NHS
North East and
North Cumbria

Annual Involvement and Engagement Report

2025 - 2026

Better health
and wellbeing for all...

Contents

Listening to people in our communities

The NHS North East and North Cumbria Integrated Care Board (ICB) has a legal duty to involve people in decisions about health and care services.

This includes:

- patients
- carers
- families
- and the wider public.

We aim to listen to everyone, especially people who may face extra barriers to getting involved.

We use different ways to hear people's views, depending on the project and who we need to reach. This includes surveys, events, group discussions, and one-to-one conversations.

We choose the right approach so people can take part in ways that work for them.

We support staff across the system to involve people properly. A specialist involvement team provides advice, tools and training. Each project has an involvement plan that sets out:

- what decisions are being made
- who needs to be involved
- how people will be supported to take part
- how feedback will be used.

We also check whether involvement is meaningful. Learning from involvement is shared through reports and updates to senior NHS groups, including the quality and safety committee (QSC) and the ICB board. This helps make sure people's views influence decisions and improvements.

Who we listened to

We hear from people in many ways, including through:

- patients and the public
- carers and families
- Healthwatch and community groups
- local councils and partners
- complaints, feedback, and social media.

We bring this information together to understand what matters most to local people. Key themes are regularly shared with the ICB's QSC.

This helps senior leaders:

- understand people’s experiences
- check that legal duties to involve are being met
- use public feedback to improve services.

This helps us:

- make sure the ICB listens to local voices
- check we are following the rules about involving people in decisions.

Annual involvement report

Each year, we publish an involvement report to show how we have met our legal duty to involve people.

The ICB works with patients, carers, the public and partners to:

- improve the quality and safety of care
- reduce health inequalities
- make services easier to access and understand.

We also collect equality information, such as age, disability and ethnicity, where people choose to share it. This helps us understand who is getting involved, who may be missing, and where extra support is needed. We use this information to help make services fairer and more inclusive, in line with the Equality Act 2010.

This report shares real examples from 2025 to 2026. It shows:

- how people were involved
- what they told us
- how their views shaped decisions and improvements.

It provides assurance that local people’s voices are heard and used when planning and changing services.

You can read more about the work we have supported in our Annual Involvement Reports.

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 system called an Integrated Care System (ICS). 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.

The type of projects we support

Planning and improving services

We work with local people to make health and care services better. This includes fixing problems, planning, and making sure services are safe, fair, and easy to use. We listen to what people tell us and use their ideas to shape how services change.

Your GP and medicines

We support projects that improve how people use GP services and medicines. This includes helping people get the right appointments, explaining medicines clearly, and checking that treatments are safe and work well for each person. We also use feedback from patients to improve annual medication reviews and pharmacy advice.

Help for mental health and learning needs

We support work that helps adults, children, and young people with their mental health, learning disabilities, autism, or ADHD. This can include crisis support, wellbeing groups, advocacy, supported volunteering, and services that make sure people get the right care at the right time. These projects focus on giving people more support in their community and helping them stay well.

Community health, wellbeing, and end of life support

We back projects that help people live healthier, happier lives close to home. This includes support for carers, community activities, healthy living programmes, and work that reduces unfair differences in health. We want communities to feel included, supported, and able to access the services they need.

Key themes from communities, patients and public:

Throughout this report we have highlighted key themes from what we have heard. These are shown using **pink headings** to make them easier to spot.

Some of the overall key themes we have heard from people and communities are included below.

Access to health and care services

Getting care is still the biggest problem for many people. People said it is hard to get appointments with GPs, dentists, pharmacies and mental health services. Waiting times are often long. These problems are worse in rural areas, where there are fewer services and staff. Some people also find it hard to use online systems, especially if they are not confident with technology. There are not always good alternatives, like evening or weekend appointments, which makes it harder for people who work or have caring responsibilities. There are also delays in hospital care, including cancer treatment, planned surgery and tests. People are worried about how easy it is to get into care homes and about the quality of care there. Moving from hospital back home is not always smooth, which can cause stress for patients and families.

Mental health and neurodevelopmental services

Mental health is one of the biggest concerns people raised. Many people said they are waiting a long time for help and do not always understand how to get support. This is especially true for ADHD and other neurodevelopmental assessments. People often feel unsure about what will happen next or how long they will wait. Some people also said it is hard to get help in a crisis. Care is not the same everywhere, which feels unfair. People said they are often passed between services or must start again, which can delay help and make things stressful.

Continuing healthcare (CHC) and funding decisions

Many people said that services do not work well together. They often must repeat their story to different professionals, and care can feel disconnected. People described being moved between services or having to be referred again, which can slow things down. This is a problem in GP services, mental health care and end of life care. There are some good examples where services have worked closely with communities to design better care. These services are more joined up and easier to use, showing that this approach can work well.

Communication and information

Poor communication is a common problem. People said they do not always get clear or timely information about their care. Some people wait a long time for test results or updates. Letters can be confusing, arrive late, or give different information. This can leave people unsure about what to do next. New digital systems and processes are not always explained clearly. This can make people feel anxious and leads to more calls or visits to services. Community groups said they want to be told about changes early and kept updated.

Workforce pressures and service capacity

People can see that services are under pressure. There are not always enough staff, which leads to cancelled appointments, long waits and less choice. These pressures make people worry about how safe and reliable services are. They can also affect the relationship between staff and patients. People understand that staff are working hard, but they are concerned about how services will cope in the future if these pressures continue.

Equity, dignity and inclusion

Not everyone has the same experience of care. Some people face extra barriers, including neurodivergent people, Deaf people, people who do not speak English well and carers. People also said that rising living costs are making it harder to stay well. For example, there are concerns about paying for gluten-free food if prescriptions stop. Some people feel they are not always treated with dignity and respect, especially at the end of life. However, there are good examples where services have worked with communities to design more inclusive care. These services are easier to use and more trusted.

Quality, consistency and accountability

People expect care to be safe and of good quality wherever they live. However, some people said services are better in some areas than others. These differences can feel unfair. People want services to be more consistent and to understand how decisions are made. They want the NHS to listen to concerns and show how it is improving services.

Trust, involvement and co-production

Some people shared positive examples where the NHS worked well with communities. These showed that listening and working together can lead to better services. However, many people feel they are not involved early enough or in a meaningful way. They want their views to help shape decisions, not just be asked at the end. Strong relationships with local communities are seen as very important for building trust and improving services.

Long-term planning and system change

People want the NHS to focus on long-term solutions, not just short-term fixes. They support better planning across all health and care services so that care is more joined up. The 10-year plan was mentioned often. People want to understand what it means and how they can be involved in shaping future services.

Main and ongoing priorities

Mental health and primary care, including GP, dental and pharmacy services, are still the biggest concerns. Access, staffing pressures and communication problems affect many parts of the system. Concerns about care homes, hospital discharge and hospital services are also growing. Overall, people want services that are easier to access, better connected, fair for everyone and built with their input.

Shaping services through listening

Planning and improving services

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.

This section shows some examples of how we use people's views to plan and improve services. We use what people tell us to make changes that support better health, clearer services and more joined-up care. This includes helping people stay well and in work, understanding how new technology should be used, improving support for bereaved families, and designing services with people living with dementia. The projects below show how this work is making a real difference.

WorkWell: helping people stay healthy and in work

Why we did this work

We worked with people across the region to help design a new service called WorkWell. WorkWell is a government-funded programme that supports people with long-term health conditions to stay in work or return to work.

How we involved people

This work took place in six stages and involved over 500 people. We spoke with members of the public, employers, staff, charities and community groups, WorkWell coaches, and Patient Advisory Service (PAS) advisors.

Phase 1: Early ideas (January to February 2025)

We started by exploring early views about WorkWell and what challenges people thought might come up. We held online focus groups with 29 members of the public and 12 staff working in health or employment support. We asked people what they thought about WorkWell and what practical or cultural challenges might affect how it is set up.

Phase 2: Learning in more detail (June to November 2025)

In this phase, we spoke to many more people to understand different needs and experiences. We carried out interviews with eight stakeholders, including staff from the Department for Work and Pensions (DWP), GP services, councils, combined authorities and commissioners. They shared their views on system-wide challenges, concerns and opportunities.

We also worked with 13 voluntary and community organisations to run focus groups with 115 people. This helped us hear from a wide range of people, including disabled people, carers, people from ethnic minority communities, people with cancer, veterans, people with mental health needs and people facing money worries.

Alongside this, we ran a public survey with 328 responses from working-age people with long-term health conditions. The survey asked about their experiences of work, the barriers they face, what support they need and how they feel about getting help. We also spoke to five PAS advisors and WorkWell coaches, who shared their experiences of delivering work and health support.

Phase 3: Testing information (November to December 2025)

In this phase, we checked whether early information about WorkWell was clear and helpful. We held three online focus groups with 13 people. During these sessions, people reviewed different materials, including a GP screen message, a leaflet, a self-referral flyer and a short animation. Their feedback helped us understand what worked well and what needed to change.

Phase 4: Lived experience workshops (November to December 2025)

To better understand real-life experiences, we ran a series of workshops with people who have long-term health conditions. We held one online session and three in-person workshops in Carlisle, Newcastle and Darlington. In total, 49 people took part.

We made sure the group included people with different health conditions, backgrounds, ages and work experiences. During the workshops, we used group discussions, real-life examples and written feedback to explore people's experiences. Each session built on what we had learned before, helping us develop a deeper understanding over time.

People shared their experiences of becoming unwell and looking for help, as well as the advice and support they had already tried. They talked about the barriers they faced when staying in or returning to work, and what good support looks like. They also shared their views on how WorkWell should be designed to build trust and meet people's needs.

This phase added real-life detail to earlier learning. It showed how the way a service is designed can affect how safe, trusted, and accessible it feels for people.

Phase 5: Speaking with small to medium businesses (January to March 2026)

Online interviews were conducted with nine business owners or HR representatives. The organisations employed between nine and 49 staff. They discussed approaches to supporting employee health and wellbeing, impressions of WorkWell, barriers / concerns and service expectations.

Generally, people were positive about the benefits of WorkWell, seeing it as a useful addition to what they could offer. They expressed willingness to promote the programme.

Some general concerns were identified:

- waiting times for services being a barrier to being in work
- costs of adjustments (and difficulties with access to work)
- disclosure, stigma and unfairness
- raising and sustaining awareness of the service.

They also discussed some practical considerations for implementation, such as how to raise awareness amongst employers, how to support employee access, practical support for employers and consideration of eligibility criteria.

Phase 6: Checking we haven't missed anything (March to April 2026)

During March and April 2026, the findings from the WorkWell involvement activity was shared widely. This included detailed involvement reports and a summary presentation with voice over. A final opportunity to comment on the summary was provided.

What we heard and learned

People mostly supported the idea of WorkWell. They said it could be helpful, but only if it feels safe, easy to use, and clear.

These views came from the public, including people with long-term conditions, as well as community groups, employers, and staff who support people into work.

Health, work and life are all linked

People explained that their health, work, and daily life are closely connected. Many people spoke about living with long-term conditions, especially mental health problems and issues with muscles and joints. They said their health can change from day to day. This means some days they may feel ready to work, while on other days they may struggle. People also said that their ability to work is not just about their health. It also depends on how supportive their workplace is, how their job is designed, and what is happening in their life. For example, appointments, caring for others, transport, housing, and money all play a part.

People want help, but do not always get it

Many people said they would feel positive about being offered support at work if their health was affecting them. However, a lot of people said they had not received any support or changes to help them. Some people said they did not want to ask for help. Others said they did not know what to ask for or did not think their employer would be able or willing to help. When support was offered, people said the most helpful things were flexible working hours, being able to work from home where possible, having time to manage illness or flare-ups, taking more breaks, and getting support to manage stress.

