

Community insight and involvement report

**What people told us, what we
learned, and what changed**

Quarter 1 – 2026/27

About this report

- This report brings together **what people and communities have told us** this quarter about health and care services across North East and North Cumbria
- Every year, thousands of people **share their experiences, ideas and feedback with the NHS** through involvement activities, community conversations, patient feedback, lived experience, Healthwatch reports and voluntary and community organisations
- Rather than reporting on every involvement activity that has taken place, this report focuses on the **key themes, insights and learning emerging from the feedback** we receive
- By bringing these voices together, we can **identify common themes, understand what matters most** to people, and **use this insight** to help shape decisions, services and future plans
- This approach supports the NHS England Blueprint expectation that Integrated Care Boards use **community insight, involvement and co-production as part of strategic commissioning** and service improvement



**This is more than engagement
activity – it is community insight
that helps shape decisions
across the NHS**

At a glance

Key themes

By bringing together feedback from patients, carers, communities, Healthwatch and involvement activities across the region, several common themes emerged this quarter:

Access to services - people continue to experience barriers accessing care, including GP appointments, mental health support, specialist services, dentistry, transport and information about available services

Communication and information - people want clear, timely and compassionate communication, including better explanations, clearer information, updates on care and honest conversations about treatment and future planning

Key themes

Relationships and compassionate care - across projects, people consistently valued being listened to, treated with dignity and respect, having continuity of support, and receiving person-centred care

Prevention, early support and community-based care - people value services that help them stay well, prevent problems becoming crises, and provide support close to home and within communities

Inclusion, equality and lived experience - people highlighted the importance of accessible services, reducing inequalities, making reasonable adjustments, and involving people with lived experience in decisions that affect them

Joined-up care and support for families and carers – people want services to work together more effectively, with better coordination across organisations and greater support for carers and families

What changed because of listening...

Community mental health conversations - 470 people helped shape future decisions about community mental health support in County Durham. Their feedback highlighted the importance of prevention, local support, community connections and lived experience

End of life care - health needs assessment - 2,631 people helped shape recommendations for palliative and end of life care, including earlier planning conversations, better coordinated care, stronger support for carers and action to reduce inequalities

What changed because of listening...

Improving information and communication - feedback from patients and communities was used to review information, improve communications and support service improvements across a range of NHS services

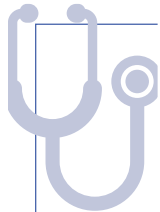
Access and quality improvement - concerns about appointments, access to services and patient experience were reviewed by local NHS teams and contributed to service reviews, quality improvement work and further engagement activities

Healthwatch influence - Healthwatch insight helped improve winter health communications, shape the development of the WorkWell programme and influence national discussions about digital healthcare and NHS online services

**Listening to your
experiences**

13

people shared their experiences
through our different feedback channels



9 responses were
received through “GP -
Tell us what you think”



2 emails were
received to the
involvement inbox



2 responses were
received to our general
“Tell us what you think”
questions

What people told us

Access to GP services and appointments

Many people told us they found it difficult to access appointments when they needed them. Common concerns included long waits, difficulties getting through on the phone, limited appointment availability and challenges accessing appointments around work or caring responsibilities.

Communication and information

People highlighted the importance of clear, accurate and timely information. Some people felt information could be easier to understand, while others wanted better explanations about treatment options, services and what to expect from their care.

Prescriptions and medication

Several people shared concerns about prescription processes, including delays, repeat prescriptions and access to medicines. People told us they wanted systems that are easy to navigate and responsive to individual needs.

Children and young people's services

Families highlighted challenges accessing specialist support for children and young people. Some felt there were gaps in available services and wanted greater involvement in discussions about future service development.

End of life care and support for carers

People shared experiences of caring for loved ones at the end of life. Feedback highlighted the importance of honest communication, joined-up care, practical support for carers and earlier conversations about end of life wishes and planning.

Access to specialist support for people with complex needs

Some families described long-term challenges accessing specialist assessments, support services and appropriate provision for people with complex disabilities and additional needs. People highlighted the importance of coordinated working between organisations and ensuring that the voices of family carers are heard when services are designed and delivered.

How services responded

Reviewing access arrangements

Local NHS teams reviewed concerns about access to GP services and appointments.

Some practices have undertaken service reviews, made changes to telephone systems, and worked with Patient Participation Groups and Healthwatch to gather additional feedback and identify improvements.

Improving information and communication

Where concerns were raised about information provided to patients, services reviewed communications and provided clarification

Some organisations updated public information to ensure it was accurate and easier to understand.

Learning from individual experiences

Feedback about children's services, prescriptions, end of life care and patient experience was shared with relevant clinical and operational teams. Services used this feedback to identify learning opportunities and consider improvements to future care.

Supporting quality improvement

Some feedback has contributed to wider quality reviews, service improvement discussions and deep dive reviews undertaken by local NHS teams.

Areas requiring further work

Some feedback highlighted wider concerns about the availability of specialist services and support for people with complex needs and disabilities. These comments have been shared with relevant teams and will help inform future discussions about service provision, partnership working and support for families.

