



North East and  
North Cumbria

# Annual Involvement and Engagement Report

2023 - 2024

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

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## Introduction

Involvement is central to improving healthcare. The North East and North Cumbria Integrated Care Board (ICB) is committed to involving people in decision-making at all levels, in our integrated care partnership strategy [Better Health and Wellbeing For All](#). Our [Joint Forward Plan](#) commits us to involving people to co-produce the best solutions.

This report demonstrates the work of our ICB in 2023/24 to:

- shape services through listening,
- to collaboratively listen and
- work with our communities.

## Shaping services through listening

### Listening to the views of children and young people, families and carers

We know that parents, carers and families of children and young people often need a range of support whilst they are waiting for assessments or treatments with an NHS service provider. To better help us plan for the types of support that are most needed and valued in Newcastle Upon Tyne, in September 2023 we undertook a survey of a patients, carers, families and children. We wanted to understand what support they had access to whilst they were waiting for a wide range of assessments and treatments, including services accessed through paediatricians, as well as through speech and language therapy (SALT) services; occupational therapy (OT); physiotherapy; children and young people's services (CYPS); children's mental health services (CAMHS); neurodevelopmental pathways (autism or ADHD assessments); 0-5 social communication pathways; and through health visitors and school nurses. The findings were provided to the SEND nurse co-ordinator and the children and young people's team in Newcastle, to help them develop and improve a range future commissioning provisions, that better meet the holistic needs of our communities.

### Women's health hubs

In December 2023, we committed £595,000 to fund new women's health hubs in Gateshead, North Cumbria and Sunderland, as part of the NHS's national women's health strategy for England. To help ensure that the design and delivery initiatives are informed by women themselves, including women who have lived experience of particular health conditions, as well as women from diverse communities.

In one of the pilot sites (Gateshead) we are undertaking an independent listening exercise and survey with members of the community, including women from the local Orthodox Jewish Community. Working through community representatives from Labriut, we will be able to better shape the design and delivery of this innovative new project. In the Sunderland area, there will be some insights work undertaken to inform the communications and branding approach for the hubs. In North Cumbria, there have been a series of round table events to learn the views of communities around women's health, with a particular focus on menopause. Services are now being delivered, and the offer will be evaluated in the coming months.

## **Newcastle urgent care review**

In 2023, we completed the first phase of our listening exercise with the public, patients, community, voluntary organisations and staff, to help inform the future direction of delivering urgent care services in Newcastle. Over 1,200 people made their views about the service known, through online and paper surveys, and through a series of public face-to-face meetings in community locations across east, central, and west Newcastle. Surveys were also distributed through GP practices, urgent treatment centres, the Royal Victoria Infirmary, and other key locations (such as libraries and community centres). In addition, over 500 on-street surveys were conducted, and seven independent focus groups were also held.

An independent report, analysing the findings, was compiled by Involve North East. The findings were reviewed by the strategic urgent care review group, made up of clinical leads and senior managers from Newcastle's urgent care centres, GP practices, emergency departments, as well as from Newcastle Hospitals NHS Foundation Trust and the Integrated Care Board (ICB). The report continues to help influence and inform discussions of the group in 2024.

As a consequence of this review, the involvement team has now been asked to establish a patient review group, made up of a small representative sample of patients from across the city, to provide periodic ongoing views and a sounding board, as different scenarios involving the future of urgent care in Newcastle are considered, in 2024 and beyond.

## **Urgent community response – County Durham**

This piece of work was undertaken as part of the implementation of the national requirements around the delivery of an [urgent community response](#). The implementation of this approach sought to build on the integrated ways of working between teams of staff and provider organisations across County Durham.

This engagement sought, initially to look at the staffing perspectives, to understand how it would be possible to maximise the use of available resources and competencies. With the desire to ensure patient outcomes consistently exceed the national and regional performance targets by starting from the basis of understanding the views and expectations of community staff teams.

Following the initial period of staff engagement, the feedback received was collated and presented back to the urgent community response task and finish group in County Durham. Many of the subjects raised by staff in their feedback related to wider system pressures. Identified below are the key themes that stood out, which have been picked up by the task and finish group such as:

- availability of social care packages
- staff pressures and the need for clarity regarding the role and purpose of the urgent care response / how it can support the work of wider teams
- the availability of intermediate care beds.