Trust and privacy really matter

People said it is very important that WorkWell is clearly voluntary. They also want clear information about whether it could affect their benefits. Some people were worried that WorkWell might feel like services linked to the DWP or Jobcentre. This made them feel anxious about being judged, monitored, or facing sanctions. Confidentiality was also very important. People want to know what information is collected, who can see it, and whether anything will be shared with their employer.

Clear information will help people take part

People said they need simple and easy-to-understand information about WorkWell. They want to know what it is, who it is for, how it works, and what will happen after they are referred. They also want to know how long things are likely to take. If this information is not clear, people may feel confused or worried. Some said they might feel judged or turned away if the rules are not clear. Some organisations also asked questions about how long the funding will last, what the service will include, and how success will be measured.

People need flexible and easy ways to access support

People said they would prefer to refer themselves and to access support through trusted local places. They liked the idea of a "no wrong door" approach, where they can get help wherever they go. There were concerns about relying too much on GPs, as appointments can be hard to get and online systems can be difficult to use. People also said it may be hard to reach those who are already in work but struggling. People spoke about barriers such as transport, caring responsibilities, language, not having access to the internet, stigma, and different needs such as neurodivergence. They said it is important to offer different ways to take part, including face-to-face, phone, and online support, as well as support outside normal working hours. Reasonable adjustments should also be available.

Joined-up support is very important

People said they want support that looks at the whole person, not just their job. This means helping with real-life issues like money, housing, childcare, transport, and health. They also said it is important to build a relationship with one person over time. People do not want to keep repeating their story or must start again if staff change. Many people said success should not only be about getting a job. It should also include feeling more confident, having better wellbeing, feeling more stable, and finding a healthy balance between work and life.

Staff and employers must build trust

People said staff should be kind, understanding, and knowledgeable. They should listen well, build trust, and support people in the right way. Some people said it helps if staff have lived experience. There were concerns about long waiting times and not hearing back.

People said it is important to have quick follow-up and to be clear about what to expect. People agreed that working with employers can be helpful, but it must be led by the person and only happen with their consent. People want to feel in control of what is shared. They are worried about being judged, watched, or treated differently at work.

What difference this has made, and what will happen next

We produced several reports to share what people told us and what we learned. These include:

- the WorkWell Involvement Findings
- the WorkWell Public Workshops report

- a WorkWell Summary that brings all the findings together, and
- a WorkWell simple summary, with a voice-over, to make the learning easier to understand.

Findings from each phase of involvement were shared with the project team as the work progressed. This meant the programme could change and develop in response to people's views, rather than waiting until the end.

The learning has already helped shape how WorkWell is being designed and delivered. Feedback has been used to improve how the service is explained, how people access support, and how staff work with individuals and employers.

Planning is now underway for the next phase of learning. Local areas are beginning to put their WorkWell support in place, and learning from this involvement is being built into the programme as it develops. This includes testing what works in practice, addressing concerns that were raised, and continuing to improve the service as it is rolled out.

Listening to people will remain an important part of WorkWell. Further involvement will help make sure the support continues to meet people's needs and works well across different communities and settings.

Acceptability of artificial intelligence (AI) in healthcare

Why we did this work

We wanted to understand how people feel about computers and smart tools such as AI being used in the NHS. AI is starting to help with tasks like checking scans, writing notes and giving health advice. Before using more of it, it was important to understand what people think.

We asked people what they like about AI, what worries them, and where they think it should or should not be used. We also wanted to know what would help them feel safe and well informed. This helps make sure decisions about AI match what local people want and need.

How we involved people

We used two main ways to gather views. First, we carried out an online survey, which 158 people completed. The survey asked about trust, privacy, safety and how comfortable people felt about AI carrying out different healthcare tasks.

We also held group discussions with 38 people across three community sessions and one stakeholder forum. One of these sessions included people with learning disabilities. These conversations helped us understand people's deeper thoughts, personal concerns and ideas.

What we heard and learned

People had mixed feelings about AI. Most people had heard of it and could see some benefits, but many were still unsure or worried about how it would be used.

What people liked

People said AI could help doctors by saving time, checking scans more quickly and offering useful support, if a doctor makes the final decision.

What people were worried about

People were concerned about privacy, fairness and safety, and worried that AI could make mistakes or use data in the wrong way.

Losing the ‘human touch’

Many people said it is important to keep real doctors and nurses involved and not replace them with machines.

Where people don’t want AI used

People felt AI should not be used for sensitive or complex care, such as mental health, end-of-life care, children’s care, emergencies or rare conditions.

What would help people feel more confident

People said they want clear information, strong data protection, and reassurance that doctors will always check decisions made using AI.

What difference this has made, and what will happen next

This work has helped make sure people’s views are heard when talking about AI in the NHS. It clearly shows where people feel comfortable with AI and where they have concerns.

What people told us has helped shape conversations about how AI might be used in healthcare. It has also made clear that people want strong rules, clear information, and doctors and nurses to stay in charge of decisions.

The findings show that people value trust, safety, and fairness. People also made it clear that AI should not be used in some areas of care. This helps decision-makers think carefully before using AI and consider what matters most to local people.

The learning from this work will continue to be used when planning and talking about AI and digital tools. It will help teams think about how they explain AI to the public and how they involve people early. As technology continues to change, we will keep listening to people’s views. Read our involvement report.

Neighbourhood health in Sunderland and South Tyneside

Why we did this work

Sunderland is part of a Neighbourhood Health Implementation Pilot. The early focus of the pilot is on frailty and supporting people in local communities to stay well.

How we involved people

A communications and involvement group has been set up to shape the engagement approach for the Sunderland neighbourhood health pilot.

Early activity has focused on stakeholder mapping, identifying key audiences, and mapping existing community assets.

A neighbourhood health summit was held at the Beacon of Light on 4 December 2025. The event brought together voluntary, community, and public sector partners. Alongside presentations on the pilot, participants took part in a “pre-mortem” exercise to explore potential risks and agree priorities for the programme.

What we heard and learned

The event was led by the local authority with partners from across the system. Alongside general feedback on what is needed to support the success of the pilot, partners highlighted a gap in capacity to carry out detailed, ongoing work with communities. There was a shared view that communities will need support to help them engage meaningfully and influence services in their area.

What difference this has made, and what will happen next

Following recent guidance on neighbourhood health, it has been recognised that more work is needed to understand how people identify with neighbourhoods and communities.

Further discussions will take place to explore what capacity and skills are needed across organisations to support this work. This will help inform the next phase of involvement and ensure future engagement activity is grounded in how people see and experience their local areas.

Neighbourhood Health in Stockton

Stockton-on-Tees has been identified as one of the most deprived areas in the region, with significant health inequalities and high levels of economic inactivity linked to long-term sickness. Rates of coronary heart disease, hypertension, and obesity are above national averages, and uptake of NHS health checks is low. The neighbourhood health initiative aims to address these challenges through a whole-system approach focused on prevention, early intervention, and integrated care. This includes tackling barriers such as financial hardship, language, and complex social needs. The work aligns with the Government’s Neighbourhood Trailblazer programme and the Tees Valley Care and Health Innovation Zone, bringing together health, housing, employment, community safety, and wider partners to improve outcomes.

Child death review – working with parents

Why we did this work

We want to listen carefully to bereaved parents so we can create a kinder, clearer, and more consistent child death review process across the North East and North Cumbria.

A child death review is a process that looks at why a child has died and whether anything can be learned to help prevent similar deaths in the future. It should also make sure families are listened to and supported after the loss of their child.

There is national guidance on how parents should be involved, but experiences are not always the same. Support can vary depending on where families live and which services are involved.

This work aims to create a more consistent, caring and clear approach for parents across the region.

How we involved people

To do this, we built on national learning, including the Birmingham toolkit, while focusing on what families in our region need. This includes:

- looking at what already works well
- finding gaps in support, communication and feedback
- listening directly to parents about their experiences
- using what parents tell us to improve the system across the region.

We plan to have sensitive conversations with bereaved parents in April and May 2026 to build upon what we have learned through the Birmingham toolkit.

What we heard and learned

Clear communication and understanding

Parents value clear and simple communication. They want information that is easy to understand, shared at the right time, and explained in a kind and supportive way. Many parents feel unsure about what the child death review is for and what to expect, especially when information arrives too late or at overwhelming times.

Support, relationships and sensitivity

Parents said it is important to have a named person they can speak to, who understands their situation and can answer questions. They value having time and space to ask questions and understand what is happening. Sensitivity is also very important, especially around difficult times such as anniversaries.

Consistency and coordination of care

Support is not the same across all NHS trusts, which can lead to different experiences for families. The role of a key worker is not always clear, and some families do not have one at all. There are also gaps in how services work together, which can make the process feel unclear and less joined up.

Learning, feedback and improvement

Parents do not always hear what has been learned from the review, or how this learning leads to change. There are also gaps in how information is shared and how learning is tracked across organisations. This makes it harder to improve services and to show families that their experiences are helping to make a difference.

What difference this has made, and what will happen next

To improve the child death review process properly, we need to understand real experiences, not just guidance and reports. Bereaved parents know their child’s journey best and can often see problems that professionals may miss. Their views help make the system more caring and meaningful. We also know that how things felt is just as important as what happened.

We are looking for clear and practical insight about what helped, what did not help, what was missing, and what could have made the process easier to cope with.

What parents tell us will directly shape improvements to the child death review process. This includes creating a clearer and more consistent support pathway for families, improving the role of key workers, and finding better ways to share information and learning.

We will also make sure there is clear feedback, so families can see how their experiences have helped improve services for others.

Shaping dementia support in South Tyneside

Why we did this work

We spoke with people living with dementia and their carers to understand their lives and support needs. We also wanted to test a new dementia care model and make sure it is shaped by people’s real experiences.

How we involved people

We did this by:

- holding a “dementia dance”. We had music, a memory wall, chat tables and fun group activities and there were also creative ways to feed back
- visiting local groups that already help people with dementia
- running a weekend session for people who couldn't come during the week.

What we heard and learned

People shared lots of important things, such as:

- there are gaps in support after someone is told they have dementia
- services don't feel joined up
- people must repeat information for different services
- carers are not always seen or supported
- more people need to know about dementia, particularly in the early stages.

What difference this has made, and what will happen next

This feedback is helping us design a dementia service for South Tyneside that puts people at the centre. The updated model includes many of the things people said they wanted. Read more in the final involvement report.

Your GP and medicines

This section shows how we listen to people about their GP care and medicines and use what they tell us to make improvements. Medicines and prescriptions are an important part of people’s health, so it is important that decisions are safe, fair and easy to understand.

The examples below show how we have worked with local people to review prescribing, improve safety, and make sure people feel informed, involved and supported in decisions about their care.

Modern General Practice Access (MGPA)

Why we did this work

GP services are busier than they were in the past, and people now have more ways to get help. The MGPA[1] programme aims to improve people’s experience of GP care. Our aim is to make access to general practice in the North East and North Cumbria clearer, fairer and easier.

People can now use different ways to get primary care support, including the NHS App, Pharmacy First, and evening or weekend appointments. To improve access, we needed to understand what people know about these options and what their experience has been when trying to get help. We wanted a clear picture of what is working well, where people are finding things difficult, and what could make access easier in the future.

How we involved people

The North East and North Cumbria Healthwatch Network helped us hear from people across the region.

We used a survey and spoke with people in person to make sure different voices were heard. Healthwatch teams talked to people in places they already visit, such as GP practices, pharmacies, community hubs, libraries, warm spaces, faith venues, ageing-well events, job centres, foodbanks, and asylum-seeker accommodation.

We also shared 15,000 leaflets about the MGPA changes. This helped people understand what had changed and how they could share their views. The survey is still open.

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[1] MGPA is the updated national approach that replaces the Primary Care Access Recovery Plan (PCARP).

What we heard and learned

Many people told us they are using the newer ways to get help from primary care, and some like having more choice. Over half of people who responded said they found it easy to access their GP.