Listening to community voices

What Healthwatch is hearing

- Healthwatch organisations across North East and North Cumbria continue to hear about people's experiences of using health and care services
- Healthwatch has a place at our decision-making forums
- They are an important part of our work, acting as a “critical friend” to make sure people’s voices are heard

Access to services

- People reported ongoing difficulties accessing GP appointments, NHS dentists and some hospital services. Long waiting times, challenges booking appointments and delays in treatment continue to affect people's experiences.

Communication and information

- Many people said they wanted clearer communication from services. This included updates about appointments, treatment plans, waiting times and test results, as well as better communication between different services.

Accessibility and reasonable adjustments

- Healthwatch heard concerns from people who need additional support to access services, including Deaf people, people with learning disabilities, autistic people, and those with mobility needs. People highlighted the importance of reasonable adjustments and accessible communication.

Travel and transport

- People told Healthwatch that travel and transport remain a barrier to accessing healthcare, particularly in rural areas. Parking, patient transport and the cost of travel were all raised as concerns.

Compassionate and person-centred care

- While many people shared positive experiences of caring and supportive staff, others described feeling unheard, dismissed or not fully involved in decisions about their care. People said kindness, respect and being listened to are just as important as the care they receive.

Digital inclusion and choice

- As more services become available online, people highlighted the need to maintain non-digital options. While many value the convenience of digital services, others worry about being excluded if face-to-face and telephone options are reduced.

Project spotlight

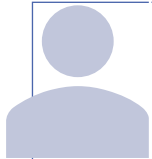
County Durham community mental health conversations

Why we involved people

We wanted to understand how community mental health and wellbeing services help people in County Durham, and what the impact could be if services change

470

people shared their views



193

- PCP service users



151

- Age UK service users



31

- Lived experience and Happiness Hubs



95

- Health and Care stakeholders

People value support that prevents crisis

- Across all groups, people described community mental health services as helping them stay well before problems become a crisis
- Many people said support helped them avoid reaching crisis point
- Some described services as life-changing or life-saving
- Stakeholders felt removing support could increase demand on NHS services

“Before the help, I was suicidal. There’s a possibility I may not have been here.”

“I truly believe without this invaluable help... I most probably would not be here to write these words.”

“I’m sure I would have ended my life! This is how much this service is **NEEDED** and not wanted.”

Local support matters

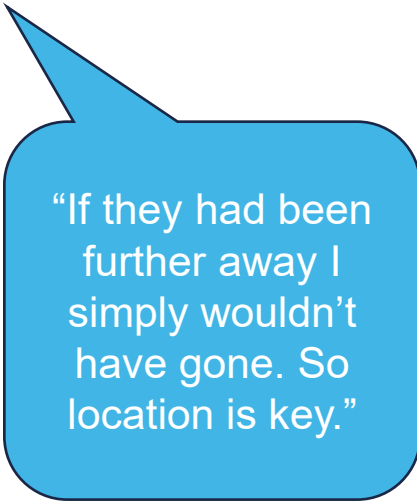
- People told us that support works best when it is:
 - Local
 - Easy to access
 - Available quickly
 - Face to face
- Many people said long waiting times can make mental health worse.



“Support that is close to home makes it easier to reach out.”



“Having access to this service on my doorstep.”



“If they had been further away I simply wouldn’t have gone. So location is key.”

Relationships make a difference

People valued:

Being listened to

Seeing the same person over time

Non-judgemental support

Trusted community spaces

People often preferred community support to more clinical services.

“Having someone consistent to talk to who listens and understands you.”

“Being able to talk to someone who doesn’t judge. It’s a lovely feeling knowing I can open up.”

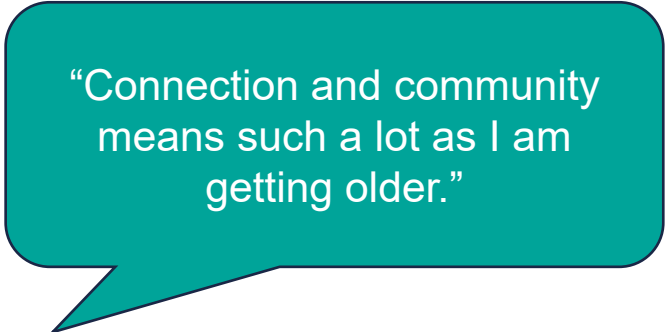
“Other professionals don’t have time to listen. To be heard and listened to, have time for me.”