## Epilepsy: young person's service user survey and focus groups

Working with the ICB's clinical lead for learning disability and autism, as well as NHS England and Epilepsy Action, involvement leads have been supporting the development of a survey and focus groups to assess how young service users with epilepsy experience NHS services.

This will be a region-wide piece of work with a survey being distributed by Epilepsy Action and other partner organisations to young service users, their families and others with an interest in the subject. Focus groups are also planned in the coming months.

## Respite services for people with learning disabilities

The work of the ICB with Twisting Ducks about respite care in South Tyneside was recognised at the 2023 Patient Experience Network National Awards. The work was shortlisted in two categories: Communicating Effectively with Patients and Families and Partnership Working to Improve the Experience



The respite centre which provided short break respite services to people with learning disabilities was temporarily closed for safety reasons in 2020 due to the Covid-19 pandemic.

An independent research report was commissioned in May 2022 to understand the needs of patients and their carers, what was important to them, and their thoughts on respite care and other short break services.

Conversations with service-users, families, carers began in November 2022 and continuing through to March 2023.

This is [a video to demonstrate how we have engaged with service-users with learning disabilities](#), including people with complex communication needs.



## Care homes: vaccine booster programme

In order to help learn lessons from the Spring Booster Vaccine Programme which was delivered in care homes in Newcastle in 2023, we undertook a short survey of care home providers. The aim of the survey was to improve the vaccination programme from a co-ordination and delivery perspective, helping to improve the service for care home residents and staff ahead of the Autumn Booster Programme. The feedback from care home staff helped us improve our processes, as well as increase vaccination uptake and work better together with the care homes themselves. For example, the feedback allowed us to develop a new vaccination pack to support care home staff, including what they can expect from the service provider, and all the necessary forms that need to be completed.

## 'Getting Help' service listening exercise

The 'Getting Help' service offers short term, evidence-based mental health support for children and young people in the Tees Valley.

We supported a review of the offer by listening to children and young people, their parents and carers and other key stakeholders (such as people working in educational settings and local organisations) about what currently works well, what can be improved, and what they'd like to see from these services in future.

Between 4 December 2023 and 9 February 2024, we invited people to share their thoughts and experiences through a variety of methods, which included:

- Facilitated conversations about mental health with children and young people, mainly in schools and across voluntary sector services
- A survey for young people aged 11-25
- A survey for parents and carers of children and young people
- A survey for stakeholders, current providers and staff
- Interviews with local authority colleagues.



We heard from over 470 people in total, of which over 200 were children and young people. Feedback gained from this listening exercise will support the ICB's objective of ensuring that all children, young people and their parents and carers can access a high-quality, equitable offer for earlier mental health support across the Tees Valley.

## Procurement of an integrated podiatry service in Sunderland and South Tyneside

Following previous engagement and service review, a business case on a new integrated podiatry model was formed. In 2023, Healthwatch in both South Tyneside and Sunderland were commissioned to gather patient views on the proposed integrated podiatry service. The involvement was clinic-based work focused on gaining views in relation to:

- moving to an integrated model with a single provider
- reducing clinic locations from 30 to a minimum of 18
- eligibility criteria – focusing clinic resource on those at greatest risk of poor outcomes and promoting self-care supported by education
- referral – moving to a single point of contact for triage.

Many of the responses were gathered via face-to-face interview, so that qualitative information on any concerns regarding the proposed model could be gathered. Some patients also completed open-ended questions via survey following their appointments. In total, there were 156 respondents (67 in Sunderland and 89 in South Tyneside). Response to the patient feedback was included in the new contract, with outcomes including the following:

- **Service provider** – the key concern was in relation to continuity of care. This was strengthened in the specification, particularly for people at high risk. The specification

stated that every effort must be made to ensure the same clinician provided continuity of care.

- **Location** – the concern was the impact on accessibility, travel and transport. There was commitment to testing the feasibility of two clinics per primary care network (PCN) during the procurement process, including a travel impact assessment, detailing testing around the transport and travel infrastructure.
- **Eligibility** – concerns were linked to decision making in relation to triage/self-care and how self-care would work in practice. Comments were also received around the impact on disabled patients. Commitment was made to ensure that part of the procurement process would be to ensure the decision making in relation to eligibility or self-care would be done in a clinically sound way. The criteria for evaluating providers would include the criteria they use to determine eligibility. This would include: what self-care would involve; how it would be monitored to ensure it is clinically safe; what education would be provided; how education would be provided; and provision of equipment or materials. Feedback to service users provided assurance that patients with existing physical and mental disabilities would not be impacted by the changes and for patients who would be triaged in future, reasonable adjustments would be made. This would be included in the specification and the procurement evaluation strategy.
- **Referrals process** – concerns were raised regarding accessibility of the referral process, criteria used to assess need and potential increased demand for service. Feedback to service users provided reassurance that the single point of access has been designed so that patients are assessed by a suitably trained clinician. There would be one clear, standardised set of criteria to get people to the right service more quickly and make sure clinic access is prioritised on need.