However, some people still experience long waits, uncertainty and confusion. Awareness of newer services is still growing.

Most people who had recently contacted their GP said they were not offered an evening or weekend appointment, and many told us they have never used this option.

Awareness of Pharmacy First varied. Some people had not used the service, and a small number were unsure what it offers.

People who use the NHS ApPp told us they value quick access to prescriptions and test results. However, some people do not use the App because of technology issues, lack of confidence, or not having the right device.

The MGPA report sets out what is working well, where people are still struggling, and what could make GP access clearer and less stressful.

You can read more about what people told us in the MGPA report.

What difference this has made, and what happens next

This feedback helps us understand where we need to focus our efforts. We will use what we have learned to improve access to primary care services and to shape our work in 2026/27.

We will continue to work with Healthwatch to raise awareness of different ways to access primary care and to keep listening to people about their experiences.

Stopping gluten-free prescriptions

Why we did this work

The ICB was thinking about stopping prescriptions for gluten-free bread, rolls, and flour. These prescriptions are given to people with coeliac disease or dermatitis herpetiformis, who need gluten-free food to stay healthy. We wanted to hear what people thought before making any decisions, because:

- gluten-free food is now easier to find in shops and online
- food labels are clearer, so it’s easier to choose safe products
- the NHS pays much more for gluten-free items than shoppers do
- the NHS has a limited budget and needs to spend money fairly and wisely
- most people with coeliac disease already manage without prescriptions.

We wanted to make sure any changes would be fair and work for everyone, especially for people who might be affected more than others.

How we involved people

To understand how changes might affect people, we asked for views in lots of ways:

- a public survey was shared, and 1,414 people responded
- four focus groups were held with people who have coeliac disease, parents of children with the condition, and professionals
- two community group discussions took place
- people could also send in letters and emails, and responses came from members of the public, an MP, Coeliac UK, and a Facebook support group.

We made sure to hear from groups who might be more affected, like people on low incomes, families with children, older adults, rural residents, pregnant women, new mothers, and South Asian communities.

We wanted everyone to have a chance to share their thoughts, so we:

- made the survey available online and on paper
- shared information with GP practices, pharmacies, Healthwatch, community groups, and Coeliac UK
- used social media and created a special webpage
- sent out a toolkit to help doctors and community groups spread the word
- invited people from different backgrounds to join focus groups
- checked responses to make sure all groups were included, especially those who might find it harder to take part.

What we heard and learned

Lots of people took part and shared their experiences. Here's what they said:

Prescriptions are very important for many people

They help people afford gluten-free food, which is often much more expensive than regular food. Most people say prescriptions help them stick to their diet and avoid getting sick.

Money worries are a big problem

Many people said they couldn't afford gluten-free food without prescriptions, especially pensioners, students, and families not on benefits. Some said they might have to skip meals or eat unsafe food if prescriptions stopped.

Health risks matter

People worried that without prescriptions, they might not stick to their diet, which could lead to health problems like weak bones or even cancer.

Feelings and social life are affected

Many described feeling anxious, left out, or sad about managing their diet. Prescriptions gave them confidence and dignity, especially when eating with others.

Getting gluten-free food isn’t always easy

Some products are only available on prescription, and people in rural areas or with limited mobility said they struggled to find suitable products in shops.

People had ideas for alternatives

Many suggested voucher schemes (like in Wales), pre-paid cards, or subsidies to help buy gluten-free food in shops. Others wanted better support from dietitians and more public education about coeliac disease.

Most people want the NHS to keep prescriptions, especially for those who need them most

They also want the NHS to fix problems with how it buys gluten-free food, so it doesn’t pay too much.

What difference this has made, and what will happen next

What people told us directly shaped what happened next.

We used feedback from surveys, focus groups, and written responses to create a clear set of options for decision makers. These options were based on two things: people’s real-life experiences and information about how much prescriptions cost the NHS.

The feedback helped decision makers understand who would be affected by change and why.

After looking at all the options, a decision was made to stop providing NHS prescriptions for gluten-free bread, rolls and flour for adults. At the same time, prescriptions were kept for children and young people up to the age of 25. This was to make sure families were not put under financial pressure and that children and young people can grow and develop without risks to their health or nutrition.

The NHS will continue to explain this decision clearly and make sure people understand what support is available to them. What we have learned from this work will also be used in future decisions, especially when changes could affect people’s health, money, or daily lives.

You can read more about our news article to learn more. You can read what people said in the involvement report.

Safer Prescribing: Valproate and Topiramate

Why we did this work

In 2024/25, we asked people about two medicines: valproate and topiramate. These medicines can help with epilepsy, migraines and bipolar disorder, but they can harm an unborn baby if taken during pregnancy. We wanted to understand if people are being told about these risks, whether they feel involved in decisions about their medicine, and if they are getting the right information and support. We also asked what could be improved.

How we involved people

To do this, we shared an online survey. 98 people responded from across England, including 24 from the North East and North Cumbria. We also carried out interviews and spoke with community groups. An easy read version was created, and we worked with charities, carers, young people, lesbian, gay, bisexual, transgender, queer, and other related identities (LGBTQ+) groups and people with a learning disability to make sure we heard from a wide range of people.

What we heard and learned

At the start of 2025/26, we wrote a report based on what people told us.

Understanding the risks

Most people said staff explained the risks, especially those who started the medicine more recently. However, around one in three people who had been taking these medicines for over five years said the risks had never been explained. Women were more likely than men to be told about risks. People taking valproate were also more likely to receive clear information than those taking topiramate.

Being involved in decisions

Experiences were mixed when it came to being involved in decisions. Around one in three people felt very involved in choosing their medicine, but a similar number felt not involved at all. People taking valproate felt more involved than those taking topiramate. Some people with a learning disability said they felt especially left out of decisions.

Support and information

Many people received leaflets or website links, and most found these helpful. About two-thirds were given the chance to ask questions, which made a positive difference. Some people were offered emotional support, and those who received it often found it helpful. However, people said they want information that suits their needs, rather than a “one-size-fits-all” approach.

Reviews and ongoing care

Regular reviews are important, but not everyone is receiving them. Around one in four people said they were not invited for a regular medicine review. Reviews were more common for people taking valproate. People also said they prefer face-to-face reviews where possible.

Birth control and pregnancy advice

Most people in our area said they were not offered advice about birth control. Some were happy with this, but others said they would have liked more support. LGBTQ+ and neurodivergent people said staff sometimes made wrong assumptions about their gender, sexuality or whether they wanted children. Around one in three people decided to have a baby while taking these medicines, but many said they would have valued clearer and earlier conversations.

What needs to improve

People said healthcare staff should explain risks clearly and early and revisit these conversations over time. They want regular reviews to check their medicine and support needs, and more personalised conversations that are not rushed.

It is also important to avoid making assumptions about people’s lives and to offer birth control advice in a supportive and appropriate way. People want information in different formats, so it is easy to understand.

Overall, people want:

- clear information
- respectful, open conversations
- support that fits their life
- regular check-ups
- no assumptions about who they are or what they want
- to feel informed, involved and listened to.

What difference this has made, and what will happen next

This feedback has been used to help improve services and support better conversations between patients and healthcare staff. For example, it is helping to review how staff talk with patients, make sure information is shared in the right format, and include patient experiences in training.

You can read the full report to learn more.

Help for mental health, people with a learning disability and neurodivergent people

This section shows how we are working with people to improve mental health support and services for people with a learning disability and neurodivergent people. We listen to people’s experiences to understand what is working well and what needs to change. The projects below show how this feedback is helping us design more joined-up, accessible and person-centred services.

Involving families in shaping respite services in Tees Valley

Why we did this work

Work has continued across Tees Valley to involve people with severe and profound learning disabilities, as well as their families and carers, in planning the future of respite services.

This followed a decision by Tees, Esk and Wear Valleys NHS Foundation Trust (TEWV) to stop providing respite care at Aysgarth and Bankfields. TEWV gave 12 months' notice in September 2024. This meant the ICB needed to plan a new service that is safe, sustainable, and shaped by what families want and need.

At an early stage, the ICB met families face to face in Middlesbrough, Stockton and Redcar. Families shared their worries, hopes and experiences of current respite services.

Families told us that staff are highly valued and trusted. However, they said the buildings feel old, clinical and not homely, and that the environment can make it harder to support people with complex needs safely.

How we involved people

To make sure feedback was independent and detailed, the ICB asked Skills for People and Inclusion North to lead a wider listening exercise.

This included 12 listening sessions held at different times, including evenings and weekends, both online and in person. A detailed survey was also shared with all families using the service. Some families took part in one-to-one conversations, where they could speak privately or get extra support. Family representatives also joined a monthly respite and short breaks partnership group.

The findings were shared with the ICB in January 2025 and continue to guide planning decisions.

What we heard and learned

What families told us played an important role in choosing Levick Court as the preferred location for the new respite service.

Families supported a setting that feels more like a home, is flexible, and can safely support adults with complex and high health needs. They told us that it is important for staff to be consistent and to know the person well. Families also said that ongoing nursing support and clear, regular communication really matter.

Many families said they wanted to work alongside the service. They wanted a service that is designed with them, not for them.

What difference this has made, and what will happen next

This project has now been completed and marks an important step in designing services together with families.

Work was carried out at Levick Court to prepare the building for the new respite service. This included internal improvements and better access, to make sure the building meets the needs of the people who use it and their families.

During the set-up stage, families stayed closely involved. They were invited to visit Levick Court and see the changes for themselves. This helped build trust and confidence in the new service and its long-term plans.

Levick Court is now fully open and running. Staff and partner organisations are working together to make sure people move into the service smoothly and feel well supported.

Parents also shared their experiences through interviews on local radio and in the local press. These interviews celebrated the opening of the redesigned service and what it means for families. You can listen to parents talking about the new service on BBC Radio and read their stories in the news.

A celebration event took place in March 2026. Families, partners and other local organisations came together to officially mark the launch of this much-valued service. Read more about the celebration event and the opening of Levick Court on the NHS North East and North Cumbria website (link to NHS news story).

Our Place, Our Say: listening across Tees Valley

Why we did this work

The Our Place, Our Say events were set up to listen directly to people about the support and services that matter most in their lives.

These events were planned after families were involved in shaping respite services in Tees Valley. During that work, people told us they wanted more chances to share their experiences in person and to learn about what support is available near them.

We wanted to create friendly, face-to-face spaces where people felt comfortable talking.

These events gave people the chance to say what works well, what is missing, and what could be improved in their local area.

How we involved people

The ICB supported five Our Place, Our Say events across Tees Valley. The events were planned and run together with local councils and Skills for People.

Skills for People is a charity that supports disabled people, including people with learning disabilities and autistic people. They help people have a stronger voice and more control over their lives. They do this by working with individuals, families and organisations to offer advocacy, peer support and chances to get involved in shaping local services.

The events took place in Darlington, Hartlepool, Middlesbrough, Redcar and Cleveland, and Stockton-on-Tees. They were designed for people with learning disabilities, autistic people, families, carers and supporters.

Each event was a welcoming and friendly space where people could share their views and talk about what good support looks like for them.

What the events were like

Each event offered a mix of information, activities and opportunities to talk. There were stalls from health, care and community organisations, along with fun and inclusive activities and entertainment. People could join workshops, speak directly with staff, and take time to talk about what works well and what could be better. Over 200 people took part across the five events. This included people with learning disabilities, autistic people, family carers, support workers and partner organisations.

What we heard and learned

Feedback was very similar across all areas and echoed what families in South Tyneside had already shared.

People said services should feel safe, warm and welcoming, and that trusting relationships with staff are essential. Many families described feeling isolated and said they rely on short breaks for support. People also told us that services should be local, inclusive and flexible, and that social opportunities and meaningful activities are very important.

Some people said it can be difficult to get assessments, diagnoses and ongoing support. The events also helped people connect with services and community groups, which is especially important for those who often feel isolated.

