



**North East and
North Cumbria**

Annual Involvement and Engagement Report

2024 - 2025

**Better health
and wellbeing for all...**

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Listening to people in our communities

The ICB (Integrated Care Board) (the group that helps plan local health services) wants to make sure it listens to everyone. This includes patients, the public, carers, and different groups of people in the community – especially those who might need extra support.

We use different ways to talk with people and hear what they think. This helps us make better choices when planning health services. We've changed how we do this over time, learning what works best, and using a mix of ways to speak with and listen to people.

We have a special team that helps others ask people what they think. They give support, advice, and tools to make this work easier. Each project has its own plan that explains what we want to do, how we will do it, and what is needed.

We also check if people's views are helping us make good changes. Staff can use a step-by-step guide to help involve people. The team also builds strong links with local groups, charities, and communities to hear what people think.

We write reports to show what we've learned. These go to important groups like the ICB's Patient Voice Group, Quality and Safety Committee and the Board. It shows we care about listening to people.

Who we hear from

We hear what matters to people in lots of different ways, including through:

- MPs and local councillors
- Healthwatch and community groups
- Complaints
- News and social media
- Speaking with patients and the public.

You can read more about how we work with Healthwatch and community groups later in the report: [working with our communities](#).

This feedback is brought together and looked at by the Patient Voice Group.

The Patient Voice Group:

- Helps make sure the ICB listens to local voices.

- Checks that we are following the rules about involving people in decisions.

A summary of this discussion is then taken to the Quality and Safety Committee, along with other feedback from complaints, MPs, Healthwatch and more.

The key themes from all these sources are shared at the meeting, so senior NHS staff can use this information to help improve local services.

We've listened carefully over the past year, and these are the most common things we've heard:

Key themes from communities, patients and public:

- **Hard to see a dentist:** people often struggle to get NHS dental care.
- **Long waits:** for things like ADHD/autism support, mental health help, and hospital appointments.
- **Hard to get GP appointments:** especially for people who don't want or can't use online systems.
- **Poor communication:** NHS letters and information need to be easier to understand and in different languages when needed.
- **Discharge from hospital:** people want better support when leaving hospital, including help from social care.
- **Digital exclusion:** some people can't or don't want to use digital tools for booking appointments or for information.
- **Problems with hearing (audiology) services:** including long waits and poor service.
- **Concerns about continuing healthcare:** people need more support with long-term health care needs.
- **Public appreciation:** many people say thank you to NHS staff and support public health campaigns.

Overview of how we work

- **Shaping services through listening:** The ICB works with patients, carers, health staff, and the public to help make health services safer and better. We want to help people stay healthy and feel well. Every year, we write a report to show what we've done and how we've listened to people.
- **Collaborative listening:** We are part of a bigger team called an integrated care system. This means we work with other groups and partners. Some of

them help us with our job to listen to people. We meet with them often to get updates and make sure things are going well. This is checked through ICB meetings.

- **Working with our communities** - It's important that we work with others in the community. We team up with groups like Healthwatch and charities. We share people's feedback with the NHS and other organisations. This happens in areas across the North East and North Cumbria. We are always looking for ways to get better at this.
- **Supporting people to involve** - The ICB has made lots of helpful tools and guides to make sure we really listen to people. These include plans, training materials, forms, and toolkits to help staff involve people in the right way.

Shaping services through listening

Annual involvement report

The ICB works with patients, carers, the public, and health partners to make care safer, improve patient experiences, and help people live healthier lives.

We want to use public money wisely and make good decisions. We make big decisions about health services together with important partners, and most importantly, with local people. We want services that are centred around people, that last a long time, and that people can help shape.

We also collect information about the people who take part in our work, including things like age, gender, and other protected characteristics (based on the Equality Act 2010). This helps us see who is getting involved, who we might be missing, and how different groups respond. We look at this data to make services fair and to reduce health problems in certain groups.

Each year, we write a report showing how we've listened to local people. It includes real examples of how people's ideas have helped us improve services, make access easier, and come up with new ways of doing things.

Right now, it's more important than ever to listen to people's feedback. It helps us understand where there are health problems and how we can make care quicker and more flexible. We've built strong connections with Healthwatch and local charities. They help us spread health information and listen to what people need.

This report shows what we've done in 2024/25 to involve people. It proves that local voices have made a real difference to the decisions we've made.

Find out more - You can read more about the work we have supported in our [Annual Involvement Reports](#).

Talking about the future of the NHS

The NHS is making a new plan for the next 10 years. As part of this, Change NHS was launched, which was the biggest conversation ever about the future of the NHS.

People all over the country were asked to share their thoughts and ideas about how the NHS should work in the future. The ICB encouraged people to take part across the North East and North Cumbria by filling out an online survey. We've shared it through social media, newsletters, and with local groups and organisations.

There was also a special event for NHS leaders in February 2025, using a national discussion guide called Workshop in a Box (WIAB). Other WIAB events were also run by the Voluntary, Community and Social Enterprise (VCSE) Partnership Programme and by the Northern Cancer Alliance.

The ICB asked Healthwatch to run more WIAB sessions in each council area in our region. In total, 14 sessions were held. Three extra sessions were run with people who don't always get heard - including people from ethnic minority backgrounds, people with a learning disability or autism, and young people.

What people said

198 people across our region took part in the local WIAB sessions with Healthwatch. Healthwatch has shared the main things people told them:

- People still believe in the NHS and want it to stay public.
- They want kind, caring staff and a service that works well for everyone.
- They want health and social care to work together better.
- People want more choice in how they get support and care that fits around their life, not the other way around.
- They said mental health and dental care need to improve.
- They want to be listened to and involved in decisions about their care.
- They want better information and more support to understand what's available.
- People like using technology when it helps – for example, faster diagnosis, but they don't want to be forced to only use online services. Some worry about online safety and data privacy.

All this feedback has been sent to the national NHS team. Healthwatch is also writing a summary report for the ICB to help shape future plans.

The Big Conversation

We ask people about health topics in a project called **The Big Conversation**. We pick one topic at a time so it's easy to talk about. Here are some examples of the Big Conversations we have had over the past year.

Listening to women's health needs: The Big Conversation

In July 2024, a big project called The Big Conversation on Women's Health began at the ICB's Women's Health Conference. It ran until September. The ICB worked with Healthwatch in the North East and North Cumbria to make it happen.

Listening to people

The project included a survey, and six group discussions called focus groups. These were made for women who are not often heard. 35 women took part from these groups:

- Women with learning disabilities in Cumberland
- Refugee and asylum-seeking women in Stockton
- Unpaid carers in Northumberland
- Women from ethnic minority backgrounds in South Tyneside
- Women with experience of mental health challenges during or after pregnancy in Westmorland and Furness
- Staff who work with women affected by sexual abuse in Darlington.

About 4,500 people filled in the survey. We asked them:

- Where do you look for information about women's health?
- How confident are you talking to a doctor or nurse about women's health?
- What is most important to you when using women's health services?
- What matters to you about your health and well-being?
- What are your top five health priorities?

What people said

The top five most important women's health topics were:

1. Mental health and well-being
2. Healthy ageing and long-term conditions (like bone and joint health)
3. Menopause and hormone treatments
4. Cancer checks (like cervical, breast, bowel screenings)
5. Period and gynaecological health.

We also learned that:

- 61% of women said they feel okay talking to a healthcare professional – but many worry they won't be taken seriously or get help.
- Many women feel ignored or not believed when they ask for help.
- GPs (family doctors) are the first place many women go – but some feel their GP doesn't listen or doesn't know enough about women's health.
- Lots of women want to see a female healthcare professional when they talk about personal health issues.
- Most people go to their GP or the NHS website for health information. But focus groups said we also need easier-to-understand information, especially in local communities.
- Women want their health records to be easy to access and kept up to date.
- Many women said we need more research about women's health.
- Each focus group shared extra thoughts. For example:
 - Women with learning disabilities said people don't understand how being neurodivergent affects their health.
 - Women who experienced sexual assault worried about confidentiality - keeping their information private.

Listening to young women

As part of this work, we also wanted to make sure the views of young women aged 16 to 18 years old was included. Their voices are often missing when we talk about health services.

We set up a special project to hear directly from young women across the region. We made sure the young people felt safe, respected, and confident to speak. There were both in-person and online sessions so more people could take part.

Young women talked about what health means to them, what matters most, and what support they need.

Here's what they said:

- Schools need to teach more about women's health, including periods and mental health.
- Doctors and nurses must listen and make young women feel safe.
- Many young women feel pressure from social media about how they should look.
- They want places where they can talk about health without being judged.

One young woman even helped present these views at the ICB's Women's Health Conference, alongside ICB staff.

These voices helped the ICB make better choices about how to deliver the National Women's Health Strategy in our region.

Find out more

- Read more information about the [Women's Health programme and Big Conversation](#).
- Read the article [Women's health in spotlight as ground-breaking report is published](#) to learn more

LOC in the Lakes 2024: A new way to tackle obesity

In 2024, a big event called LOC in the Lakes was held to look at how we can help people live healthier lives. It focused on obesity (having too much body fat) which can lead to health problems. LOC stands for Learning Organisations' Collaborative.