Community connections improve wellbeing

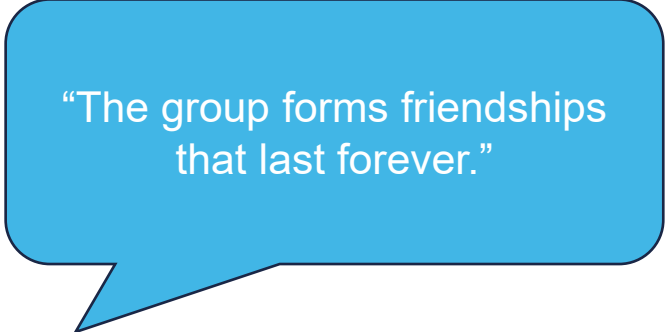
- People said services helped them:
 - Reduce loneliness
 - Build confidence
 - Meet other people
 - Stay connected to their community
- Activities such as walking groups, arts activities and peer support were seen as important



“Peer support groups helped me make new friends.”



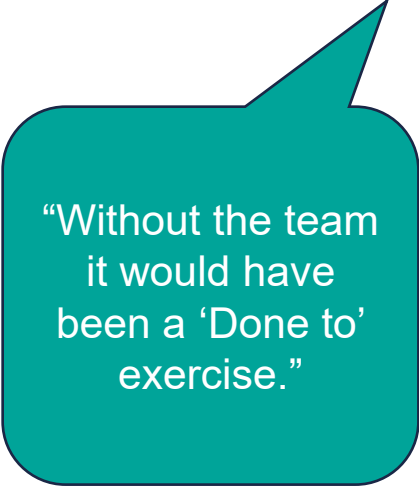
“Connection and community means such a lot as I am getting older.”



“The group forms friendships that last forever.”

Lived experience should shape services

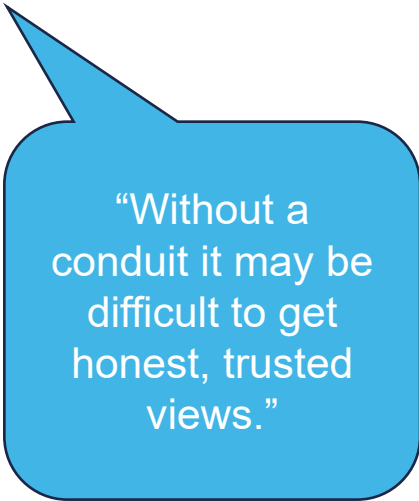
- Stakeholders strongly supported the role of lived experience in service design.
- People said lived experience:
 - Helps services understand real needs
 - Builds trust
 - Improves decision making
 - Makes services more inclusive



“Without the team it would have been a ‘Done to’ exercise.”



“Historically, many things were done to people rather than with them.”



“Without a conduit it may be difficult to get honest, trusted views.”

Different views from different groups

- Personal support
- Recovery
- Preventing crisis
- Reducing loneliness

Service users
focussed on



- Pressure on NHS services
- Early intervention
- Community resilience
- Long-term sustainability

Stakeholders
focused on:



- Having a voice
- Co-production
- Trust
- Better service design

Lived Experience
Network focused
on:



What happens next

The feedback we received will be used alongside other evidence to help inform future decisions about community mental health support in County Durham.

Decision makers will consider:

Impact on people	How any changes may affect people who use services, their carers and families.
Impact on communities	The wider effect on local communities, including loneliness, wellbeing and access to support.
Equality considerations	Whether any groups may be affected differently and what action may be needed to reduce inequalities.
Alternative support options	What support may be available if services change and how people can access it.
Continuing involvement	How people with lived experience can continue to shape future plans and decisions.

**How your feedback
made a difference**

End of life – health needs assessment

2,631

people helped shape the future direction of
palliative and end of life care across the North
East and North Cumbria

How this shaped the recommendations

Earlier conversations and planning

- People told us that many families avoid conversations about death and do not know how to start planning.
- This directly informed recommendations to improve advance care planning, increase awareness of the palliative care register and support professionals to have compassionate conversations earlier.

Better coordinated care

- People described repeating information, delays in equipment and funding, and difficulties navigating different services.
- The Health Needs Assessment recommends improving coordination between health, social care and voluntary sector services and exploring named care coordinator approaches.

More support for carers

- Many carers described feeling exhausted, overwhelmed and unsupported.
- As a result, the Health Needs Assessment highlights the need for better information, practical support, respite services and greater involvement of carers in decision-making.

Reducing inequalities

- People from some communities described barriers linked to disability, rurality, poverty, culture, language and discrimination.
- This informed recommendations to improve culturally competent care, strengthen outreach and reduce inequalities in access to services.

Dignity and compassion

- People consistently said they wanted care that was compassionate, respectful and person-centred.
- These themes have been embedded throughout the Health Needs Assessment recommendations and identified as core quality standards for future services.

Keep the conversation going

Thank you to everyone who shared their experiences, ideas and feedback this quarter

Your views help us understand what matters most to people and communities, and play an important role in shaping health and care services across North East and North Cumbria

If you would like to share your thoughts about NHS services, tell us about your experiences, or find out more about how we involve people in our work, we'd love to hear from you

 Email: **NENCICB.Involve@nhs.net**

 Share your feedback:
<https://www.smartsurvey.co.uk/t/R8YDKY/>

 Find out more and get involved:
<https://northeastnorthcumbria.nhs.uk/get-involved/>

Together, we can help improve health and care services for everyone