What difference this has made, and what will happen next

Skills for People is bringing together all the feedback into a single regional report. We are expecting this report later in 2026. This will be used alongside local insights to guide future planning and co-design for learning disability services and autism support.

Following the success of the 2025 Our Place, Our Say events, similar events are planned for 2026. The aim is for these to become a regular, annual opportunity for people to share their views and shape services.

Reasonable Adjustments Digital Flag

Why we did this work

We wanted to understand how well the NHS Reasonable Adjustments Digital Flag is being used in Sunderland. This flag helps health services know what support someone needs to access care safely and comfortably.

How we involved people

To do this, we spoke with autistic people and people with a learning disability about the questions and language we should use. This helped us design a survey. We also worked with the Learning Disability Network to create a more accessible version of the survey.

Between January and June 2025, GP practices shared the survey with people after their annual health checks. More than 600 people responded, including 281 autistic people and 361 people with a learning disability.

The survey asked whether GP practices were having conversations about reasonable adjustments, asking for permission to share this information, and meeting people’s needs.

What we heard and learned

The results showed mixed experiences. Many people said they need help when visiting their GP, with around 80 per cent saying they require some form of support. However, almost half of people said they had not been asked about their support needs.

There are still gaps in awareness of reasonable adjustments, and some people face challenges when booking appointments or accessing services. People also shared difficulties with understanding systems and navigating services.

Despite this, there were also positive findings. Around two thirds of people said they received the help and support they needed at their GP practice, and over 70% said they were given information in a way they could understand.

Feedback from open questions also highlighted issues with access, communication, staff understanding, and physical or sensory barriers. People shared what works well, but also where improvements are needed.

What difference this has made, and what will happen next

The findings have been shared with the local delivery team to help them understand how GP practices are meeting their responsibilities through Local Enhanced Services.

This feedback is also being used to support conversations with GP practices and improve how the Reasonable Adjustments Digital Flag is used, so that people get the right support when they need it.

Speech and Language Therapy (Sunderland & South Tyneside)

Why we did this work

Between January and March 2025, we asked families and professionals about speech and language therapy services for children and young people. We wanted to understand:

- what families need and experience
- what professionals think about the service
- what works well
- what needs to improve.

This work was first reported in the Annual Involvement Report 2024 to 2025. That report shared what people told us. This update explains what we learned in more detail and what has happened since.

How we involved people

A parent carer forum helped plan the work so that lots of different people could take part. Healthwatch checked the plan to make sure it was fair and inclusive.

We used several ways to hear from people:

- a workshop for professionals

- a survey for parents and carers
- a survey for staff who refer children to the service
- face to face conversations in family hubs.

We shared information about the work by:

- using hospital trust communications
- putting up posters in family hubs
- using local networks and contacts
- sharing information with schools, nurseries and other organisations.

After the first report was published, young commissioners in Sunderland carried out extra work with young people. Their views were added to the findings, and the full involvement report includes all feedback.

What we heard and learned

People shared several common themes.

Clear communication and understanding

Families and staff said communication needs to be clearer at every stage, from referral through to waiting, therapy, and after support ends.

Support around the whole journey

People said more support is needed beyond therapy sessions, including while waiting, between sessions, and after therapy finishes. Many also want support that is more tailored to their child's needs.

Involvement and confidence to support children

Parents and schools want to be more involved in supporting children. They said they need better tools, training and guidance to feel confident in helping.

Access and waiting times

Waiting times were a major concern and strongly affected how people felt about the service. Families also said that the time and location of appointments can be difficult to manage. Feedback from young people, gathered by Sunderland's young commissioners, supported these findings and added further insight to the report.

What difference this has made, and what will happen next

Several improvements are already being made, building directly on what people told us in 2024 to 2025.

New early support tools have been developed with Speech and Language UK. These help schools and nurseries spot speech and language needs earlier and offer support straight away. The ICB worked with the NHS trust and local authorities to fund this work. Over time, this will become part of the pathway into NHS services.

More training is being developed for people who work with children. This is being done with the local NHS Trust and will help staff feel more confident supporting speech and language needs.

New online support is being introduced, with clear sections for parents and for professionals. These resources explain what help is available and provide support while families are waiting. Lunch and learn sessions are helping raise awareness of these tools.

Communication is also improving. Letters and information are being rewritten to make them clearer and easier to understand.

Other changes include testing new ways to reduce waiting lists and using a triage system so children with the greatest need are seen sooner. Clinics are starting to move into community settings, and over time therapists will work more closely with schools.

Children and young people's mental health in Sunderland

Why we did this work

In October 2024, we listened to people’s views on children and young people’s mental health services in Sunderland. We knew that the mental health and wellbeing service needed updating, and we wanted to hear directly from those who use and work with the service.

We shared our approach and early findings in the Annual Involvement Report 2024 to 2025. This update explains what has happened since and how the feedback is being used.

How we involved people

We spoke with:

- children and young people
- parents and carers
- staff and other professionals.

This work took place between September and October 2024 and included:

- a dedicated event for professionals
- three online surveys, one for young people, one for parents and carers, and one for staff.

We shared information about the surveys in lots of ways, including:

- social media, with posts aimed at younger people
- the ICB and Healthwatch websites
- schools, colleges, youth services, charities and mental health groups.

Healthwatch and other partners helped spread the word. They shared the surveys with:

- schools and colleges

- youth groups and services
- parent and carer forums
- mental health charities
- public health and NHS organisations.

The work also linked with local events, including World Mental Health Day.

What we heard and learned

Waiting times and support while waiting

People said waiting times were too long, especially for children who need long-term support or who are neurodivergent. Many said that having support while waiting would make a big difference.

Clear pathways and joined-up services

Children have different needs, including those linked to trauma and neurodivergence. Some children do not meet the rules for getting help, and services can feel disjointed and hard to navigate. People want clearer routes to support and better joined-up working between services.

Flexible and personalised support

People want support that fits each child. This includes offering help earlier, providing support over a longer time, and giving choices about how support is delivered, such as online or face to face.

What difference this has made, and what will happen next

A new Neighbourhood Mental Health Model is being developed for Sunderland and South Tyneside. This model will create a more joined up, local approach to mental health support, with a stronger focus on primary care and ongoing support.

This will make it easier for children and families to find help, get support earlier, and receive care that adapts as needs change. It will also reduce the number of times children are moved between services and improve access for groups who often find it hardest to get help.

Alongside this work, several improvements are already in place.

Mental health support teams are being rolled out to all Sunderland schools. Two new teams are now in place, with full coverage expected by January 2027. All schools can also use the Stronger Schools platform, which helps staff get advice on supporting pupils.

Two wellbeing hubs are now offering advice and support for people of all ages. A new mental health service for LGBTQ+ young people will begin on 1 April 2026 and was shaped with support from Youthwatch. Support is also now available for children affected by sudden death.

A crisis text line has been introduced and is working well, especially for neurodivergent young people. Work is also taking place with Sunderland College to strengthen mental health support through primary care. You can read more about what we heard in our involvement report.

Planning a new short break service in South Tyneside

Why we did this work

Some people with learning disabilities need short breaks away from their usual care. These breaks can support their wellbeing and give families and carers time to rest.

In 2019, Elmville, a local short break service, closed because of Covid-19. In 2022, we asked families whether this type of support was still needed. Families told us clearly that it was.

During 2024/25, we worked closely with people with learning disabilities, their families and carers to co-design a new short break service. This work helped set clear expectations for what a good service should look like.

In 2025/26, the focus has been on building on that learning and making sure families remain involved as the service moves from design towards delivery.

How we involved people

The Annual Involvement Report 2024/25 outlined the earlier involvement and co-design work, which included families, carers, people with learning disabilities, adult care staff and partner organisations. A full report of this work is available online: short breaks project report.

Since that report was published, families have continued to be involved during the service design stage. Commissioners have held ongoing conversations with families and carers to discuss how the service will work in practice, including quality expectations and timescales.

A workshop was also held with adult care staff and partner organisations to review plans, share learning from the earlier co-design work, and identify anything that needed further consideration.

What we heard and learned

Families told us it was important that the new service continued to reflect the principles they helped shape during earlier involvement. They wanted reassurance that the service would feel personal, be well planned, and meet individual needs.

Ongoing conversations also highlighted the importance of preparing well for each short break, with enough time taken to understand what each person likes, needs and enjoys.

What difference this has made, and what will happen next

Continuing to involve families has helped ensure that the service design remains grounded in lived experience. It has strengthened confidence that earlier feedback has been listened to and carried forward.

The short break service has now been designed to provide a holiday-style experience. Before each break, detailed work will take place to understand and plan for the individual's needs and preferences. People will also be supported to record and share information about their break in ways that work for them.

People with lived experience continue to be involved as work progresses to identify the right organisation to deliver the service. Families are being kept updated as this work moves forward.

From emergency to planned care

This section shows how we are listening to people to improve urgent and same-day care. We want services to be easy to access, quick to use, and clear for patients. The example below shows how feedback from people using Acute Respiratory Infection (ARI) hubs is helping us understand what works well and where improvements are needed.

ARI hubs

Why we did this work

ARI hubs have been running across our area to help with winter pressures on health services. This has been happening for the last few winters.

These hubs are open in winter to help people with breathing problems, such as chest infections. They help adults and children get a health check, without needing to go to hospital.

The involvement team worked with regional staff to see how well these hubs are working for patients. We focused on whether people can get the care they need without going to hospital.

How we involved people

To make sure patient experience helps improve the service, we used the same set of questions at all ARI hub sites. We asked people:

- if they had heard about the ARI hubs before
- how their appointment was booked
- which hub they went to and how easy it was to get there.

We also asked about their overall experience. This included the care they received and whether they would use the service again. The questions helped us understand:

- how quickly people were seen

- how clear the staff were when they spoke to patients
- how good the care felt to them.

We also asked about travel, parking, and how easy the hubs were to use.

What we heard and learned

People said they had a very positive experience of using the ARI hubs. They said:

- staff were friendly and kind
- appointments were easy to get
- information was clear and easy to understand.

Overall, 95% of people said their experience was “very good". People also talked about how caring the staff were. They said staff listened carefully and explained things well during their appointment.

Some people shared ideas for improvement. These included:

- parking problems at some sites
- wanting to be seen even more quickly in the future.

What difference this has made and what happens next

The feedback we received was very helpful. What people told us has been shared with the teams who run the ARI hubs. This information will help them think about how the hubs can work better in the future. We will continue to listen to people and gather feedback when the ARI hubs run again. This will help make sure the service continues to improve and supports people in the best possible way.

Community health, wellbeing, and end of life support

This section shows how we are working with communities to improve health, wellbeing and end of life support. We listen to people’s experiences to understand what matters most, especially for those who may not always get the support they need. The examples below show how this is helping us improve care, reduce inequalities, and make services more compassionate and easier to access.

End of life care health needs assessment (HNA)

Why we did this work

Palliative and end of life care help people live as well as possible until they die. It supports people with serious illness, as well as their families and carers.

We wanted to update our end of life care HNA. This looks at what people need now, what they may need in the future, where services work well, and where improvements are needed. It is important that this work is shaped by real experiences, not just data.

How we involved people

We used a range of ways to listen to people across the region. We ran a public survey to understand what matters most at the end of life, where people would prefer to die, how comfortable people feel talking about death, and how easy it is to get support.

We also worked with Healthwatch teams and community partners to hold conversations with carers, people with learning disabilities, people from minority ethnic communities, faith groups, people living in rural areas, and professionals working in health and care. Some people took part in one-to-one conversations, supported by community organisations.

We also reviewed other lived experience insights, including focus group notes, a personal letter, video and podcast discussions, and a story shared through the Learning Disability Network. This helped us understand the needs of people who may need reasonable adjustments.