Obesity is a big problem in our area. It also puts pressure on the NHS. Right now, almost 1 in 3 children are overweight or obese before they turn 15. This can lead to problems with:

- Physical health (like heart problems and diabetes)
- Mental health (like low confidence or anxiety)
- Social health (like bullying or feeling left out).

The event was run with help from Boost and Health Innovation North East and North Cumbria (HINENC).

What people said

- Children and families need help to make healthy choices
- We need fun and bold new ideas
- Working together makes a big difference.

What happened at LOC in the Lakes

The event brought together people who work or volunteer in health and care. They shared local ideas that are already helping and came up with new ones too. Because of the event:

- A community of practice was created (a group of people working together to make changes)
- New training and learning sessions are now offered through the [Boost Learning Academy](#).

Find out more - Find out more about what happened at the [LOC in the Lakes 2024](#) event.

Working well and caring better

We want to make health and care better for everyone. That means listening to people, learning from what they say, and using their ideas to improve services. One way we're doing this is by helping more people stay in work, even if they have health problems. Another is by making sure health and care services are safe, clear, and easy to use. These two projects show how we're working with local people to make real changes that matter.

Work well: helping people stay healthy and in work

Some people can't work because of health problems. We're starting a new service to help them stay in or get back to work.

This service will give people the right kind of support based on their own needs. First, we wanted to understand more about why people can't work or are finding it hard to stay in work.

Listening to people

In February 2025, we held six online focus groups to talk about:

- What people think about the new service

- How it could help
- What challenges it might face
- Ideas to make it work well.

We asked for help from:

- People who are working but have health condition
- People who can't currently work because of their health
- People whose job is to support others to stay in work.

41 people took part in these chats. Some were working full- or part-time, some were on sick leave, and others were out of work due to health. Some worked in roles that support others to stay in jobs.

What people said

Good things people said:

- The service could help people with long-term health conditions get back to work or stay at work.
- It could give employers support and confidence to help their staff.
- The service could help employers and employees talk and understand each other better.

Concerns people had:

- Some managers don't understand certain health problems.
- People worried about how and why employers might refer them to the service.
- Using GP records to find people for the service might not work well – the records might be out of date or not show who really needs help.
- Some people were worried about how their personal data would be shared and kept safe.

Ideas to make it better:

- Let employers or people themselves refer into the service.
- Make sure joining the programme is voluntary and done at the right time for the person.
- Give people clear information before they are invited.
- Use GPs, health professionals, charities, and Job Centre Plus to tell people about the service.

- Make sure employers are on board and ready to make reasonable changes to support staff.
- Work together with other services that help people into work – not repeat what's already being done.

Next steps:

We heard it's important to include people with real-life experience in building and testing the service. We will run different activities during 2025 and 2026 to hear what people think. This will help us build the new service and understand what it's like to use it.

Find out more - You can read more about this in the [news article on the ICB website](#)

ICB quality strategy - Listening to people to make care better

We wrote a strategy to help health services be safer, clearer, and always improving. This plan will help health and care services across the North East and North Cumbria to work in the same way.

Listening to people

We wanted to know what people thought about our first version of the plan. We shared an online survey with:

- Local people
- NHS staff
- Different organisations.

The survey closed in early June. We received 723 answers to the survey, and 689 of these were from the public. People told us:

- The words in the plan were too difficult
- Some of the statements didn't match their real-life experiences.

What we learned

We asked people what they thought. We changed the plan based on their ideas. Now there's a one-page version and an easy-read version. This means more people can understand and use the strategy.

Find out more - You can read our [quality strategy](#) to learn more.

Shaping respite services

Learning disability respite services in Tees Valley

In the Tees Valley, people with learning disabilities can go to special places called Aysgarth and Banksfields for short stays. This is called respite care. It gives families a break and helps everyone stay well.

These places are run by TEWV (Tees Esk and Wear Valley NHS Foundation Trust). In September 2024, TEWV told us they will stop running these services.

Listening to people

We want to make sure the new service is what families and service users need. We held four “Meet the Commissioners” events in Middlesbrough, Stockton, Redcar, and online in September 2024. Families came to share their views and concerns.

We also asked two groups - Skills for People and Inclusion North - to run more listening sessions. About 23 families took part.

In November 2024, they held:

- 12 sessions (online and in person, at different times of the day)
- A survey for families to share their thoughts.

What people said

How families are feeling

- Families felt tired, isolated, and sometimes desperate
- Respite care helps their mental and physical health
- It gives them a break and reduces stress
- Families want the chance to be heard and understood.

What's good about the current service

- Staff give good care
- It feels like a community
- People feel safe and comfortable
- Some families struggle with transport
- Being able to book short stays flexibly is important.

What families want for the future

- Keep the service as close to now as possible

- More notice and flexibility when booking
- Staff who have good training and understand complex needs
- Small, homely places close to where families live
- Good bathroom facilities
- Many families are worried about the future, especially as parents get older.

What happens next?

The first part of listening to people's views ended in December 2024. A report was shared with everyone who took part. Some people who use the service were then asked to join regular meetings to help plan the future. These people made sure service users' voices were heard.

Together, they are helping to design a new respite service. Families were also given the chance to look at buildings that might be used for the new service.

The ICB and families are still working together to plan the new service. TEWV will keep running the current service until the new one is ready.

Planning a new short break service in South Tyneside

Why we needed to do something:

Some people with learning disabilities need a short break from their usual care. This helps them and gives their families and carers a rest too. In 2019, a place called Elmville that offered short breaks had to close because of Covid-19.

In 2022, we asked families if they still needed this type of service. They said yes. So, in 2024, we worked with families again to help design a new short break service.

Who we worked with:

- We worked with South Tyneside and Sunderland NHS Foundation Trust.
- We asked Stand, a specialist company, to help us with the involvement.
- We asked Twisting Ducks, a voluntary group, to help us talk with people with learning disabilities, their families, and carers.

How we involved people:

We used what we heard in 2022 and then added lots of new ways for people to get involved in 2024:

- One-to-one chats with families and carers

- A survey to gather more views
- Field trips – three families visited other short break places to try them out
- A feedback session – people talked about what worked and what didn't
- A co-design session – people helped create ideas for the new service
- Ongoing chats with families
- A workshop with adult care staff and other organisations.

What we learned:

Families liked the chance to visit other short break services. They said a good short break service should:

- Be local
- Be easy to get around
- Have friendly, trained staff
- Include the right equipment
- Offer fun and interesting things to do.

Creating the new service together:

With families' help, we came up with:

- 11 ideas about how the service should work
- 12 things that must be included.

We then worked together to sort these ideas into five main principles:

- Good communication and trust with staff
- Person-centred care – support that fits the person's needs
- A place where people feel safe
- Some flexibility – like choosing when to book
- Working together with other services.

What happens next:

This work showed us what really matters to families and people with learning disabilities. Their ideas are helping us build a service that is:

- Safe
- Supportive

- Clear in communication
- Well-planned
- And meets different people's needs.

We have shared early plans with families and asked what they think. We also held a workshop with adult care staff and other organisations. They gave feedback on the plans and told us if anything was missing.

We will use all this information to finalise the service design. Then, we will begin the process to find the right organisation to run the new service. We will keep everyone updated along the way.

Shaping speech and language therapy (SALT) services

Improving speech and language therapy in Tees Valley

The NHS in Tees Valley is planning a new speech and language therapy service for children and young people. Right now, there are two different services - one in the North Tees area (Darlington, Stockton and Hartlepool) and one in the South Tees area (Middlesbrough and Redcar and Cleveland). These two services work differently, and we want to make it fairer and more equal for everyone.

Listening to people

We asked parents, carers, and professionals what they think about the current service and what could be better.

- 540 parents and carers filled in a survey.
- 92 professionals who referred children to the service also shared their views.

What people said

Things that are going well:

- Professionals liked how easy the service is to use - the online referral form was simple, and the therapists were friendly, quick to respond, and skilled.
- Parents and carers said good things about:
 - Friendly and helpful staff
 - Staff who work well with schools
 - Good advice online and in person
 - Access to support digitally.

Things that could be better:

- Some parents said communication could be improved.
- People also said there were:
 - Long waiting times
 - Not enough therapists
 - Not enough guidance between sessions.

Ideas for improvement

People had lots of good suggestions:

- Hire more therapists
- Give children earlier assessments
- Shorter waiting times
- Better communication between professionals and families
- More frequent sessions
- Clearer and quicker reports
- Help for families between sessions
- Training for staff who work with children.

What happens next?

All the feedback has been written up in a report. NHS staff and therapists will discuss this feedback and use it to help plan the new service.

Speech and language therapy in County Durham

The NHS in County Durham is changing who provides speech and language therapy for children. Before the change, we asked parents, carers, school staff, and health professionals what they thought of the service and how it could be better. The [information about these conversations](#) was added to the County Durham Care Partnership website.

Listening to people

To make sure the questions were easy to understand, staff from the service and a children's rights group helped design them.

People were asked to share their views in different ways:

- Text messages were sent to families using the service
- Face-to-face events were held during the summer holidays (but not many families came)
- Online surveys were used so people could answer in their own time.

There were different questions for:

- Parents and carers
- Health staff
- School staff.

What people said

Families shared:

- Waiting times were often too long
- Support levels felt different for different people
- Therapy plans weren't always clear
- Some parents looked for private services
- Families said good things about the therapists themselves.

