peer Supporters
employed in CNTW



Peer Supporters

24

Senior Peer
Supporters

6

Peer Support
Supervisors



The Together Strategy:

Service Design and Delivery

Co-Design in Action: Shaping NHS Services Together 2025



The Lived Experience Service, together with George Moat (Involvement Contributor), were delighted to be invited to the 'Co-Design in Action: Shaping NHS Services Together 2025' event, hosted by Northumbria Healthcare NHS Foundation Trust. The day brought together service users, carers, and clinicians from across the North East and Yorkshire to highlight the pivotal role that lived experience plays in the design, development, and enhancement of NHS services.

The event highlighted the significance, value, and impact of integrating lived experience throughout each stage of service development and improvement, and provided those in attendance with the opportunity to share good practice and learn from one another.

"I can't thank you all enough for taking part in the event yesterday afternoon. It was a brilliant opportunity to come to together and share all of the fantastic work happening in our region! The work you and the team are doing is gold standard – I am sure you inspired many people in the room"

Jo Mackintosh- Chief Experience Officer

The team have been invited by NHS England to host a North East & Yorkshire Experience of Care Lunch and Learn session on Tuesday 20th January to showcase how people with lived experience play a vital role in shaping and strengthening the services that we provide.

Operational Care Group Meetings

Involvement Contributors were previously invited to the former 'Operational Management Group' meetings to share their personal narratives and experience. However, with the move to 'Operational Care Group' meetings, Inpatient Services have taken the involvement of Service Users and Carers a step further by welcoming Involvement Contributors as members, aiming to incorporate Lived Experience expertise into the development and improvement of Inpatient Services, ensuring that the Care Group effectively delivers on the Trust's Quality Priorities.

A Contributor has been allocated in the role as an equal partner for an initial six-month period to support embedding Lived Experience and to develop resources and processes which effectively support meaningful involvement within meetings. Key developments so far include:

- Monthly pre-meetings with the group Chair (Group Nurse Director) and Involvement Facilitator, providing support during and after the meetings, as well as offering opportunities to reflect on what did and didn't work well.
- Developing a reference book to support understanding terminology, specific roles, and projects.
- Consulting with the Information Governance team regarding information sharing.

This work is on-going, and we look forward to sharing further updates in the next year.



The Together Strategy: Workforce

Peer Support Education Programme

The Peer Support Educational programme (PSEP) has been supporting Peer Supporters in Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust (CNTW) since its creation in 2021 after securing funding from Health Education England (HEE) to provide an educational programme in our region.

Having recently completed its 5th year, the 12-week PSEP started in April and finished in July. The completion of the course was celebrated with attendees sharing their own reflections on the programme. The students prepared a presentation about their learning journey during the programme and presented this in the form of a fantastical cruise around the islands of PSEP, even taking in a sea shanty lead by Captain Birdseye.

Attendees rated the 2025 programme as excellent, this included the course content, the structure and organisation, the student packs, the schedule and timings and the delivery method. Attendees shared feedback on what was the most valuable part of the programme;

“It has helped provide reassurance about how I’m approaching the role and how I try to support service users.”

“Group discussions.”

“Networking with other peers and presentations from other services in the Trust.”



The following areas are some of the topics covered in the weekly sessions;

- Peer Support and Recovery journeys
- The Peer Relationship
- How do we bring our experience, listen and use language as peers?
- Meaningful involvement and co-production
- A trauma informed, strength-based approach
- Working in Mental Health Services

The next PSEP is due to start on 16th April 2026, if you would like to be part of this cohort please email livedexperience@cntw.nhs.uk to reserve a space.



The Together Strategy: Training

Collaborative working with CNTW Academy

CNTW Academy supports learning and development across the Trust. The Lived Experience Service continue to work closely with CNTW Academy on a range of Involvement projects which include:

- Supporting people with lived experience of inpatient services to share their own testimonies about use of restrictive practices. Co-produced videos are now used as part of the Trusts Prevention and Management of Violence and Aggression (PMVA) training and HOPES training which is delivered nationally.
- Co-designing training with Occupational Therapists about Dysphagia. Dysphagia is the medical term for swallowing difficulties. This training is now provided to staff working in Care homes across Sunderland.
- Supporting the design and delivery of learning disability and autism training across the Trust.