What we heard and learned

Clear communication and understanding

People said clear, honest and compassionate communication is essential. They want open conversations about dying, clear explanations, time to ask questions, and to feel listened to. Families said poor communication can cause fear and distress. People with learning disabilities said information should be easy to read, explained slowly, repeated if needed, and shared by someone they trust.

Trust, relationships and continuity

People feel safer when supported by professionals who know them well. Changes in staff or poor coordination between services can increase anxiety. People want continuity, respect, and staff who understand their personal needs.

Choice, dignity and cultural needs

Most people want good pain relief, to be treated with dignity, and to be with people they care about. Many said they would prefer to die at home, but not everyone knows what choices are available. Some communities said that cultural and religious beliefs are very important. People want services to respect faith, modesty, family roles and spiritual needs.

Joined-up care and clear pathways

Some families described services as fragmented and hard to navigate. People were often unsure who to contact and said services do not always work well together. This can lead to families having to push for support at a very difficult time.

Emotional impact and support for families

End of life care is not only about clinical care, but also emotional support. People spoke about fears of pain, being alone, and upsetting family members. Carers described feelings of guilt and exhaustion. When care is well coordinated and compassionate, people feel safer and more prepared.

What difference this has made, and what will happen next

This work shows that good end of life care depends on early conversations, clear and accessible communication, and care that respects people’s culture and needs. It also highlights the importance of reasonable adjustments, joined-up services, and strong support for families and carers. While clinical care is important, how services communicate and work together makes a big difference to people’s experience.

The feedback from this work will directly shape the updated end of life care HNA, future service planning, and workforce training priorities. It will also support improvements in communication and coordination. We will continue to work with communities to make sure services reflect what matters most to people.

Helping people understand winter care and pharmacy options

Why we did this work

The ICB worked with Healthwatch to look at whether information about winter care and pharmacy services was clear and helpful for local people.

What we heard and learned

People told us that some messages were useful, but others were confusing or easy to miss. This was a bigger problem for people who do not use the internet or who need information to be clear and simple. By testing information face to face, Healthwatch helped show where messages needed to be clearer, more consistent, and easier to act on.

> **“I’d seen the posters, but I didn’t really understand what they were asking me to do until someone explained it.”**

> **“Pharmacies can help with more than people realise, but the information isn’t always clear.”**

> **“If you’re not online, it’s easy to miss important messages.”**

What difference this has made, and what will happen next

Healthwatch shared this insight with the ICB to help improve winter communications. This helped us make information about pharmacy services and how to get care easier to understand and more likely to reach people who might otherwise be missed.

Working with Healthwatch helped the ICB see which messages were working well and where more clarity was needed. This supported improvements in how winter and pharmacy information was shared across the region.

Unmet health needs of people struggling with alcohol and other drug use

Why we did this work

Since January 2024, Sunderland City Council has used ICB funding to work with a university research team to understand how health services can better support people affected by alcohol and other drug use.

From the start, a community advisory board was set up to guide the work. This included people with lived experience, community organisations and partners such as the ICB, helping to make sure the work was shaped by real experiences.

How we involved people

During 2024 and 2025, the research team worked closely with people with lived experience, community and voluntary groups, and health professionals. Together, they designed new ways to offer health support.

One of the main outcomes was the launch of a mobile health bus. This was designed to support people who often miss out on healthcare because of stigma, past experiences, or difficulty accessing GP services.

The bus offered support to register with a GP, health checks, and links to other health and support services. The pilot ran during 2025 and was very successful, winning a Fuse Award for its impact. A Fuse Award recognises excellence in public involvement and engagement, communication and translational research.

What we heard and learned

The evaluation in 2025 showed clear improvements. More people were able to register with a GP, and old or unfair “exclusions” were removed from health records. People who had previously struggled to get help were able to access support.

The project also showed how important trust and relationships are. Many people first came with physical health problems, but as trust grew, they also accepted support with mental health, substance use, housing and general wellbeing.

What difference this has made, and what will happen next

This work showed the value of working together from the start. It helped build stronger relationships across services and reduced barriers between organisations. Community and voluntary groups were treated as equal partners, helping to create a shared network focused on improving access and reducing stigma.

Because the project was so successful, the GP Alliance has agreed to fund the mobile health bus as a permanent service for inclusion groups. This means the work will continue beyond the pilot.

An early economic review suggests a positive return on investment, with £1.10 returned for every £1 spent. If the model is expanded, this could rise to £2 for every £1 invested. A full report will be published.

Caring in North Tyneside

Why we did this work

The North Tyneside carer friendly practice award scheme was launched on 7 March 2022 in response to feedback received from carers. It aimed to:

- help practices identify and support more carers
- provide an accredited framework, within which to develop services and good practice
- acknowledge the work already being undertaken by general practice to support carers
- help demonstrate they meet the CQC endorsed 'quality markers for general practice'.

How we involved people

All 20 practices signed up to the scheme. The ICB evaluated this scheme, in partnership with Healthwatch North Tyneside and the North Tyneside Carers Centre:

- We asked practices to send an online survey via text to all carers to seek their views on the support they received as a carer from their practice. 18 out of 20 practices participated and 1,761 responses were received.
- Feedback was sought from practice carers champions via a face-to-face meeting. Five practice staff attended this meeting.
- Feedback was sought from practice managers via a face-to-face meeting. Seven practice staff attended this meeting.
- Feedback was sought from practice managers via an online survey. Four responses were received.
- We reviewed Healthwatch North Tyneside’s annual carers survey.

What we heard and learned

The evaluation found that the scheme has delivered some important benefits, including:

- increased awareness of carers within general practice
- appointment of carers champions in all participating practices
- a significant increase in referrals to local carers support services.

However, the evaluation also identified significant limitations in the current model which led to the decision to discontinue the scheme.

Carer experience remains inconsistent

Despite increased activity, many carers reported that they still do not feel recognised or supported by their GP practice, and opportunities to offer information or help are frequently missed.

Carer identification remains below expected levels

The proportion of patients recorded as carers on practice registers remains well below population estimates, indicating that the scheme has not delivered the level of improvement in identification originally intended.

Impact varies significantly between practices

While some practices have embedded carer-friendly approaches, others have found it difficult to sustain activity, leading to uneven support for carers across the borough.

The scheme is resource-intensive and difficult to sustain

Practices consistently reported that the evidence requirements and tiered award structure were onerous, particularly in the context of workforce pressures and staff turnover.

Value for money cannot be sufficiently demonstrated

Although funding has supported engagement, the evaluation did not provide enough evidence that the current incentive-based model delivers consistent, measurable improvements in carer outcomes to justify ongoing recurrent investment.

What difference this has made, and what will happen next

For these reasons, we concluded that continuing the scheme in its current form would not represent the best use of resources, and that a different approach is needed to support carers more effectively. The learning from the evaluation will help shape any such interventions to support carers in the future.

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)

Why we did this work

The SDE helps the NHS use health and care data safely to improve services, research and planning across the North East and North Cumbria. To do this well, people need to trust how their data is used and protected. This means being clear about decisions, keeping data secure, and involving the public from the start. National guidance is clear that SDEs only work if public involvement is built in early and taken seriously.

Health Innovation North East and North Cumbria (HI NENC) support the ICB by leading much of the patient and public involvement work. This helps make sure that local people's views shape how data is used, explained, and protected. HI NENC has helped create public information, including videos and animations, and supported the programme to build a strong regional and national profile.

How we involved people

Over the last year, involvement work has grown across the region.

Public members and decision-making

A regional public members group meets regularly and plays an active role in the SDE programme. Public members are supported to take part in discussions, test information, and raise concerns. They also have a formal role in reviewing applications to use data, through the public evaluation group (PEG).

Reviewing data access requests

Public members review data applications to decide whether they are in the public interest. They look at things like public benefit, fairness and clarity, and can recommend approval, conditions, or changes.

Workshops on complex issues

Workshops have been held to explore more complex topics, such as plans to link data across regions (known as federation). These sessions gave people time to ask questions, think through risks, and share their views.

Community engagement (early stages)

Work has started with voluntary, community and faith organisations to begin wider conversations about health data. This community engagement work is still at an early stage, with more activity planned for the coming year.

What we heard and learned

Several key messages came through clearly.

Trust depends on clarity and honesty

People want clear, simple explanations about how data is used, who can access it, and how it is kept safe. Technical or unclear language makes trust harder to build.

Public benefit must be clear

Public members want reassurance that data is only used in ways that benefit the public. They expect strong checks before any project is approved.

Governance and security really matter

Feedback from workshops, especially on data federation, showed strong concern about governance, accountability and security. People want to know who makes decisions, who is responsible if something goes wrong, and how risks are managed.

Language matters

Public members highlighted when summaries or explanations were not clear or easy to understand. This showed the importance of plain English and good quality lay summaries.

What difference this has made, and what will happen next

Public involvement has already made a difference to how the SDE programme works. Public members have reviewed three data access applications. Two were recommended for approval, and one was supported only with conditions. As a result, the project team had to rewrite their lay summary after public members said it was not clear or suitable.

Public members have also developed their own criteria to decide whether projects are in the public interest. This has strengthened how decisions are made and made the process clearer and more consistent.

Feedback from the federation workshop has highlighted important issues that must be addressed before any further decisions are taken. Community engagement is still developing, and more impact is expected as this work expands over the next year.

You can read more about the North East and North Cumbria SDE programme.

Child Health and Wellbeing Network

What this network is for

The Child Health and Wellbeing Network helps make sure children, young people and families have a real say in decisions about health and care across the North East and North Cumbria.

This year, the network has continued to grow and strengthen how children, young people and families are involved. A key part of this has been the development of the know our impact (KOI) young people’s group. KOI grew from the original young advisors' group and is now a strong and confident voice that helps influence leaders and shape health and wellbeing priorities.

How we involved people

Over the past year, the KOI group has grown in confidence, membership and influence.

KOI members now have clear links with the child health and wellbeing strategic oversight group (SOG). This includes meetings before and after SOG sessions, so young people can share their views and see how these are used in decision-making.

The youth voice network has also grown through the fund your future campaign. This brought 77 more youth voice groups into involvement activity across the region.

The KOI group and wider youth voice network are now more diverse. This includes young people from LGBTQ+ communities, care-experienced young people, and young people who are neurodiverse.

In April 2025, KOI moved to a new provider, Rise NE. This helped make sure the group could continue its work and grow further.

What we heard and learned and worked on together

Young people have been involved in many areas of work, including:

- health and wellbeing, such as mental health, poverty, diet, asthma and screen time
- inclusion, including LGBTQ+ health inequalities, care-experienced young people, and neurodiversity
- speaking up and driving change, through manifesto pledges, accessible language and creative health projects
- education, including flexibility in attendance policies for health needs
- practical opportunities, such as work experience, leadership training and first aid.

Young people have also helped design recruitment campaigns, induction materials and action plans, and have led workshops and shaped meeting agendas. Some have written directly to decision-makers, such as the North East Mayor, to make sure youth voices are heard.

What difference this has made, and what will happen next

Young people’s voices are now clearly built into decision-making and governance.

They are helping shape policies and services, not just sharing opinions. The KOI group and youth voice network have grown and become more diverse, and youth-led involvement is now part of how work is done as standard.

Ways of working are more accessible and inclusive, youth voice is visible at regional and national level, and collaboration across the region is stronger.

North East and North Cumbria Local Maternity and Neonatal System (LMNS)

What this network is for

The LMNS brings together local health services, women, birthing people, families and other organisations.

Everyone works together to improve care during pregnancy, birth and the early days with a baby across the North East and North Cumbria.

The aim is to make sure everyone receives:

- safe care
- kind and respectful support
- care that works for them and their family
- support from skilled, caring staff.

The LMNS wants the region to be the safest and best place to be pregnant, give birth and become a parent.

How we involved people

There are three different types of service user roles within the LMNS currently. Our service user model requires ongoing review to ensure it is reflective of the NHS England Maternity And Neonatal Voices Partnership Guidance.