Health and education staff said:

- The referral process could be made simpler
- Communication between the therapy team and other services could be improved
- Families needed more support during the whole process.

What happens next?

The feedback from families, schools and health staff was shared with the Health and Care Engagement Forum. It's being used to help make the new service better when the new provider takes over. The new provider took over the delivery of the service early in 2025 following the conclusion of this piece of work.

Speech and language therapy in Sunderland and South Tyneside

From January to March 2025, we asked families and professionals about the speech and language therapy service for children. The aim was to learn:

- What families need and experience
- What staff think who work with or refer children to the service
- What is going well
- What could be improved.

Helping everyone get involved

A parent carer forum helped plan how to include as many people as possible. Healthwatch also checked the plan to make sure it was fair. Activities included:

- A workshop for professionals
- A survey for parents and carers of children who use the service
- A survey for staff who refer children to the service
- Face-to-face chats in family hubs.

We let people know how to join in by:

- Sharing information through the hospital trust
- Putting up posters in family hubs
- Using local networks and contacts
- Telling schools, nurseries and other organisations.

What happens next

The feedback from families and staff has been analysed. A report has been written, pulling together the themes from all the involvement activity. The report is being considered by the team reviewing the service. The feedback will help shape the future service. We will publish updates on the outcome.

Supporting mental health, neurodivergence and disability

Pre and post autism diagnosis support in Tees Valley

In the Tees Valley, around 5,000 people are autistic, and another 1,400 are waiting for an autism diagnosis.

Right now, there is no support for people waiting for a diagnosis or for those who don't qualify for extra help after being diagnosed.

As commissioners (the people who plan services), we wanted to create a new service to support people before and after an autism diagnosis.

To do this, we spoke with people who are waiting for an autism assessment and autistic people to find out what kind of support they want.

Who we worked with

A group called Involve North East made a survey to find out what people need. An autistic person who is also a researcher helped design it.

There were also focus groups (in person and online) where people could talk more about what support would help them.

Everyone got easy-to-understand information about where the meetings would take place and how to join in.

Over 100 people shared their ideas.

What people said

- There is a big need for support services
- People want help with school, jobs, benefits, and mental health
- People want support with personal problems and day-to-day life
- They asked for information about autism to help them understand more
- The service should be flexible - offering online and in-person support, one-to-one and group sessions
- The service should be run by people who are trained to work with autistic people, and where possible, include autistic staff too.

Listening to feedback

The ideas shared helped shape the new service. It will include:

- One-to-one support
- Peer support (support from other people with similar experiences)
- Help with housing, education, family life, and personal needs
- Advocacy and help with making decisions
- Support to use different services.

Pre and post autism diagnosis support – County Durham

In County Durham, a project looked at how to support people before and after they have an autism assessment. The goal was to find ways to help more people and their families while they wait for their assessment.

We asked two groups of people:

- People already using the service
- People waiting for an assessment.

We wanted to know what support would have helped while waiting, and what people thought about the help they got.

How we listened

Staff from the support services helped us design the questions. This helped make sure they were easy to understand and covered the right kinds of support.

Everyone on the waiting list or already getting help was asked to share their views - either by filling in a form online or by speaking with staff on the phone.

We wanted to know:

- What is working well
- What difference has support made.

Listening to feedback

People using the service said:

- The staff were friendly and helpful
- They liked getting regular updates.

People still waiting said:

- They were worried about how long they would have to wait
- They wanted help to look after their mental and emotional health
- They wanted clear information about what was happening
- They wanted help to understand autism and their own needs.

This feedback helped the team make a new plan to improve the service in the future. The range of support has also been expanded. So that more support is being provided to people while they are waiting for their assessment.

Find out more - This information along with the [summary engagement report](#) is available on the County Durham Care Partnership website.

Children and young people's mental health in Sunderland

In Sunderland, the children and young people's mental health and wellbeing service needed updating.

To help with this, we asked people what they thought about the current service and how it could be better.

We spoke to:

- Children and young people
- Parents and carers
- Staff and other professionals.

This took place from September to October 2024 and included:

- A special event for professionals
- Three online surveys (for young people, parents/carers, and staff).

We used many ways to tell people about the surveys, including:

- Social media (including posts aimed at younger people)
- The ICB and Healthwatch websites
- Local schools, colleges, youth services, charities, and mental health groups.

Healthwatch and other partners helped share the surveys with lots of people and organisations like:

- Schools and colleges
- Youth groups and services
- Carer and parent forums
- Mental health charities
- Public health and NHS organisations
- Local events like World Mental Health Day.

Listening to feedback

249 people took part in total:

- 74 children and young people
- 80 parents or carers

- 84 staff and professionals
- 11 people at the stakeholder event.

Young people said:

- Most young people say they talked to a parent, friend, or no one
- Fewer talked to someone at school or a health professional
- Just over half had received help, mostly from community mental health services
- Of those, about 43% said it was good, but 30% said it was poor
- Young people said their biggest worries were:
 - Friends, bullying, or peer pressure
 - Their body or health
 - Negative thoughts about themselves
 - Worries about the future.

Parents and carers said:

- Most had worries about their child's mental health (90%)
- Nearly 80% had accessed support
- Of those who hadn't, some had tried but couldn't get it
- Main services used: Children and Young People's Service (CYPS) and Child and Adolescent Mental Health Services (CAMHS)
- Many said communication was poor or fair
- The biggest concern was long waiting times and not enough support while waiting - 89% said both were poor
- Most felt confident talking about mental health but only 10% felt confident their child would get the right support.

Staff and professionals said:

- They had positive things to say about the staff and the support in schools
- They wanted more mental health support in schools
- They were worried about waiting times and suggested better advice while families are waiting
- Some said more staff and better training are needed
- They wanted more awareness and support for neurodivergent children.

This feedback has helped inform a new Children and Young People Mental Health and Emotional Wellbeing Strategic Plan. Subject to approval, this will be published in August 2025 and will help drive mental health improvements for children and young people in Sunderland.

SEND strategy refresh in Northumberland

Getting families involved

We needed to update the plan for Special Educational Needs and Disabilities (SEND) in Northumberland. We wanted to do this together with families to make sure the plan works well for them.

The ICB worked with the Council, Healthwatch, and the Northumberland Parent Carer Forum. We all created a survey to find out what families needed from the SEND plan. This included support for:

- Education
- Social care
- Health.

Making things easier

We worked with the Parent Carer Forum and Healthwatch to make sure we asked the right questions in the survey. They helped us figure out the important things to ask. We also gave people a phone number to get help if they needed it or had any questions about the survey.

Listening to what families said

410 families filled out the survey, and we are looking at the answers. Some early things we've learned are:

- Most people who answered the survey came from mainstream schools
- A lot of people said that communication was poor and transitions (moving from one service to another) were hard
- Parents were happier with physical healthcare than mental healthcare
- More needs to be done to help people understand eating disorders and neurodivergence
- Health staff leave too often, so people must keep telling their story over and over
- It's too hard to get therapy when it's needed, and the requirements are too high.

The updated SEND plan will take these ideas into account to make things better for families.

Specialist services and communities

Relocation of a musculoskeletal (MSK) service in South Tyneside

An MSK clinic in South Tyneside was considering moving to a new location. The ICB supported the service provider to involve patients before making any decisions. The aim was to understand any concerns or unintended impacts of the move.

Involvement took place between August and October 2024 and included:

- An online survey promoted by text message
- Paper copies available in clinic
- Two face-to-face sessions for people who preferred to give feedback in person
- Additional feedback gathered by Healthwatch South Tyneside.

Listening to feedback

A total of 303 people shared their views. Key findings included:

- Most patients travelled to appointments by car, though many also walked or used public transport
- Patients said the most important factors for the service location were:
 - Being close to home
 - Free and convenient parking
 - Easy to drive to
 - Good bus links
 - Within walking distance
- One-third of respondents had concerns about the proposed move, while over half did not
- Common concerns were:
 - Parking availability
 - Distance and travel time
 - Difficulty using public transport
 - Walking distances

- Quality of the new clinic
- People who could drive were generally less worried about the move
- Healthwatch raised concerns about parking and the suitability of the proposed venue.

Next steps

As a result of the feedback, the service was allowed to move but with extra steps in place to support patients:

- Assess parking availability at different times and share this information with patients
- Model and communicate public transport routes
- Offer more flexible appointment times for three months, including leniency if patients arrive late.

The impact of the move will be monitored through regular meetings between the service provider and commissioners.

Women's health – Gateshead

As part of the development of a new women's health hub in Gateshead, work began to better understand local needs. The aim was to gather insight from women about their experiences and priorities to help shape the new hub.

Independent charity Involve North East was commissioned to carry out this research. They spoke with 1,001 women across Gateshead, covering key topics including menopause, contraception, and gynaecology.

Listening to feedback

Menopause

- 195 women shared their experiences
- Most found existing menopause information easy to understand and services easy to access
- Women highlighted the importance of quick appointments and access to GPs with specialist knowledge
- Some said better staff awareness of menopause would have improved their experience.

Contraception

- 120 women shared their views on contraception
- Many said dedicated contraception clinics in GP practices were important
- They also valued clear information on contraception options and side effects
- Timely and accessible appointments were a recurring theme.