As part of the CNTW Academy Team Away Day, the Lived Experience Service were invited, along with two Involvement Bank Contributors, to lead on an Involvement presentation. This included Contributors sharing their own experience of being part of the Involvement Bank and what a difference this has made to their own mental health recovery journeys.



Both Contributors received positive feedback from everyone in the Academy team, with further opportunities also arising for the Academy and Lived Experience Service to work collaboratively on new projects.

“It is so important to work together to ensure our training content has lived experiences at the heart of it. Thank you for inspiring us.”

CNTW Academy



The Together Strategy:

Recruitment and Selection

Youth Involvement in Peer Support Recruitment



A Youth Involvement Bank Contributor with lived experience of the Complex Neurodevelopmental Disorder Service (CNDS) recently played a vital role in the recruitment process for a new Peer Supporter.

As part of an assessment day, the young person joined the panel to observe candidates and provide feedback from a service user perspective. The assessment focused on how candidates interacted with the team and demonstrated warmth, empathy, and communication skills—qualities essential for supporting young people and families.

The Contributor's role was to watch group activities and discussions, noting how approachable and inclusive each candidate appeared. Their insights were invaluable in highlighting which applicants truly understood the importance of connection and compassion in mental health care.

This Involvement Activity reflects the Trust's commitment to co-production and ensuring that lived experience shapes recruitment decisions. By including a young person in the process, the team gained a unique perspective that goes beyond professional qualifications, focusing on relational qualities that make a real difference to service users.

Feedback from the day was overwhelmingly positive. Staff praised the young person's maturity and thoughtful observations, which will support and guide decisions about which candidates progress to interview. For the young person, the experience reinforced a sense of belonging and the belief that their voice matters in shaping services.

"I had an absolutely amazing day – I really enjoyed it and the feedback I got from people was so lovely. It made me feel like I was a part of the team and gives me the motivation to keep going so one day I can be a part of a team like that!"

Youth Bank Contributor

"It was wonderful to have a Youth Involvement Bank Contributor with us. I felt their contributions were really helpful. Their enthusiasm to be part of the day was infectious and their comments insightful. A valuable contribution to the success of the day."

Activity Lead



The Together Strategy:

What's working well and why?

ADHD Programme

This year, 70 people completed the ADHD Lived Experience Programme across Carlisle and Whitehaven. The programme was co-developed by people with ADHD for people with ADHD and continues to be shaped by the experiences and feedback of those who take part.

Across six sessions, people explored what ADHD is, how the ADHD brain works, emotional wellbeing, practical strategies, and neurodiversity. Sessions combine lived experience with evidence-based information, delivered in an accessible, ADHD-friendly way. The programme supports people to understand the nature of their struggles, offering validation so they feel empowered to explore strategies that work for them. All January cohorts in Carlisle and Whitehaven are now full, and referrals are temporarily on hold while we plan the next phase of the programme. We will share further updates in the new year.

"The group has helped me become more social, and want to put myself out there again. It's helped me see myself differently, as well as helped my self esteem. I'm happy to say that, because of this course, I'm starting back at work this next week on a phased return, so thank you for everything, and giving me a second chance at life essentially."

ADHD Programme attendee



**Have
completed
the 6 week
programme.**

**Feedback consistently highlighted
the following key themes:**

**A sense of
belonging.**

**The value of
sharing lived
experience.**

**Improved self
understanding.**

**Validation and
self-acceptance.**

**Emotional safety
and connection.**

**Accessible
delivery.**

**Reflection and
growth.**

**A need for
continued ADHD
support.**

269 pieces of feedback
submitted and evaluated...



**ensuring lived
experience voice
remains at the
heart of ongoing
programme
development**

73%

**reported using
crisis or urgent
mental health
services less
often after the
programme.**

**People experienced
growth in an average
of 5 out of 8 areas,
measured using the
ADHD Outcome
Star™.**



Carer Well-being Group



A new Carer Well-being Group has been collaboratively developed in partnership with carers of adults with learning disabilities and/or who are neurodiverse. The group's design was directly informed by carers, incorporating their lived experiences, priorities, and insights into the ongoing challenges associated with their caring responsibilities. Throughout the development process, carers identified the need for a dedicated space that acknowledges their emotional, social, and practical needs, as well as the significance of peer support.