Service user voice (SUV) leads

Two SUV leads sit on the LMNS board. They share the views and experiences of women, birthing people, families and carers. They work across the whole North East and North Cumbria and help shape decisions at a regional level.

Maternity and neonatal voices partnerships (MNVPs)

There are 10 MNVP groups across the region. Each one is linked to a local area or hospital trust.

MNVPs work closely with maternity and neonatal services to make sure the voices of women and birthing people are heard. They help services understand what is working well, where change is needed, and how care can be improved.

There is a strong focus on including women from Black, ethnic minority and deprived communities. These groups are more likely to experience health inequalities and poorer outcomes.

MNVP representatives are part of key decision-making groups, and each MNVP produces a yearly work plan based on local needs. These plans are reviewed by the LMNS board.

Patient and public voice (PPV) partners

Members of the public also sit on LMNS sub-groups, such as quality and safety groups, and on clinical expert groups, for example those focusing on pre-term births.

Their role is to speak up for women, birthing people, babies and families, and to help shape how maternity and neonatal services are designed and delivered.

To further support this work, an involvement manager joined the LMNS team in June 2025. Her role is to lead work on involvement and engagement policy and to support service user involvement across maternity and neonatal services.

What we heard and learned

Care Quality Commission (CQC) maternity and neonatal survey

The CQC ran a national maternity survey in 2025. This survey asked pregnant women, birthing people and new mothers about their experiences of NHS maternity care in 2024.

People who gave birth between 1 and 28 February 2025 were invited to take part. In some areas, people who gave birth in January were also invited. In total, 16,755 people responded, with a response rate of 39%.

Each of the 10 MNVPs has worked with their local hospital trusts to review the results and create an action plan to respond to the findings.

What difference this has made, and what will happen next

Personalised care

The LMNS has developed a personalised care toolkit. This toolkit is designed to help women and birthing people feel confident, informed and involved in decisions about their care.

It was co-designed with women, midwives, doctors and MNVP leads. The toolkit supports open conversations, shared decision-making and personalised care throughout pregnancy, birth and after birth.

The toolkit includes:

- videos from each NHS trust showing local birth options
- tools to help families and health professionals have clear conversations
- leaflets and posters with QR codes linking to trusted information
- a communications toolkit to help promote the resources.

Supporting vulnerable migrant women and birthing people

A new regional care pathway has been developed to support vulnerable migrant women and birthing people. This helps make sure their health, social, economic and safeguarding needs are recognised and supported.

This includes:

- a migrant care pathway to support additional needs alongside standard maternity care
- My maternity profile, which helps people share their needs and preferences
- a local directory of charities and services offering support and advice.

Perinatal pelvic health service

The perinatal pelvic health service is now in place across all eight provider trusts in the region. It supports women and birthing people during pregnancy and for up to one year after birth.

The service was co-developed with women who have lived experience, along with primary care and specialist staff. Information and resources were also co-produced, including videos of women sharing their pelvic health experiences.

Improving postnatal care

There is growing recognition of the need for better coordinated postnatal care in the first six to eight weeks after birth.

Following national guidance published in 2026, work is now underway to hear from women, birthing people and families about their postnatal experiences.

This learning will be used to map postnatal services across hospitals and community organisations. It will help identify gaps and priorities, so services can work better together and provide the right support for women, babies and families.

Learning Disability Network

What this network is for

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 the 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.

How we supported people to get involved

People with a learning disability, families and carers are involved at every stage of our work. We do this through workshops, group discussions and partnership working with local organisations and services.

This approach helps people share their experiences, shape decisions and create resources that meet real needs.

What we worked on together

Learning disability menopause diamond standard passport

The network worked with the Clover Group, a learning disability day service, and the Tees, Esk and Wear Valley NHS Foundation Trust (TEWV) learning disability health facilitation team to focus on menopause.

Together, we ran co-production workshops to create the learning disability menopause diamond standard passport. This is an easy-read resource for women with a learning disability, their families and carers.

The passport explains:

- what menopause and perimenopause are
- common signs and symptoms
- treatment options
- where to get support
- reasonable adjustments
- how to track signs and symptoms
- what to talk about with a healthcare professional.

The passport is now being used across the system. Read about the passport.

Flu vaccination campaign for people with a learning disability

The network worked with a parent carer forum, a family and the stop people dying too young group to co-produce a flu vaccination campaign. New films and posters were created to explain why the flu vaccine is important and what happens when people go for their vaccination.

- Watch Dan’s story about getting the flu vaccine.
- View the full co-produced flu vaccination communications campaign.
- View the The full communications toolkit.

Supporting people with a learning disability after a cancer diagnosis

This work was led by network cancer workers, with support from the Northern Cancer Alliance and Northern Cancer Voices. We spoke with people with a learning disability who have experience of cancer to understand where they got support after their diagnosis.

We wrote a report called: Where do people with a learning disability get help and support following a cancer diagnosis.

- Read the full report.
- Read the easy read summary.
- Watch the lunch and learn webinar about this work.

What difference this has made, and what will happen next

This work is helping services better understand the needs of people with a learning disability and respond in more accessible and supportive ways. Resources created through co-production are now being used and shared across the system. Learning from this work will continue to shape future projects, training and service improvements so people with a learning disability, their families and carers receive the right support at the right time.

Northern Cancer Alliance

What this network is for

The Northern Cancer Alliance works to improve cancer care across the North East and North Cumbria. It brings together health services, patients, families and community partners to make sure cancer services meet people’s needs. A key part of this work is listening to patients and using what they tell us to improve care, support and information.

Cancer patient experience survey

Why we did this work

The cancer patient experience survey is a national survey that takes place every year. It asks people about their care, from diagnosis through to treatment and support. We use the results to understand what is working well and where things could be improved.

How we involved people

Patients shared their views by completing the survey. We then shared the results widely through meetings, webinars, newsletters and social media so that patients, families and staff could see what people said. We also brought people together through forums and discussions. This helped us explore the findings in more detail and understand what matters most to patients.

What we heard or learned

Most patients said they had a very good experience of cancer care. In our region, scores were higher than the national average. People told us that staff were kind and respectful, communication was clear, and they felt well supported by their care teams. However, some people said they needed more emotional support at home and better information about side effects.

What difference this has made and next steps

We have used this feedback to focus on improving emotional support for people at home and making information about treatment and side effects clearer. We are working with hospitals, GPs and community groups to make these changes. We also share updates using “You said, we did” messages so people can see how their feedback has made a difference.

We will continue to listen to patients and reach out to groups who are often not heard, so we can keep improving cancer care. Read the National Cancer Patient Experience survey results.

South Asian bowel cancer screening

Why we did this work

Bowel cancer screening can save lives, but not everyone takes part. We found that fewer South Asian men in Middlesbrough were taking part in screening.

There are several reasons for this. These include low awareness of the test, a lack of clear and relatable information, and cultural and religious beliefs. We wanted to better understand these barriers and help more people take part.

How we involved people

We worked with a local partner, Nur Fitness, to connect with the community. We invited South Asian men of screening age to take part in focus groups. In total, 36 men took part. They were joined by their Imams and supported by community leaders, local groups and mosque representatives. These sessions gave people a safe space to talk openly about bowel cancer screening and what might help them take part.

What we heard or learned

Men told us that handling stool samples was a big barrier and made them feel uncomfortable. Some also believed that illness is part of fate or destiny, which affected their decision to take part. There was also fear and worry about finding out they had cancer. Some men said they did not want to know, especially as they felt they needed to stay well to provide for their families.

They told us they would be more likely to listen to messages from people they trust, such as their Imam, GP or others from their community. They suggested using videos that could be shared in mosques and on social media.

What difference this has made and next steps

We used what we heard to design a campaign with the community, rather than for them. This helped make sure the messages were trusted and culturally relevant. Community members chose to take part in the campaign video alongside faith leaders and healthcare staff. This has helped make the message more real and relatable.

The video has now been filmed and will be shared through mosques, community spaces and social media. We will gather feedback from people who see the campaign and work with partners to understand if more people start to take part in screening. This will help us learn what works and continue to improve how we support this community.

Integrated Stroke Delivery Network

About this network

The Integrated Stroke Delivery Network helps people who have had a stroke and their families. Together they have been making a plan for how people can help improve stroke services. This plan was made with people who have personal experience of stroke.

The network worked with the ICB involvement team to improve how people are involved. They now hold regular meetings and send a newsletter every three months to patient representatives. The newsletters explain what the network board has been working on and show how people can get involved.

Examples of our work

The network held regular meetings with people who have had a stroke and their families. These meetings gave people time to share their views and helped make sure their voices were heard.

People told us they want a clear role in helping to decide what is most important. This includes how technology and online support could help recovery after a stroke. They also said they want:

- clear information about changes in the NHS
- to know how their feedback has been used.

Because of this, the network board agreed a new way of involving people. People with lived experience now help guide smaller pieces of work and support plans for the future of stroke services. In the future, involvement will focus on:

- better emotional and mental health support after stroke
- new ways to help people recover at home, including online rehabilitation.

Developing a learning disability advisory group in County Durham

Why we did this work

People with a learning disability, autistic people, and their families told us they want regular ways to share their views. They want to help shape services and affect decisions. In County Durham, there was no single group that brought these voices together regularly.

We started this work so people with lived experience could:

- be heard more clearly
- have their views listened to more often
- see real changes happen.

We worked with Durham County Council and local service providers to help set up the learning disability advisory group. This group was designed around what people told us they wanted.

How we involved people

With support from Inclusion North, we asked people how they want to be involved in the future. We spoke with:

- people with a learning disability
- autistic people
- families and carers
- local authority staff
- service providers.

We listened to what everyone said and the views they shared with us. The report we produced explains the main things people told us were important.

What we heard and learned

Regular involvement is important

People told us they want to be involved often, not just once or at the end of a choice.

Ongoing conversations help people feel listened to. They also help build trust and make involvement feel more meaningful.

Strong support for an advisory group

More than nine out of every 10 people who answered the survey said an advisory group is the best way to support regular involvement. People felt a group would help make sure:

- views are shared often
- voices are listened to
- feedback is not forgotten.

Lived experience and staff views are sometimes different

Some focuses were the same for staff and people with lived experience. Others were different. This showed how important it is for people with lived experience, families and carers to be directly part of discussions and decisions.

Feedback must lead to real change

People told us their views must lead to real actions, not just talk. They also said it is important to hear back about:

- what happened
- what changed
- how their feedback was used.

This helps people know their time and effort matter.

Accessibility is essential

People said meetings must be easy to join and take part in. This includes:

- using clear and simple language
- offering support where needed
- making sure people can join in ways that work best for them.

What difference this has made and what happens next

We will keep support available for members of the advisory group. This will help extend the chance to speak up with other groups and services they are part of. This means more people will be able to share their views on important topics. Advisory group members will work alongside staff from support services to help these conversations happen.

As ways of working change, the local authority in County Durham will support the future running of the group. There will still to be chances for services to:

- talk with the group
- hear directly from its members
- learn from their experiences.

Community mental health conversations

Why we did this work

This review looked at some mental health and wellbeing support in County Durham. The support is provided by Age UK County Durham and the Pioneering Care Partnership (PCP). We wanted to learn what works well and what could be improved. We asked people who work in:

- the NHS
- Durham County Council
- local charities.

We also spoke directly with people who use these services. Helping us to hear their experiences first-hand. In total, 490 people told us their views.

How we involved people

When planning the project, we worked closely with staff from the teams who offer this support. Together, we:

- designed the questions used in surveys
- helped create clear information to explain the project.

To see how possible changes could affect people, the ICB carried out an engagement process that included:

- an online survey for people who use the services
- face-to-face discussions with service users, supported by staff
- group discussions at existing meetings and groups linked to the services
- a separate survey for people from other local services

This helped us hear from many different people in different ways.