Gynaecology

- 473 women provided feedback on gynaecological services
- Women asked for clearer information about hospital waiting times and support during the wait
- They also wanted information on treatment options, including alternatives outside the NHS
- Convenience and local access to services were important.

Removing barriers

To reach a wide and representative group of women, we worked with:

- Connected Voice – local voluntary and community sector
- Haref – Health and Race Equality Forum
- Labriut – supporting the Orthodox Jewish community
- Local Community Facebook Groups.

Paper and alternative formats of the survey were also made available. Despite broad engagement, younger women were slightly underrepresented.

The data showed that:

- Younger women (18 - 44) were more likely to rate gynaecology services as very important (86%)
- Ethnic minority women and those from more deprived areas also prioritised gynaecology highly
- Menopause services were most important to women aged 45 - 64 and to Asian, mixed, or other ethnic backgrounds
- Contraception was most important to younger women and bisexual women, and those from more deprived communities.

Using the feedback

The findings are directly shaping the development of the Gateshead Women's Health Hub. The project team is now:

- Focusing on shorter waiting times for gynaecology, improving menopause information, and delivering services at more convenient times and locations
- Increasing clinical input into future service design, with an emphasis on co-design and co-production
- Developing a clear vision for future provision, including hub and spoke models.

Find out more - For more information about the Women's Health Hub pilots, visit the [NENC Women's Health Programme webpage](#).

Extending Monty's reach: Community health bus

Monty is a health bus that brings care into local communities. It started in Newcastle and was shaped by feedback from local people. They helped decide where the bus should go, what times it should be there, and what services it should offer.

Because Monty was a success, in 2024 the project grew. We worked with Newcastle GP Services, Gateshead Health NHS Foundation Trust, and other partners to bring Monty to Gateshead.

We asked women what services they needed and how they wanted to use them. They told us they wanted:

- Easier access to services
- More flexible times and locations
- To get care without needing an appointment.

So, we added more services to the bus, including:

- Menopause support
- Cervical screening
- Contraception
- Gynaecology care
- Sexual health services.

We also made the service easier to use. Women can now:

- Drop in without booking
- Visit the bus at times that suit them

- Find the bus at different local places.

We worked with local women to choose the bus stops and times. This helped make sure Monty fits around real lives.

Thanks to this feedback, more women and girls can now get the care they need - closer to home, and in a way that works for them.

Find out more - You can read more about the introduction of the [new community health bus](#) (nicknamed "Monty") which has been a huge success.

Supporting the system to listen

Safer prescribing: Valproate and Topiramate

Valproate and Topiramate are used to treat conditions such as epilepsy, bipolar disorder, and migraines. However, both medicines can harm an unborn baby. Valproate can be harmful no matter which partner is taking it. Topiramate poses a risk when taken by someone who is pregnant.

To improve how we support people making decisions about these medicines, we asked for feedback from:

- People who currently take or have previously taken the medicines
- People who considered taking the medicines
- Carers and family members
- Organisations that support these groups.

We ran a standard and an easy read survey between December and February. People could also share their views through one-to-one conversations. We promoted the work through meetings and by working with local and national organisations.

Removing barriers


We knew this was a sensitive subject, so we worked with partners to make sure our language and approach were appropriate. This included advice from:


- The LGBT Foundation
- The Learning Disability Network
- The Regional Network of Parent Carer Forums
- The Child Wellbeing Network.


We also worked with organisations like:

- Daisy Chain
- Skills for People
- Epilepsy Action
- Local NHS Trusts.


These groups helped share the survey and encouraged people to take part.

 Safer Prescribing Survey Easy read

 Which medicine do you take? Please tick one box.

☐

Valproate

☐

Topiramate



Listening to feedback

We received 88 responses to the main survey and 10 to the easy read version. We also held interviews with two people with a learning disability and their carers. The feedback showed a range of experiences across both medicines. Key points included:

- People wanted clearer information about the risks - especially for women taking Topiramate and for men taking Valproate
- Decisions to continue the medicine when planning a pregnancy are not always fully informed - especially in the case of men
- People wanted support tailored to their needs, but many said they would feel more confident if they had a better understanding of the risks and the alternatives.

What happens next

A report is being prepared and will be used to inform how staff support and speak with patients. This may include new training, updated information materials, or changes to clinical conversations.

Direct payment service in County Durham

In County Durham, fewer people are using direct payments than in other parts of the North East. We wanted to understand why this is happening so we could improve the information, advice, and support available. The aim was to make sure people are better informed and more confident about using direct payments in the future. Some information about how we approached this work [was added to the County Durham Care Partnership website](#).

Removing barriers

We worked with five local organisations that already support people with experience of direct payments. Together, we co-produced the engagement materials and planned how to reach the right people.

These partner organisations led the conversations themselves. This helped people feel more comfortable sharing their experiences. We also worked with a wider local network to spread the word about the project.

As a result, we had 30 in-depth conversations. These helped us understand what people with learning disabilities knew about direct payments - and why some people might not be using them.

Listening to feedback

We found that awareness of direct payments was lower than expected. Many people didn't fully understand what they are or how they could help them. The conversations showed us that:

- People need clearer explanations about what direct payments are and how they work
- Direct payments are not always consistently offered to people when they need them
- Some people are worried that using direct payments might affect their benefits
- There are still gaps in the information and advice available in our area.

This feedback will help shape improvements to the way we talk about and offer direct payments, making the system clearer and more supportive for those who could benefit from it.

Livi contract review

Livi provides video and phone GP appointments in North Tyneside, including appointments during evenings and weekends. The service helps increase access and appointment capacity. A three-year contract with Livi was due to end in March 2025, with the option to extend for two more years.

To support a review of the contract, we brought together Livi, the NHS commissioner, and the North Tyneside Patient Forum to gather insight. Healthwatch North Tyneside also included a question about Livi in their annual survey to understand wider patient views.

Removing barriers

The Patient Forum explored barriers that may prevent people from using or attending Livi appointments. These included:

- A lack of awareness about the service
- Difficulty booking or joining an appointment, especially for those who don't use smartphones or feel confident with technology
- High levels of missed appointments (Did Not Attends).

Listening to feedback

The Patient Forum shared their views on:

- How practices promote the Livi service to patients
- Their personal experiences of using Livi
- What could improve attendance and awareness.

Healthwatch's annual survey is still collecting wider feedback about the service, which will be used alongside this engagement to support decision-making around the contract.

Collaborative listening

The ICB has a legal duty to listen to people and involve them in decisions. We follow a plan for working with people and communities.

We share this job with others. Because we are part of a bigger health and care system, we work with different partners. Some of them help us carry out our duty to involve people. We all work closely and share updates. We also check that everything is being done properly through ICB processes.

The ICB has lots of projects across the area, and involving people is an important part of all of them.

Secure Data Environment (SDE)

The Secure Data Environment (SDE) is a special, safe place where the NHS keeps important health and care data. This data is about local people, but it is kept anonymous so no one can tell who it belongs to. Researchers and experts can use this data, but only for specific projects that help improve health and care services. The data cannot be copied, downloaded, or removed from the SDE.

There are 11 SDEs across England, and the one for the North East and North Cumbria is run by HINENC on behalf of the ICB. These SDEs are part of a national network that helps researchers learn more from health data to improve services for everyone.

Involving the public

There are 16 public members who help guide the project and make important decisions. They attend meetings, give advice, and help shape how the SDE works. They also make sure the information about the SDE is clear and easy to understand for everyone.

Public members have been involved in:

- Helping create rules to ensure the data is used properly
- Giving input on how the program should work, like how to get permission to access the data
- Helping create surveys and focus groups to hear from the public
- Reviewing whether the use of data is in the public's best interest
- Talking to different communities.

The project has created “personas,” which are examples of different types of people in the area. These personas help the project understand what different groups of people need. The personas are:

- **Remote residents:** People living far from cities, who may not have easy access to services.
- **Affluent educated:** People with higher incomes and good education.
- **Starting outers:** Younger people, like students and young couples, who are just starting out in life.

- **Cautious women:** Women aged 30-59 who may not want to share their health data.
- **Diverse deciders:** People from lower-income backgrounds who face challenges in their daily lives.
- **Cultural collectives:** People from different ethnic backgrounds or minority communities.

By thinking about these groups, the project can make sure the messages reach everyone, in a way that makes sense to them.

Hearing from people

We listened in lots of different ways. Including:

- **Running focus groups** - Using these personas, the team set up targeted focus groups to ask different communities for their opinions. These groups help the project hear from people who might not have responded to surveys. There are currently six focus groups across the region, working to get feedback from people who might have been missed before.
- **Growing the public members group** - The public members group is growing. The programme wants to include more people under 50 years old and more people from rural areas like Cumbria. They've worked with Stand (a group that supports public involvement) to plan how they can bring in new members. They're also creating training and support systems to help new members feel welcome.
- **Supporting local groups** - The project is giving small grants (money) to local groups to make sure everyone's voice is heard. These groups work directly with their own communities and will use the funding to help people get involved. They will also get training and support to make sure the engagement is done well.
- **Listening to feedback** - The public members have had a big impact on how the SDE works. For example, when they tested the application process for using data, they found problems and suggested changes. These changes made the process better, and now the public members are part of the final step to make sure the data is being used in the public's best interest.