Carers consistently indicated that, while support services for those they care for are often available, their own well-being can be neglected. They expressed a desire for a group that provides relief from social isolation, opportunities for sharing experiences, and access to strategies that promote resilience and self-care. In response, the group has been created to offer a supportive environment where carers can connect, reflect, and access relevant information.

The Carer Well-being Group aims to boost carers' confidence, alleviate stress, and promote overall well-being by fostering mutual support and delivering tailored sessions on topics chosen by the carers themselves.

The next meeting will take place on Friday 23rd January, 10:30am at Cramlington Hub.

St Georges Park - New service user and carer groups



St George's Park has been a hub of busy. Peer Supporters have been working hard on creating and developing groups on site to support patients.

On a Monday afternoon the community centre has been hosting a Recovery College session that has been doing amazing work. This time of year, a number of fun activities have been taking place, including: Christmas decorations, baking and lots of arts and crafts.

On a Wednesday afternoon a new Photography group has started, allowing patients not only to learn new skills but also explore the area and beyond with weekly tasks to get them out and about in the community. This is looking like it's going to become a permanent fixture on site run by Peers and the Occupational Therapy team and is helping patients connect more in so many ways; exploring ideas, creativity and helping in their recovery.

A new 'future focus' group has also been established, highlighting developments that are happening in the community in preparation for when patients are discharged. The group has been popular on site and been a key development for the wards.



The Together Strategy: Leadership

Chatterbox - Walkergate Park Forum

Involvement Bank Contributors who have lived experience of Walkergate Park Services have led on the development of a new patient and carer forum.

The Walkergate Park Chatterbox group meets monthly and aims to bring patients, carers and staff from Walkergate Park services together to:

- Support people to provide feedback about their care and treatment.
- Share information and encourage relationship building.
- Work together to make positive changes for everyone.

All meetings are held as a drop-in session so that people can join at any time and stay for as little or as long as they want to. Activities are also designed to ensure that meetings are relaxed and informal, so that everyone feels able to share their own thoughts and experiences.

Feedback from patients, carers and staff is acted upon as part of a 'You Said, We Did' way of working and the Chatterbox group team have worked hard to support this approach.

"Each month it is such a privilege to be part of such a fun friendly and supportive group in which the smallest suggestion from one person can make such a positive difference for so many people's lives. Together we can make the change."

Pat Melvin – Involvement Bank Contributor



Do you use services at Walkergate Park? Are you a family member or carer of someone who does? We welcome you to the Walkergate Park Chatterbox where we can learn and share together. Pop along for a chat, a cuppa and meet our friendly group.

Our next Chatterbox group meetings will be held on:

Thursday 29th January 1.30-3.30 – Conference Room 2, Walkergate Park.

Friday 20th February 1.30-3.30 – Conference Room 2, Walkergate Park.



The Together Strategy:

Communication

Secure Involvement Strategy

At October's Service User and Carer Reference Group, Secure Services were asked to present on the new Secure Involvement strategy. This co-produced strategy has taken many months to create, utilising monthly Lived Experience Advisory Group (LEAG) meetings to work on the strategy. Once it was finalised, patients and carers wanted it to be accessible to all, and not simply a document in a file.

Service users and carers involved in producing the strategy thought about different ways to bring the strategy to life and give it meaning, working with Secure Service's Artist, Recovery Team and Peer Supporters to develop an animation. Two patients from Northgate, supported by Lyndsey Tunney (Peer Supporter) presented the strategy to the Trust-wide Service User and Carer Reference Group, working together to present the animation and answer questions.

"The opportunity to do this was daunting for the patients at first but the feedback afterwards really empowered them. It isn't easy to stand up in a room of 150 people but our patients enjoyed the experience."

Lyndsey Tunney, Peer Supporter



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.



The next Service User and Carer Reference Group is on the **26th February 2026**. This will mark the last meeting before the group restructures into Lived Experience Networks. To book a place, please contact: referencegroup@cntw.nhs.uk



LivedExperience@cntw.nhs.uk