What we heard and learned

The support makes a real difference

Many people told us the support helps them:

- stay safe
- feel more stable
- support their recovery.

Some people said that without this support, they may have reached crisis point or needed emergency care. Others said the services help reduce loneliness and support people who find it hard to use other mental health services.

Support should be easy to access

People said mental health support should be:

- close to where they live
- able to respond quickly when help is needed.

People also said support should be based on individual needs, not a one-size-fits-all approach.

Community-based support works well

People spoke positively about:

- face-to-face support in the community
- places that feel safe, friendly, and non-clinical.

This type of support was said to:

- reduce anxiety
- help people feel more comfortable asking for help.

Many people shared how important it is to have:

- kind and understanding staff
- support from someone they know and trust
- consistent support over time.

This approach helps people build confidence, reduce loneliness, and manage daily life.

Flexible, long-term support was strongly preferred over short-term or strictly clinical services.

What difference this has made and what happens next

The feedback helped build a clear picture of what people experience when using these services. The valuable feedback we collected help demonstrate:

- what people value most
- how support fits into their everyday lives
- where this type of service makes the biggest difference.

This helped the ICB better see what a priority for similar services in the future should be. After the involvement work ended in March 2026 a report was produced. The full report, bringing together all the feedback, was shared with senior leaders. These leaders were responsible for the wider review that this work was part of. At the time this summary was written, the final decisions from the review had not yet been shared. However, the feedback collected was being directly used to help tell local decision-makers about the value of these services to those who use them.

Other examples of collaborative listening

Co-Design in Action: Shaping NHS Services Together

In November 2025, Northumbria Healthcare hosted a regional event to share learning from public involvement activity. NHS England presented the national context, the ICB outlined why involvement matters locally, and examples were shared showing how involvement has influenced planning and commissioning. The North East and Cumbria Learning Disability and Autism Network also shared learning on the value of working alongside people with lived experience. The event inspired participants and a similar event is planned for next year.

Co-production charter for North Cumbria

Cumberland Council is leading the co-development of a co-production charter with members of the public, the council, the Health Determinants Research Collaboration (HDRC), the ICB, and Healthwatch. The charter sets out the importance of working together as equal partners. The next stage will involve co-designing the final version. The ICB will promote the work through the People’s Hub newsletter and Boost and explore opportunities to apply the charter in practice.

Lived Experience Network - improving access for d/Deaf people

The Lived Experience Network in North Cumbria has worked with d/Deaf people and organisations that support them to understand barriers to accessing services. They published a report outlining issues and recommendations for health, care, and council services. North Cumbria Integrated Care is taking these recommendations forward for local health services.

Continuity of care

North Tyneside has been exploring ways to improve continuity of care in GP practices, so patients are more likely to see the same clinician or team. Engagement has taken place at practice level, and a summer event was held to share good practice. Some practices in Northumberland are now considering adopting similar approaches. The team is developing learning tools to help the spread of this good practice. This includes how practices involve patients in the changes. These resources are being tested with patient groups.

Dementia services and listening over time

We have worked closely with people and local partners to plan this dementia work together. Using the local dementia action plan, we are looking again at the full dementia journey, from staying well and getting a diagnosis, through to support, living well, and end of life care.

We are working with organisations such as Age UK County Durham, the Alzheimer’s Society and Durham County Carers Support. Each partner brings different skills and experience, which helps us reach more people and understand a wider range of experiences. Together, we have created shared materials and an engagement plan that fits with local priorities.

We are running separate conversations for each part of the plan over a 12-month period. These conversations are designed to hear real experiences from people affected by dementia, including people with dementia, carers and families. We are using both face-to-face and online sessions so that more people can take part in ways that suit them.

All engagement activities are shared on the Let’s Talk County Durham platform. This helps us gather feedback quickly and see what people are telling us across different topics. At the time of writing this report, the involvement activity was just being launched. What we learn, and the changes this leads to, will be shared within the organisation and published on our website once available.

North Tyneside Big Community Conversation

In summer 2025, North Tyneside Council led a Big Community Conversation, combining an online survey with in-person engagement at local events. Residents were invited to share views on living, working, and visiting the borough. A total of 82 comments and questions related to health services. Responses have been published on the Big Community Conversation website (you need to log in to read the responses).

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 (VCSE) sector

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 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 VCSE.

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. Sometimes we lead these forums and groups. Sometimes other people lead these forums and groups.

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. Over the last year, these conversations helped us:

- listen to people's thoughts on the proposal to stop gluten-free prescriptions
- understand what is important to people for end of life care
- improve the effectiveness of the ICB's dental and oral health strategy
- make patient information easier to understand
- help developments to make sure people get the best care in the right place, e.g. home not hospital.
- help residents understand urgent and emergency care pathways
- improve understanding of barriers faced by Deaf people.

North Tyneside Patient Forum

The forum has helped improve services across urgent care, hospital services, dentistry, and digital programmes. The forum’s feedback has directly changed materials, removed inaccurate information and ensured patients have a stronger voice in how services are designed. Across the year, the forum has helped improve patient information, highlight gaps in services, and strengthen public involvement.

Some of the topics discussed at this forum last year include:

- Improved patient experience across urgent care, hospital services, dentistry and digital programmes by acting on forum feedback, correcting inaccurate information and strengthening the patient voice in service design.
- Raised concerns about confusion around wound care after falls or surgery, including people being directed to the wrong service and an incorrect leaflet referring to a non-existent wound care hub; this led to the leaflet being removed and all North Tyneside wound care services being mapped to improve understanding.
- Shared lived experience of wound care at QSC, helping senior leaders understand the real impact on patients.
- Took part in two visits to urgent and emergency care departments in North Tyneside and Cramlington to understand the new streaming model and how people are guided to the right service.
- Now act as community champions, helping explain urgent and emergency care services and where to go for help.
- Worked with the local hospital trust to improve the clarity and readability of

patient letters and written information, stressing the importance of testing materials with patients.

- Joined a patient testing panel to review new patient letters before use, influencing wider health literacy work and communication approaches, including for dentistry.
- Advised on how the dental and oral health strategy should be communicated, recommending simpler language and clearer messages, which strengthened the public communication approach before launch.
- Supported the hospital at home service and helped move away from the term virtual ward, which was felt to be confusing and less reassuring.
- Contributed directly to the development of hospital at home through membership of Northumbria Healthcare's working group, including shaping patient-facing materials and sharing information within local networks.
- Discussed the use of digital technology and AI in healthcare, welcoming potential benefits while raising concerns about data security, fairness, human oversight and transparency, including how AI may be used in services such as NHS 111.
- Fed views on digital and AI developments into wider regional engagement activity, including work linked to the SDE.
- Shared updates from local patient participation groups (PPGs), exchanged good practice, discussed challenges and provided peer support, helping strengthen involvement and engagement across North Tyneside.

County-wide patient reference group

The county-wide patient reference group meets regularly with patients from across County Durham. The group talks about issues that matter to local people. Helping to hear views based on real life experiences.

Some of the topic discussed with this group include:

- Took part in regional conversations on proposed changes to gluten-free prescribing, future use of AI in healthcare, and how local dental services are communicated, ensuring regional work reflects the lived experiences of people in County Durham.
- Shared patient perspectives on GP access when a practice manager attended a meeting to explain changes to appointment systems, including the use of total triage, helping both patients and staff better understand each other's experiences.
- Reviewed an ICB dental campaign, providing feedback on clarity, accessibility and how information could be shared more effectively within local communities.
- Heard directly from North East Ambulance Service (NEAS) about how ambulance services operate, with a focus on the challenges and responses in rural areas such as the Dales.

- Welcomed the chief executive of TEWV to discuss mental health services, raising concerns about care plans and sharing what matters most to people using services, while also learning how local work links to national priorities.

Health and care engagement forum

The health and care engagement forum meets regularly to support involvement and engagement across County Durham. The group brings together local Healthwatch, VCSEs, NHS provider trusts and local authority partners. Members are regularly asked to review draft plans and materials and share their views.

Some of the topics discussed at this forum include:

- Worked together to shape involvement activity on local priorities, including supporting materials for dementia engagement work and contributing to regional discussions on the use of AI in healthcare and proposals for gluten-free prescribing.
- Used the forum as a space to discuss wider system developments affecting health and wellbeing, including the work of the poverty truth commission and support provided by Investing in Children through emotional wellbeing locality forums in schools.
- Gained a better understanding of how different organisations are working together across the system and where involvement can make a meaningful difference.
- Heard directly from the local authority on the council's budget consultation, giving members the opportunity to ask questions and share views.
- Received updates from County Durham and Darlington NHS Foundation Trust on plans for Shotley Bridge Community Hospital, including proposals for a new build, with further engagement expected during 2026.
- Welcomed new adult health colleagues from the local authority, who introduced their roles and shared work focused on understanding access to services for people with protected characteristics, strengthening links between involvement teams across the county.
- Recognised and thanked the County Durham lay member for involvement, who stepped down at the end of December 2025, for their strong leadership and long-standing contribution to partnership working across County Durham.

Community involvement group

This group is part of the County Durham Together partnership and brings together involvement staff from different organisations across County Durham. The group meets every two months to support joint working and shared approaches to involving people.

Some of the topics discussed with this group include:

- Provided a supportive space for involvement staff to understand each other's roles, share ideas, learn from practice, and improve how organisations listen to and work with communities.

- Welcomed the introduction of the ICB’s community engagement library as a shared online space to view reports and findings from involvement and engagement activity across the system. Highlighted strong interest and positive feedback from a wide range of public sector partners about the library’s potential to support shared learning and reduce duplication.
- Heard about the Rural Durham Community Research Network, including early work focused on the Derwent Valley, Weardale and Teesdale, with plans to expand into other rural areas.
- Welcomed the focus on rural communities and the opportunity to better understand the experiences and needs of people living in these areas.
- Reviewed how the group works and what it has achieved to date at the start of 2026, with strong continued support for its purpose and role.
- Agreed the group has an important part to play in supporting closer partnership working and improving conversations with communities in the years ahead.

Sunderland and South Tyneside involvement partnership

This partnership brings together voluntary and community groups, NHS organisations, and local authority partners. The group meets regularly to share how they are involving people and what they are hearing from communities.

Each meeting includes a topic discussion and time to share updates. This helps partners learn from each other, test ideas, and improve how they listen to local people.

Some of the information shared at this group include:

- Focused on reducing health inequalities and improving access to care, with partners sharing work to support ethnic minority communities, including cancer awareness activity led by the Sunderland Bangladesh International Centre.
- Highlighted the importance of culturally relevant information and trusted community engagement to better meet the needs of different communities.
- Held regular discussions about people with a learning disability and autistic people, focusing on making information easier to understand, increasing use of easy read materials, and improving involvement in decision-making about care.
- Discussed LGBTQ+ inclusion, including concerns about rising distress among young people, particularly those who are trans or identify as LGBTQ+, and the need for safe, supportive and inclusive services.
- Explored how services support people as they age, including those living with dementia and people nearing the end of life.
- Heard findings from Healthwatch’s work with people living with dementia and their carers, including feedback on emergency care that led to improvements such as changes to waiting areas and the development of a dementia support booklet shaped by carers.