What public members think

The public members feel like they're making a real difference and that their opinions matter. They've said:

- They feel their views are listened to and respected
- They know what's expected of them and feel properly supported

- They would like more training on things like research and data sharing
- They want better communication about meetings and tasks.

The project is working on making sure there is more time for questions in meetings and that everyone gets information in advance, so they have time to prepare.

Find out more - You can [read more about the North East and North Cumbria Secure Data Environment \(SDE\) programme and the survey feedback](#).

Risk stratification

We asked people what they think about risk stratification, which is a way to figure out which patients need more care. We first talked to a group of public members from the North East and North Cumbria Secure Data Environment (NENC SDE). Their thoughts helped us create a survey.

Removing barriers

We made it easy for people to get involved by using:

- A website, posters, leaflets, and a survey
- Social media posts and a news story
- Sharing the survey through:
 - ICB networks
 - Partner groups
 - Healthwatch
 - GPs
 - ICB news.

Listening to feedback

A total of 136 people answered the survey. Here's what they said:

- 88% understand what risk stratification is
- 74% want more information about it
- 77% think it's okay to use risk stratification in the NHS
- 46% think it's okay to use it without asking patients for permission
- 65% believe the NHS keeps patient data safe
- 84% think it's important to consider local health needs when using risk stratification.

People said the benefits of risk stratification are:

- Helps plan and decide where resources are needed
- Helps patients get care early to prevent problems
- Helps find health trends.

But some people are concerned about:

- Data security
- The effect on patients
- Not understanding what it is
- Getting permission from patients.

How we listened

This feedback will help improve the way risk stratification works in the NHS. Part of the response to the feedback was to improve online information about risk stratification. You can look at the new information on the link below.

Find out more - Find out more about how your information is used for risk stratification on the [North East and North Cumbria ICB website](#).

Northern Cancer Alliance

The Northern Cancer Alliance is reviewing cancer care services (oncology) across the North East and North Cumbria. This review is happening because there are two main problems:

- a shortage of oncologists (cancer doctors) and
- an increasing number of people needing cancer care.

The aim of the review is to create a system that works better for everyone.

In 2023, due to the shortage of oncologists, temporary changes were made to the oncology services at Newcastle Hospitals NHS Foundation Trust. These changes affected how people received cancer treatment, so the NHS wanted to understand how these changes impacted patients. To do this, we ran several activities like surveys, focus groups, and phone interviews.

Improving information and access

In 2024, we held additional conversations with Black, Asian, and minority ethnic people who were either cancer patients or caregivers. We also spoke with a patient who has learning difficulties. In total, we talked to 12 people and got valuable insights to help improve the service.

Key feedback from participants:

- **Language barriers:** Many patients whose first language is not English told us that they had problems understanding medical information. They suggested that better translation services were needed during appointments, and that written materials about their care should be provided in their language.
- **Clearer information:** While patients generally felt well-informed about their first appointment, some said that information about extra support, such as help with treatment or accessing services, could be made clearer.
- **Appointment information:** Patients said that the information they received during appointments was mostly clear, and having written summaries of what was discussed helped them remember important details. However, some patients experienced delays in receiving appointment letters and information, which caused confusion.
- **Remote appointments:** Many patients said they liked having phone or video appointments because they were easy to attend. However, some people still preferred face-to-face appointments, especially because they felt these provided more emotional support.
- **Continuity of care:** Patients mentioned they liked seeing the same healthcare staff regularly. This helped them build trust and understand their treatment better.
- **Local appointments:** Patients appreciated appointments being held at local hubs, as this reduced travel times. Many patients expressed frustration at having to travel long distances for their appointments. They suggested that the NHS should provide better information about travel support and parking options to make it easier for patients to get to appointments.

Summary

By listening to feedback from patients, especially those facing extra challenges like language barriers and learning disabilities, we can make oncology services better. The feedback shows that patients want clearer information, more support in their language, and more local appointments. We'll use these insights to improve cancer care and ensure that it's more accessible to everyone.

Improving breast cancer awareness for South Asian women

The NHS Screening and Immunisation team, along with staff on the frontline, noticed that many South Asian women weren't getting regular breast screenings. They were worried that these women, especially in poorer areas, might not be looking for signs of breast cancer as early as they should.

To understand this better and help with the problem, the Northern Cancer Alliance decided to work with NUR Fitness, a community-based organisation in Middlesbrough. NUR Fitness focuses on health and wellbeing for South Asian, Arabic, and African women. Together, they wanted to find out what might be stopping women from getting breast cancer information or attending breast screenings.

Hearing from people

30 women joined the study, and some invited their friends and family to join too. Some of the women had important roles in their community, like teachers or leaders. Many of the women had personal experience with breast cancer, either through a family member or a friend.

The women took part in three focus groups, where they talked about things like:

- How often they checked their breasts
- What they thought about breast cancer prevention
- Their access to healthcare.

What we learned

- Breast screening: Just over half of the women who were eligible for screening had gone for a checkup in the last four years
- Breast self-checks: Only 15 women said they checked their breasts regularly. The main reasons they didn't were:
 - They weren't sure what to look for
 - They feared finding a lump
 - They didn't have enough time
 - Confusion about changes in breasts: Many women weren't sure if changes in their breasts were normal (like changes due to the menstrual cycle or pregnancy) or if they were something to worry about and go to the doctor for
- Fear of wasting a GP's time: 35% of the women said they were worried that if they went to their GP with symptoms, they might be seen as wasting the doctor's time

- Difficulty seeing a female doctor: Some women said they had to wait longer to see a female doctor, which made it harder for them to access care
- Lack of awareness: 98% of the women didn't know all the possible symptoms of breast cancer
- Preferred materials: The women wanted:
 - Information in poster form (A4 size) or smaller, for easy carrying in a handbag
 - Information on social media, where they could view it on their phones
 - Trusted websites like the NHS website to share information
 - Materials available at women-only events and spaces.

How we listened

The project created a strong partnership between the Northern Cancer Alliance and NUR Fitness, and led to a few important results to help raise awareness about breast screening:

- **Walk-through video:** A video was made showing how breast screening works at North Tees Hospital. It was presented by NUR Fitness.
- **Posters and translations:** The “Know Your Lemons” posters, which help women learn about breast self-examination, were translated into other languages.
- **Updated video:** The Northern Cancer Alliance updated its own breast self-examination video based on the feedback.

This work has helped improve the way breast cancer screening and self-examination information is shared with South Asian women in the community.

Find out more - Learn what happens at a breast screening appointment and how to prepare by watching this [video](#).

Child Health and Wellbeing network

The Child Health and Wellbeing Network makes sure that children, young people, and their families have a say in decisions that affect them. We work closely with the Know Our Impact (KOI) Young People's Group and other youth groups in the North East and North Cumbria.

This year, the KOI Group has grown, and new members have joined from all over the region. The group works with the Children and Young People's Health and Wellbeing

Strategic Oversight Group (previously called the Executive Board) to come up with important ideas. The young people help decide what topics to talk about, and professionals also come to the meetings to share their work.

The Young People's Manifesto

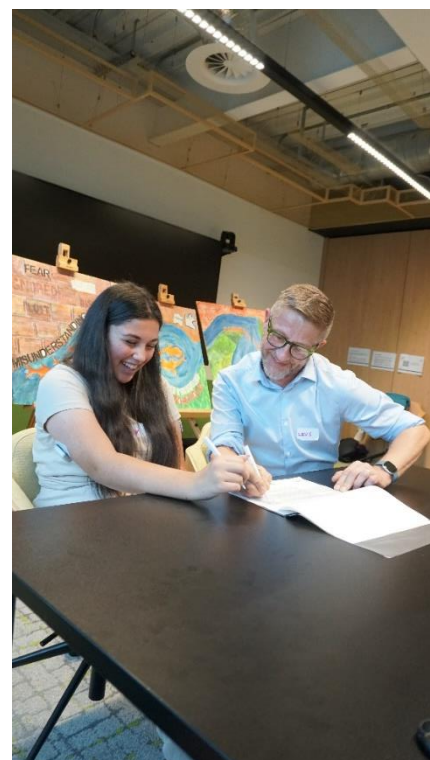
The young people, with help from Dr. Deborah Ralls at Newcastle University, Children North East, and the previous Executive Board, made a manifesto. This document explains their ideas for change and how they want to work with professionals. Here are the four main requests:

- **Be involved from the start:** Young advisors should be part of decisions from the beginning, so they can help shape rules and ideas.
- **Meet different groups of young people:** Young advisors should meet different groups of young people with different needs to get their opinions and share them with the network.
- **Meet more often with the adult board:** The young people want to meet the adult board more to improve communication and respect between both groups.
- **Clear language:** Use simple language that everyone can understand in meetings and explain medical terms before using them.

Supporting the Manifesto

The professional board has worked to support the ideas in the manifesto. Here are some of the ways they've done this:

- **Agenda sharing and feedback Loop:** Young people get the agenda before meetings, share their thoughts, and those ideas are included in the meeting papers. After the meeting, the results are shared with young people.
- **Meeting other groups:** The young people have met with other youth groups in places like Newcastle and Darlington.
- **Joint board meeting:** There was a meeting in Newcastle where both groups discussed important issues like poverty, bullying, and mental health.
- **Jargon wall:** There is a "jargon wall" at meetings to explain any confusing words.



How we listened

- **Professional pledges:** Professionals in the group have made promises (called pledges) about how they will follow the manifesto's ideas in their work. These pledges are shared with the young people to make sure everyone is working together.
- **Future plans:** Looking ahead to 2025/26, we are excited about the next joint meeting with young people and professionals. We also want to grow the group of young people involved.

This work helps make sure that the voices of young people are heard and that they can shape the services and rules that affect them.

Find out more

- You can watch the Youth Board explain the manifesto [here](#).
- If you'd like to join, please email nencicb.northernchildnetwork@nhs.net for more information.

Local Maternity and Neonatal System (LMNS)

The LMNS is a team made up of local health services, women, birthing people, families, and other organisations. We all work together to improve care during pregnancy, birth and the early days with a baby in our area.

Our goal is to make sure everyone has:

- Safe care
- Kind and respectful support
- Care that suits them and their families
- Staff who are skilled, caring and supportive.

We want our area to be the safest and best place to be pregnant, give birth, and become a parent.

What we are focusing on

We want to make care during pregnancy, birth and after birth safer, more personal, and kinder for everyone. To do this, we are focusing on these main areas:

- Setting clear goals to help us keep improving safety and giving care that is right for each person and their family

- Following our three-year plan, which has four big aims:
 1. Listening to and working with families – we want to treat everyone with kindness, listen to their experiences, and involve them in decisions
 2. Supporting our staff – we want to keep great staff, help them grow in their jobs, and make sure they feel supported
 3. Creating a safe and learning culture – we want staff to feel confident to speak up, learn from each other, and always put safety first
 4. Using clear standards and systems – we want everyone to get the same high-quality care, no matter who they are or where they live
- Reducing health inequalities – this means making sure that people from different backgrounds get the same good care, and that no one is left out
- Working together with others – we co-produce our work with the people who use our services, healthcare staff, local leaders and partner organisations. We make plans with people, not for them.

Who gets involved and how

We believe care works best when people using the service help shape it. That means we listen to women, birthing people, and families when we make plans and changes.

There are three main ways people get involved:

- **Service User Voice (SUV) Leads** - These are two people who sit on the LMNS Board and speak up for women, birthing people, and families. They help make sure real-life experiences are heard in big decisions.
- **Maternity and Neonatal Voices Partnerships (MNVPs)** - There are 10 local MNVP groups across our area. Each group works with a local hospital. They:
 - Listen to what women and families say about their care
 - Share feedback with hospital staff
 - Help make sure care meets people's needs.
- **Patient and Public Voice (PPV) Partners** - These are members of the public who join LMNS working groups. For example, they might help with plans for digital tools or safety checks. They help design services and give advice from a user's point of view.

Examples of involvement in action

Personalised care toolkit

We made a toolkit to help people make informed choices about their pregnancy, birth, and postnatal care.

It was made together with service users, midwives, and doctors.

The toolkit includes:

- Videos from local hospitals about birth options
- Tools to help with open and respectful conversations
- Leaflets and posters with QR codes linking to useful videos and information
- A communication pack to help spread the word.



Support for vulnerable migrants

We made a care plan to support migrant women and birthing people who may need extra help.

This includes:

- A clear care pathway to make sure staff understand migrant people's needs
- A maternity profile to help personalise care
- A local directory of charities and services that can offer extra support.

Care Quality Commission (CQC) maternity and neonatal survey

Thousands of women and birthing people shared their views in the 2024 national maternity survey. There were 18,951 responses, a response rate of 41%.

All 10 MNVPs worked with their local hospitals to look at the feedback and create action plans for improvement.

Perinatal pelvic health service

In 2024, we launched a Pelvic Health Service to help women and birthing people during and after pregnancy.

This service was co-designed with service users, including three women with personal experience.

We also created helpful resources, including:

- Videos of women talking about their experiences
- Information for families and professionals.

These resources can be accessed [here](#).

By working closely with women, birthing people, families and local communities, we are making care safer, kinder, and more personal for everyone.



Learning Disability Network

The North East and North Cumbria Learning Disability Network is committed to putting people with a learning disability, their families, and carers at the heart of everything we do.

Much of our work is co-produced, meaning we work with people with lived experience to shape our projects. This has helped us make sure our work is relevant, accessible, and more effective. Below are examples showing how people were involved - and the impact their involvement had.

Examples of involvement in action

Be Cancer Aware

This is a training course we made with people who have a learning disability. It started in 2018 and was refreshed in 2024.

The course helps people:

- Learn what cancer is
- Spot signs and symptoms early
- Know when to visit the doctor
- Understand cancer screening and treatment.

How people were involved in refreshing the course:

- Six teams of peer trainers (people with a learning disability) helped update the training
- They worked alongside GPs, nurses, Macmillan, and the Northern Cancer Alliance
- Sessions included fun activities, group discussions, and feedback.



How we listened:

- Training is now easier to understand and more engaging
- More people with learning disabilities can learn about cancer signs, risks, and screening
- The new version will be rolled out in 2025/26.

Lung cancer screening

Lung cancer screening is a new NHS programme. We want to make sure it's easy for people with a learning disability to take part.

We worked with:

- People with lived experience
- Health experts.

How people were involved:

- People with lived experience helped check if the screening pathway was accessible
- They reviewed easy read information, venues, and how invites were sent
- They helped create a new 'Be Screening Aware' training and social care pack.

How we listened:

- Changes were made to make the screening easier to access
- New tools and training are now being used to support both staff and people using services.



This helped make the programme better for everyone.

Annual Health Check prompt sheets

People with a learning disability often have worse health. They can die up to 24 years earlier than other people (LeDeR 2023).

One way to help is the Annual Health Check – a full check-up every year at the GP.

How we involved people

- People with a learning disability, support workers, and carers shared views on how health checks could be better
- Accessible sessions were held with easy read materials and support allowed.

People told us:

- People wanted better quality health checks and to feel more confident
- New prompt sheets were co-produced to help people prepare and speak up during their appointment.

Be Epilepsy Aware

People with a learning disability are more likely to have epilepsy. It can be dangerous if not understood.

We worked with:

- Experts by experience
- Health staff
- Epilepsy Action.

Together we created a course for:

- People with a learning disability
- Carers, families, and staff.



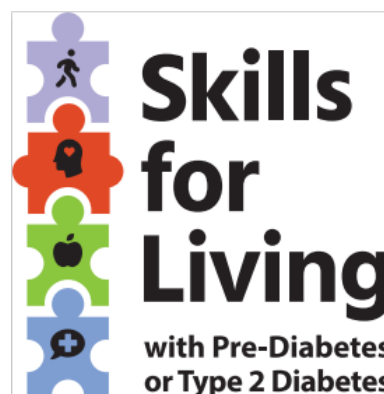
We ran the course in person and online. It covers:

- What epilepsy is
- Types of seizures
- How to stay safe and give support.

It has been very popular, with hundreds of people joining and giving great feedback.

Skills for Living with Pre-Diabetes or Type 2 Diabetes

In 2018, a course was created to help people with learning disabilities understand and manage type 2 diabetes. In 2025, we updated the course to also include people with pre-diabetes. We also made the course easier to follow and more interesting.



The course helps people to:

- Learn what pre-diabetes and type 2 diabetes are, and why they happen
- Learn how to look after their health — by eating well, exercising, and going to medical appointments
- Understand how mental health and having the right support can help manage or prevent diabetes in the long term.

How people were involved in the update:

- Peer trainers (people with learning disabilities who had helped run the course before) gave their ideas on what needed to change
- Diabetes UK and health professionals also joined in to help make it better
- We held three workshops with group discussions, fun activities, and time to give feedback.

What changed because we listened:

- The course now includes people with pre-diabetes as well as those with type 2 diabetes
- The new version is easier to understand and more engaging
- The updated course will be available to people from Autumn 2025.

Learning from the Lives and Deaths of People with a Learning Disability and Autistic People (LeDeR)

LeDeR is a national programme in England that looks at why people with learning disabilities and autistic people often die younger than others — and what can be done to stop this from happening.

It helps stop unfair early deaths.

National LeDeR rules say that people with lived experience - those who have learning disabilities, autism, or are family carers - must help lead the work.

The below two projects are part of the LeDeR.

Confirm and Challenge Group – North Cumbria

We worked with People First in Cumbria to set up the Confirm and Challenge Group. The group helps ask questions, share ideas, and speak up about unfair treatment.

What we did:

We brought together people with lived experience and family carers. They meet often, supported by People First. They look at reviews of people's deaths and help pick out what we need to learn. They also help write action plans to make services better and help share what we learn across the system.

How we made it easier to take part:


This work can be very sensitive, so we made sure everyone felt safe and supported. Everyone gets the reviews four weeks before the meeting and can go through them with a supporter. The meetings follow a clear plan and always ask for the group's views first.

What people told us:




The group said they needed clear rules about how we work together. So, we made a 'Working Together Agreement' to help everyone take part fully and feel respected.









What changed because we listened:

By giving people more time and support to get ready, and by listening to them first in meetings, we have made sure people with lived experience are at the heart of this important work.