- Shared updates from Sunderland City Council on dementia research and a healthy ageing network, alongside discussions on palliative and end of life care and the need for culturally sensitive support and better community awareness.
- Created space to discuss sensitive issues affecting health and wellbeing, including gambling harm, stigma and the value of creative approaches to support people to share their experiences.
- Discussed sexual violence and domestic abuse, including experiences of disclosure and the additional challenges faced by disabled people, neurodiverse people and those living in rural areas.
- Tested and improved how services communicate with the public, including feedback on urgent dental care and oral health messages to make information clearer, more accessible and easier to understand.
- Emphasised the importance of accessible materials, including easy read versions, and ensuring messages reach both adults and children.
- Contributed to discussions on the NHS 10 year plan to help ensure local views and experiences are reflected.
- Explored the use of digital technology and AI in healthcare, recognising potential benefits while raising concerns about trust, fairness, bias, transparency and the need to maintain a human approach to care.
- Discussed the SDEs focusing on how health and care data is used for research and how the public can be involved in shaping this work.
- Shared updates on digital engagement tools, including the community engagement library, supporting shared learning and reducing duplication across organisations.
- Brought together a wide range of voices from across Sunderland and South Tyneside, helping improve communication, shape local campaigns and better understand the needs of communities who face barriers to care.
- Agreed to continue meeting regularly to support open discussion, shared learning and joint working, ensuring services are shaped by the people who use them.

GP contract changes

When GP practices or dentists want to make big changes, they must ask patients what they think and the ICB supports them to do this in the right way. Over the past year, we have supported more than 100 practices to involve patients in changes such as:

- changing the area they accept patients from (boundary changes)
- joining with other practices (a merger)
- closing part of a practice (a branch)
- closing a branch for a short time

- changing how medicines are given out
- moving to a new building.

Each practice asked patients for their views. They then looked at any concerns, made changes where needed, and wrote a report explaining what people said and what would happen next. The ICB reviews both the practice's application and their patient involvement report before making a final decision.

Supporting practices to involve people

To help make this process clear and consistent, we developed a simple guide for GP and dental practices.

This guide brings together everything practices need to involve patients when planning changes. It helps make sure information is clear, easy to understand, and consistent across the region.

The guide explains what practices must do, including NHS requirements and their legal duty to involve patients and the public. It also gives practical advice on how to do this well.

It includes guidance on how to:

- communicate clearly with patients
- plan involvement activity
- understand legal responsibilities
- follow the right timescales
- use good practice when involving people.

The guide also includes useful tools such as example letters, factsheets, survey questions and checklists. Having everything in one place helps practices involve people properly and in a consistent way.

This work was developed with involvement specialists and primary care colleagues. Working together helped make sure the guide is practical, easy to use, and supports meaningful involvement.

Examples of GP involvement we have supported

GP practice merger

We advised on public involvement in the practice mergers of Normanby and Eston practices and Riverside and Arrival practices. People were given the opportunity to raise issues about the possible mergers. Both mergers are now complete.

Sunderland GP Alliance holds three separate contracts for Silksworth, Monument and South Hylton practices. The GP Alliance would like to merge these into one contract. Patients were contacted in February 2025 to communicate what the potential merger would mean for them and to give them opportunity to give their views.

GP branch closure

If a practice is considering closing a branch, the ICB works closely with them to look at options and likely impact. We make sure that residents and stakeholders are involved in the decision making, by getting clear information and different ways to share their views.

Lagan Practice in Teesside involved patients carefully when considering to close a branch direct people to one of the other two branches. This closure is going ahead.

One practice was considering a temporary branch closure. However, they were able to temporarily reduce branch hours and increase phone appointments, whilst recruiting more staff.

A rural practice was considering a branch closure. We supported preparation of a public involvement plan, however the practice decided to keep the branch open.

There was a proposal to close a satellite site in St Helens Auckland. However, following patient engagement, the proposal was not supported at the local executive committee. Funding for site improvements has since been identified, alongside additional support from the primary care team.

GP boundary expansion

Several practices around the ICB are considering increasing their practice boundaries. This would give patients more choice. Bridges practice in Gateshead is considering expanding into Newcastle. They were listening to what patients and stakeholders had to say over the winter and are now considering the issues raised.

Reducing GP boundary

Several practices were considering reducing their boundaries, for example due to a patient list that was growing too fast. We support the practices develop involvement plans. One Newcastle based practice, Roseworth, was considering reducing its boundary. This change would only impact on people who move into the area in Newcastle and North Tyneside. Over 1,000 people responded during the listening period (October to November 2025). What people said has impacted on the practice's application to reduce the boundary, which is now under consideration.

GP relocation

One practice has secured funding to buy a new building that could be used to move to. Initially it is considering expanding into the ground floor space. We are in discussion as to what patient involvement is needed, to make sure people can raise issues that shape the proposal.

Another practice, in Northumberland, is considering relocation to a larger building 500 metres away. Feedback on parking and accessibility has been gathered to develop the proposal.

Other GP changes

We have supported involvement in potential practice name changes. The final decision is still pending. We have also advised around involvement about potentially moving practices from one PCN to another. There has also been advice for practices considering temporary list closures to manage pressures.

Supporting people to get involved

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.

Working together through co-production in County Durham

We worked with public health and adult health services to set up a local way of working that supports involvement and co-production in County Durham. This includes a clear framework and simple guidance for staff in adult health services. The guidance helps staff understand what co-production is and how they can use it in their day-to-day work.

Removing barriers

We ran two sessions on co-production for members of the adult health senior management team in County Durham. Having time set aside for these sessions gave people the chance to:

- talk openly about what is working well
- identify what could be improved
- explore any challenges to using co-production locally.

The sessions also helped move forward actions from the last CQC visit. We shared local examples from social care where co-production is already being used or developed. This helped start discussions about how these approaches could be used more widely in the future.

What this has helped achieve

There was strong and positive feedback about the progress already made in this area of work. People also shared a clear understanding of what needs to happen next to keep improving co-production. This will help both staff and local people by making services work better for everyone.

Community engagement library

We worked with our partners to improve how we collect and use what people tell us about health and care services. We know that lots of different organisations hear from communities, but this information is often kept in different places. This makes it hard to see the full picture of what matters most to people.

The community engagement library is a shared place where organisations can bring together research, feedback and involvement insight in one system. It helps partners share what people are saying, learn from each other, and use existing information better. By bringing insight together, we reduce the need to ask people the same questions again and make sure what people have already told us helps shape decisions across the system.

We set up a partnership group to design the library. The group looked at similar systems, often called “insight banks”, used in other ICB areas. The partnership included Healthwatch, VCSE, local authorities, universities and NHS providers.

The partnership:

- agreed the name community engagement library
- agreed how organisations would work together
- helped design how information would be tagged and organised.

We then created a shared workspace that can:

- store information in one place
- tag information by topic and theme
- link to useful reports and data
- support better joint working
- allow users to search for information easily.

The system was first tested in South Tyneside and Sunderland. Partners told us that:

- the layout and structure worked well
- the process for adding information was clear
- some changes were needed to tagging
- some changes were needed to make navigation easier.

The community engagement library has now been expanded to cover all of North East and North Cumbria. We are raising awareness of the library and supporting organisations to understand how to use it, so that community insight is shared and used consistently across the system.

Tell us what you think

To support our ability to continually listen, we established a short set of questions to gather public feedback and their experiences: Tell Us What You Think. These questions are available through the ICB website for anyone to anonymously complete, at a time that suits them. The opportunity for members of the public to share their experiences of services has been promoted by the involvement team amongst local networks they are connected to.

In October 2025, the questions were expanded to include data capture about 'You and Your GP' in line with new guidance. This new guide tells people how they can help their GP and what to expect from their GP surgery and includes:

- when and how they can contact the practice
- what happens when they contact their practice
- who might help them
- information if extra help is needed.

The main themes of the comments so far relate to experiences around:

- Families affected by Foetal Alcohol spectrum Disorder (FASD). Specifically, the lack of awareness of this as a condition and non-existent pathways in our region to directly support these individuals and their families.
- A high number related to people's interactions with their GP practices, and the broad range of experiences (positive and negative) that people want to share with us.
- The lack of clarity that people are getting about their hospital appointments in letters they receive. Not helping them understand clearly who they are seeing and exactly what the appointment is for.

Establishing our People’s Hub

We heard that people want clear, easy-to-read information. They also want to know how their views and ideas make a difference. The People’s Hub was set up to help with this. It is a new way for people to get involved in shaping health and care services.

The People’s Hub gives local people a simple way to:

- sign up to involvement opportunities
- get a monthly newsletter about engagement and involvement work.

Since the People’s Hub launched in September 2025, a newsletter has been sent out every month. The newsletters share information about involvement work happening across health and care services, including work with NHS trusts and local councils.

The early response has been positive. Over 2,600 people have signed up to receive the newsletter so far, and work will continue to promote it and reach more people. Some people have shared feedback about the sign-up process. We are working with Boost colleagues and the platform developers to improve this where we can.

The People’s Hub is led by the ICB and aims to:

- help people get involved and have a say in health and care
- make sure people’s voices are heard
- show how feedback leads to change

- build trust with the public
- support meaningful involvement
- co-design learning to help people feel confident
- learn alongside citizens to have the biggest impact.

Previous newsletters can be found on the ICB website on The People's Hub page.

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.

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

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 QSC 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:

Understanding different family roles in healthcare

One carer shared their experience of attending healthcare appointments with a child they care for under a legal guardianship arrangement. They explained that staff often did not understand their role and asked personal questions in front of the child.

This meant the carer sometimes had to explain difficult family situations in public, which was upsetting and could bring back past trauma. They also shared that healthcare forms and systems do not always have space to record their legal role clearly.

The carer asked for better awareness from staff and clearer ways to record family and care relationships. This story highlights the need for respectful, trauma-aware care and better understanding of different family arrangements.

Making care easier to understand for people with learning disabilities

Two stories focused on the experiences of people with learning disabilities and their families.

One adult with learning disabilities and asthma had frequent emergency visits because they did not fully understand their condition or how to use their inhalers. Information was given in ways that did not meet their needs, and no adjustments were made. Once staff recognised this and provided clear explanations and personalised support, their asthma became well controlled. They have not needed emergency care for a long time and now feel more confident and independent.

A parent also shared their experience of trying to get support for a teenage child with autism, learning disabilities, and challenging behaviour. They described long waiting times, poor communication, and services not working well together. Support was often stopped too quickly, even when it was not helping yet. The family felt tired and unsupported and asked for services to listen more and work together better.

These stories show how making small changes and working together can make a big difference for people and families.

Delays in diagnosis and long-term impact

An older person shared their experience after a fall at home. At first, hospital staff told them nothing was seriously wrong. Later, it was found that they had a fracture that had been missed. This led to delays in treatment, several hospital moves, and a long and difficult recovery.

The person and their family described poor communication and feeling left out of decisions. While some later care and rehabilitation support was positive, the early delays had a lasting impact. The person has not regained their previous level of independence and still needs extra support.

This story shows how important early diagnosis, clear communication, and involving people in decisions about their care really are.

What we have learned

Across these stories, people told us that it is important to:

- be listened to and treated with respect
- make reasonable adjustments so care is easy to understand
- improve communication between services
- work together better so people do not fall through gaps,

Sharing lived experiences helps us learn, improve services, and make sure the voices of patients and carers are heard at every level.

Acronyms used in this report

AI	Artificial Intelligence
ARI	Acute Respiratory Infection
BSL	British Sign Language
CHC	Continuing healthcare
CNTW	Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust
DWP	Department of Work and Pensions
FASD	Foetal Alcohol Spectrum Disorder
HDRC	Health Determinants Research Collaboration
HI NENC	Health Innovation North East and North Cumbria
HNA	Health Needs Assessment
ICB	Integrated Care Board
ICS	Integrated Care System
KOI	Know Our Impact
LMNS	Local Maternity and Neonatal System
MGPA	Modern General Practice Access
MNVPs	Maternity and neonatal partnerships
NEAS	North East Ambulance Service
PAS	Patient Advisory Service
PCARP	Primary Care Access Recovery Plan
PCN	Primary Care Network
PCP	Pioneering Care Partnership
PEG	Public evaluation group
PPG	Patient participation groups
PPV	Patient and public voice
SDE	Secure Data Environment
SOG	Strategic Oversight Sessions
SUV	Service User Voice
TEWV	Tees, Esk and Wear Valleys NHS Foundation Trust
VCSE	Voluntary, Community and Social Enterprise