Learning from the Lives and Deaths of People with Learning Disability and Autistic People (LeDeR)
Working together Agreement - Panel



	This agreement is to support members of the LeDeR review panel to work well together. We will review and update this agreement regularly.		Plan to be present in person at the meetings. Where this is not possible, arrange for someone else to represent you.
	All information will be shared in Easy Read before meetings. All members to review information sent and come prepared to meetings.		Remember how sensitive the discussions that take place can be. Breaks and time out will be available as needed. A quiet safe space will be identified.
	Communicate clearly - no jargon or abbreviations. Explain any medical terms used. All members are responsible for seeking the clarity they need.		Keep information shared confidential. Remember the experiences belong to the people and their families. It is only the learning we can share.
	Where there is a difference of opinion, challenge with kindness. We can agree to disagree.		
	Respect the roles and experience that everyone brings. We all have a contribution to make.		

Stop People with Learning Disability and Autistic People Dying Too Soon

We invited people with lived experience to join the group. They meet regularly and are supported by Inclusion North. The group looks at reviews of people's deaths,

shares ideas, and helps improve services. They also join another group called the Learning into Action Group. This group turns learning from reviews into actions that can make health and care services better and fairer.

How we made it easier to take part:

We gave Inclusion North funding to support the group. Because the topic is sensitive, it is a closed group. We made sure everyone gets information in easy read format. We agreed ways of working together, so everyone felt included and supported in meetings.



What people told us:

To take part fully, the group helped write a clear agreement about how we will work together. This helps everyone understand what to expect and feel safe and supported.

What changed because we listened:

Everyone in the group gets review papers four weeks before meetings. They have time to prepare with their supporters. In meetings, they are always asked to share their views first. This helps their voices be heard clearly and respectfully.

Other organisations helping us to involve people

Integrated Stroke Delivery Network

This network helps people who have had a stroke, and their families. They are creating a long-term plan for how patients and carers can get involved in improving stroke services. They want to keep talking to stroke survivors and their families regularly to make sure their voices are heard.

The plan was created with help from stroke survivors already involved in the network, and the groups that support them. The plan was shared with the North East and North Cumbria Integrated Stroke Delivery Network Board in December 2024, and they agreed to move forward with it.

Working with our communities

Who we work with

Healthwatch

The ICB is dedicated to listening to local communities and working with community groups to have conversations with people. One important way we do this is by partnering with Healthwatch.



Healthwatch is a group that helps make sure people's opinions are heard and used to improve health and social care. They represent patients and are involved in many meetings. We have secured funding to work with Healthwatch to include community feedback in everything we do.

You can read more about [how we work with Healthwatch](#).

Voluntary, Community and Social Enterprise sector (VCSE)

We know that organisations and community groups in the North East and North Cumbria are important. They help bring together many different voices from our local communities. There are many different organisations in our third sector, which is full of knowledge and support. These groups help us reach and involve different people in shaping health services in the area.

Working with the VCSE and its groups is very important to what we do. The VCSE Partnership Programme makes sure the VCSE sector is involved at all levels of the North East and North Cumbria Integrated Care System (ICS). This includes everything from planning services to delivering them in local areas.

The [VCSE Partnership Programme](#) allows organisations to join the ICS at any level that suits them. They can also change their level of involvement as needed.

You can read more about [how we work with the Voluntary, Community and Social Enterprise sector \(VCSE\)](#).

Working with Haraf to talk to minoritised communities

We work with the Haref Network in Newcastle to make sure our health information reaches everyone, especially people from ethnic backgrounds that are often left out. This year, Haref helped us share health information and surveys with different

community organisations. They connected us with groups that support asylum-seekers and refugees. We meet with these groups to talk about health issues and share information.

If you would like more information about the Haref Network, you can read about it [here](#).

Talking with local communities

We want to have real, meaningful conversations with people in our local communities. To help do this, we go out and visit community groups and meetings across the North East and North Cumbria.

At these meetings, we:

- Share updates about the work we're doing
- Listen to help shape our services
- Listen to what matters most to local people.

The people who come to these meetings help choose the topics we talk about. They tell us what they want to learn more about or what they think should change.



What we've done over the past year

These conversations helped us:

- Write our plan for involving people in our work (called the Involvement Strategy)
- Come up with questions for our "Tell us what you think" feedback forms
- Create fair and inclusive equality questions
- Develop clearer, easier-to-read health leaflets
- Make health information easier to understand (health literacy work).

Example: Bowel screening leaflets

In North Tyneside, a group called the Patient Forum worked with our Health Literacy team. They helped check if a leaflet about bowel screening was easy to read.

The person who wrote the leaflet said:

“I used some of the group’s ideas in the final leaflet. I checked all their suggestions with the doctors and used the ones that worked best. Even if we don’t use every idea, patient feedback helps us see where things might be missing.”



Example: Health literacy and communication

We worked with Haref on an event about health literacy. This means making sure health information is clear and easy to understand.

At the event, our team explained why this is important - especially for people from different ethnic backgrounds.

We did an activity where we looked at how to make language easier.

People had different views:

- Some thought it’s best to keep things simple
- Others were worried that too-simple words might leave out important health messages.

After the event, we decided to:

- Make more of our documents easier to read
- Offer them in different languages or formats if people ask.

This helps everyone understand health information better.

Example: Checking health literacy projects

The North Tyneside Patient Forum has worked closely with a university professor. They have been thinking about how to check if work is easy to read, as part of a health literacy project. The professor found the group’s help useful. She invited members of the group to have their names included on a paper for an international conference.

Example: Lived Experience Network (Special Interest Groups) North Cumbria

In March, we helped run a meeting for people with lived experience to start creating a co-production charter for North Cumbria. Since then, special interest groups have formed, and two events have been held to listen to people with hearing loss talk

about their experiences with health and social care services. We are putting all the feedback together and will share it with NHS and Local Authority team

How feedback shapes our services

We've had important conversations with people about different services, such as:

- NHS changes (called Change NHS)
- Urgent and emergency care
- Social prescribing (when non-medical support helps health)
- Mental health support in a crisis
- Virtual wards (care at home instead of in hospital).

Example: Change NHS

In Sunderland and South Tyneside, people joined a "Change NHS" workshop. They said the NHS should be:

- Easy to use
- Fair
- Cost-effective
- Good at communication
- Focused on prevention and listening to patients.



They also talked about:

- Technology being helpful, but still needs human support
- More funding and staff
- Health services that work better in local communities
- Making healthy choices easier.

We shared all this feedback through the Change NHS national system.

Example: Health Passport for Asylum Seekers and Refugees

We have worked with Carlisle Refugee Action Group to create a Health Passport. This will help people find their way through the health system when making an appointment at a GP practice or hospital. The Health Passport has been paid for by the Health Literacy grant scheme. We are working with service users and staff to make sure the document is easy to use.

Example: Medicines optimisation

In January 2025, staff from the ICB's Medicines Optimisation team talked about their new plan for using medicines in the best way. They shared this information at the Health and Care Engagement Forum in County Durham.



The new plan works with other health plans across the region. Its aim is to make sure people get the right medicines early, to stop health problems from getting worse.

At the meeting, people from the community, including charity workers and members of the public, asked questions and shared their thoughts. They talked about:

- How the plan supports people's well-being by working closely with staff in the community
- How it helps people manage their health at home in different ways
- How it deals with problems around getting help for drug and alcohol use
- How it makes sure doctors and nurses are checking in with patients to help them take their medicines safely at home.

All the feedback was collected by the Medicines Optimisation team and used to help improve the plan. Once the updated version is ready, it will be shared on the ICB website.

Listening to what matters to you

We've also talked with people about:

- Community champions
- Women's health services
- Getting to the right service
- Pharmacists helping people with medicines at home.

Example: Women's health services: views and experiences of contraceptive services

As part of the ICB's plan to improve women's health services, they asked women in Gateshead about their experiences with contraception services. They wanted to know how women felt about getting contraception and specifically about Long-Acting Reversible Contraception (LARC), such as coils and implants.

Out of 120 women who spoke to us, more than half (56%) said they had not had any problems with the contraception care they received. However, 44% of the women had faced difficulties. The most common issue was trouble getting an appointment (44%). When the women were asked how services could be better, most of them (64%) said they wanted it to be easier to get GP appointments to talk about contraception. A quarter (24%) said they wanted more services to be available at GP practices.



Regarding LARC, six out of ten (60%) of the women had never used it, but over a quarter (26%) said they would think about using it in the future.

To make it easier for women to get contraception, the CBC Health Federation, which works with 26 GP practices in Gateshead, has created a new service where women can get LARC directly from their GP. They are also planning to offer more services, such as emergency contraception, the contraceptive pill, and injections, in more places and at different times to better fit into women's lives.

Find out more - For more information about the new LARC service and updates on other women's contraception services, visit the [CBC Health Federation's website](#).

Example: County-wide patient reference group

The County-wide Patient Reference Group meets regularly with patient representatives from across County Durham to talk about issues affecting local people. One of the main topics they have discussed is the complaints process in hospitals.

Some members of the group shared negative experiences they had when trying to make a complaint. The group also listens to feedback from the wider community. These concerns were raised with staff from the local foundation trust. The Trust was already working on improving how complaints are handled and solved.

Members of the group have been part of regular talks about changes to the complaints process. This has allowed them to see how the changes have helped patients and families be more involved in solving problems and learning from complaints.

Supporting GPs and Dentists to involve patients

GP and Dentist contract changes

When GP practices or dentists want to make big changes, they need to ask patients what they think. The ICB helps them do this in the right way.

Over the past year we have helped 40 practices talk to their patients about changes like:

- Changing the area they accept patients from
- Joining with other practices (called a merger)
- Closing part of the practice (called a branch)
- Closing a branch for a short time
- Changing how medicines are given out
- Moving to a new building.

Each practice asks patients what they thought. Then they:

- Looked at any worries patients had
- Changed their plans if needed
- Wrote a report explaining what people said and what they will do next.

The ICB then reads these documents before making a decision:

- The practice's application
- The report about patient involvement.

We use a template plan to help every practice think about the right way to involve people. This includes how to involve different community groups.

Examples of practice involvement we have supported

- **Mobile GP service** - A GP practice in Northumberland wanted to try using a mobile GP van. They worked with Healthwatch and the ICB to ask patients what they thought. Patients said they didn't think it would make the service better. So, the practice decided not to do it.
- **Dentist moves** - Two dental practices - one in North Cumbria and one in Northumberland - wanted to move to bigger, easier-to-access buildings. We helped them ask their patients for feedback. The feedback was used in their plans, and both moves were approved.

- **GP practice merger** - Four GP practices in North Tyneside wanted to join. We helped them listen to their patients as part of the plan. The merger has been approved. We also helped two GP practices in North Tyneside listen to patients about joining together. Patients supported the idea. The two practices have now merged.
- **Temporary GP branch closure** – A GP practice in North Tyneside needed to have building work done. We helped them tell their patients about the 12-week change, and to listen to patient concerns.
- **Size of GP boundaries** – Two practices were thinking about increasing their boundaries, to accept more patients. We have helped them think how they will involve patients in their planning. Both practices were in North Tyneside.
- **GP branch closure: Flagg Court Branch Central Surgery** – Central Surgery in South Tyneside were thinking about closing their branch at Flagg Court. We helped them think about the best way of involving patients before deciding. This included supporting the involvement plan, communications and survey design.
- **GP relocation: Surgery relocation** – We have been working with a GP practice in Gateshead to help solve a problem with their building. The old surgery was too small, hard to change because of planning rules, and not easy for disabled people to use.

By working with the council, local people, and a community group, a better building nearby was found. The new place is bigger, more modern, and easier for disabled patients to get into. The GP practice will share the new building with a local group that helps people with their health and well-being. When it's ready, the new surgery will be easier to get to and will also have parking, which is something the old one didn't have.

Support for other GP engagement

Sometimes we need to support other involvement activities about GP practices and dentists. We might want to learn more about people's experiences of using these services, things that work well, and things that could work better.

Example – How we listened to patients at Wrekenton Medical Group

In 2024, Wrekenton Medical Group in Gateshead asked for our help to find out what local people thought about their GP practice. We worked with them to create a short survey with questions about:

- How easy it is to contact the practice by phone
- If the website is easy to use
- What people think of face-to-face appointments
- Waiting times, appointment times, and how helpful the staff are.

The survey ran in August. We made it available on paper and in other formats. We also sent the survey by text message to patients. This helped more people take part. Nearly 1,500 people filled in the survey.

We looked at all the answers and shared what we found with the practice:

- 67% of people said it was good or very good when they contacted the practice
- Nearly 85% said the admin staff were helpful
- 67% said their overall experience (with both doctors and staff) was good or very good.

The practice looked at our survey results and compared them with another national patient survey. They could see how changes they had made - like a better phone system - had helped improve things for patients.

Find out more

- The patient feedback helped shape the content and design of the new website, which you can visit [here](#)
- The website also provides more details about how the new phone system works and the service improvements made based on the feedback received.

Example - Primary Care Access Recovery Plan

The Primary Care Access Recovery Plan is a plan to help improve how people get help from their GP practice. This includes:

- Stopping the 8am rush – so people don't all have to call at the same time to get an appointment
- Give answers quickly – so people know on the same day how their GP will help them.

We wanted to hear what people think about getting help from their GP. So, we made a survey and asked people to share their thoughts. We heard:

GP appointments

- Most people phone their GP to book appointments
- Some people say it's easy to get an appointment, but others find it hard
- Older people often find it easier than younger ones
- Most say nothing has changed in the last six months, but some think it's getting worse.

Phoning the GP

- Most calls happen early in the morning
- Some people wait a short time, others wait longer
- Not everyone gets told how long they'll have to wait.

Booking by phone

- Most people can book over the phone
- Some are told to go online instead
- Some get an appointment quickly; others must try again later
- More people say booking is getting harder than those who say it's getting better.

Online forms

- Not everyone uses online forms to contact their GP
- People who do use them mostly like them
- Most people get help or an appointment after using the form
- Some must call the GP anyway because the form didn't help.

NHS App

- Many people use the NHS App to order medicine
- Some use it to check their health records
- Most people say the app is easy to use.

Evening and weekend appointments

- Most people haven't been offered these
- People who did get one said the time worked for them.

Seeing other health workers

- Some people know they can see other health workers (not just a GP)
- Many people are happy with the care they get from them.

Pharmacy services

- Most people haven't used the Pharmacy First service
- The ones who did were mostly happy
- Some say they are now more likely to go to the pharmacy for help.

Supporting staff to involve people

We have made a range of tools to help our staff listen to people in a meaningful way. This includes our involvement plan, step-by-step guides, training materials, toolkits, and simple forms to help with planning and feedback.

Involvement strategy

In 2022, we wrote our first plan to show how we involve people and communities in our work.

In 2024, we asked Healthwatch to look at this plan and help us make it better. Healthwatch spoke to local people and shared what they heard with us.

We used this feedback to write a new version of the plan called the 'Involving People and Communities Strategy 2024–28'.

In this updated plan, we talk about how we will keep involving people. We know people want to help improve health services. We also know there is already lots of great work happening in our region. We want to keep having honest conversations to build trust.

We also changed our main ideas (called principles) based on what people told us. These are now:

- Meaningful involvement
- Removing barriers
- Listening to feedback.

We shared the new draft with more people and made extra changes based on what they said. This included:

- Making the plan easier to read
- Making it shorter
- Adding a work plan to show how we will check our progress.

Listening to lived experiences

We want to hear what people think about their health care – both the good and the bad – so we can make services better in the future.

We listen to patients, carers, staff and others to learn what is working and what could be improved. This helps us make better decisions and give people better care.

To help with this, we made a guide called the "Hearing Lived Experience Protocol". It explains how people can share their health stories, how we keep them safe, and how staff can collect stories in the right way.

In 2024, we updated the guide based on what people told us:

- We made it easier to read and understand
- We used simpler words
- We made the consent form clearer
- We added ways to support people while they tell their stories.

Young people told us the name should change, so we changed it from "Storyteller Protocol" to "Hearing Lived Experience Protocol".

We only share stories when we have permission. Stories are shared with health leaders and at big events to help make services better.

We also made a short animation to explain how people can share their experiences. This was shared with Healthwatch and on social media.

Find out more - You can watch the animations and learn more about how we collect lived experience [here](#)

Examples of people's lived experience we have shared

Hearing from people about their experiences using the NHS helps us understand what's going well and what could be better. These stories help the NHS make good decisions and improve care for everyone.

We sometimes share people's stories at NHS meetings like the Quality and Safety Committee or the ICB Board. These meetings help NHS staff check that care is safe and good.

Before we share any story, we always check with the person first. We ask if they are happy for us to share it, and where it can be shared. Some meetings are public and may be recorded or shown online.

We might also include a summary of the story in reports (like this one), newsletters, or on the NHS website or social media – but only if the person says yes by filling out a consent form.

Here are some examples of the stories we've heard:

- **Mental health support for a Deaf woman** - A Deaf woman who uses British Sign Language found it very hard to get help for her mental health. She couldn't use the phone, found it confusing to get support, and didn't always have an interpreter. Sometimes staff spoke to her mum instead of her. Charities and support workers helped her get the care she needed.
 - **What we learned:** Health leaders now better understand how important it is to give people information in the right way – especially when they're feeling unwell.
- **Moving from hospital to independent living** - A 54-year-old with a learning disability spent years in hospital and prison. They felt scared and frustrated. Local NHS staff helped plan their move to a new home with support. They helped choose the home, learned new ways to cope, and now live independently.
 - **What we learned:** This shows that with the right support and planning, people can move safely out of hospital and live full, independent lives.
- **Missed diagnosis after a fall** - A 78-year-old woman fell at home. It took too long to find out she had a broken bone. She was in pain, and the delay meant she now needs a wheelchair.
 - **What we learned:** This shows how delays in care can have long-term effects on people's lives.
- **Autism diagnosis waiting times** - A family in Tees Valley is waiting a long time for their daughter to be diagnosed with autism. This has caused stress for the whole family. The child struggles with anxiety and school, and the parents don't know how best to help.
 - **What we learned:** Families want faster support and clearer advice while they wait for a diagnosis.
- **GP access for Bangladeshi women in Sunderland** - Women from the Bangladeshi community had trouble booking GP appointments using eConsult. They were invited to meet with a Practice Manager at their local centre. He explained the system and listened to their concerns.
 - **What we learned:** The women now feel more confident using the system. The Practice Manager will share what he learned with other GPs to help more patients.