## **Health coaching and social navigation in South Tyneside**

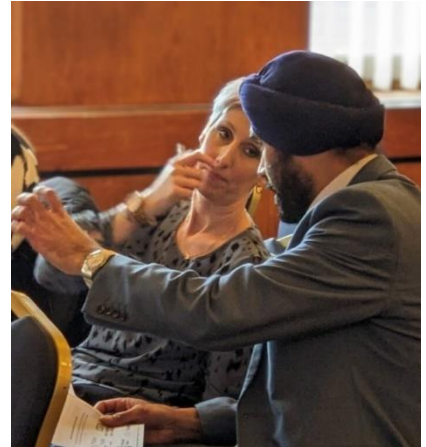
The health coaching and social navigation contracts in South Tyneside were being reviewed prior to recommissioning in 2023. Although the services are tailored to different needs, they include linking people with other services or activities to support health and wellbeing, or to help manage health conditions. This includes health coaches, social prescribers, link workers and social navigators. An online survey was developed, which the provider then highlighted to patients via text and during patient contact. 287 responses were received.

Patient engagement was undertaken during July and August 2023 to support the recommissioning of the health coaching and social navigation contracts. This was done via an online survey, which resulted in 287 responses. The results were largely with over 80% of respondents being satisfied or very satisfied with the support they received.



## A new community health bus

In Summer 2023, a partnership between Newcastle GP Services (NGPS), local GP surgeries and other healthcare providers across Newcastle, proposed to create a new community health bus, that could provide both health care and health information services in a more accessible way, across the city. To help decide what services the bus should offer, and how we can make it easier for the public to use the bus, we undertook a short public and patient survey. We publicised the survey with patients through GP practices, but also with a range of face-to-face engagement activities, as well as online and through social media in local community groups.



We used an independent charity, Involve North East, to review the findings, and draft [an independent report](#). The views of the public helped inform and influence everything from the hours the service is provided, to the locations that the bus travels to, and the type of services that are provided. The new service went live in October 2023.

## Supporting GP practices to improve patient involvement

We have been working with GP practices and PCNs to support the development of their involvement work. In Gateshead, we have helped facilitate events around the Support Level Framework “Moving to Modern General Practice” to help practices improve their patient participation groups. This also helped us proactively seek out and use broader patient feedback to ensure patients are involved in the decision-making process and co-development of services.

### Crawcrook Medical Centre, Gateshead

Organisations like Healthwatch provide us with genuinely independent feedback about local health services. They are a useful source of information when we are reviewing whether a current service provider is meeting local service user expectations.

In autumn 2023, we asked Healthwatch Gateshead to speak to patients of the Crawcrook Medical Centre, to find out a bit more their experiences of using this service.

The areas covered by the provider included services in Crawcrook, Rowlands Gill, Grange Road and Blaydon. Healthwatch Gateshead developed a survey which was delivered in person to patients and also electronically, advertising it online, on social media groups, and also in local community locations, through



community leaders, and via the GP Practice. 2,283 individuals responded to the survey, and Healthwatch undertook a review of the data collated, and [made some recommendations in their report on how services could be improved](#). These recommendations were presented to local commissioning managers, and also to the service provider, to help inform where service improvements could be made.

## South Grange Medical Group Practice and Coatham Surgery Cross-site Working Pilot evaluation

SOUTH GRANGE MEDICAL GROUP PRACTICE  
Branch Site: LAGAN SURGERY

### Did you know?

If you are registered at South Grange Medical Group Practice or Coatham Surgery, you can access appointments at both sites?

Since 1 May 2023, South Grange Medical Group Practice have started a 12-month cross-site pilot scheme with Coatham Surgery to help improve the quality of care for all our patients.

This pilot allows us to offer our patients the choice of where they attend their appointment, between both sites and also our branch site at Lagan Surgery, allowing patients access to more clinical staff.



#### Have your say:

- Scan the QR code
- Or visit <https://eu.surveymonkey.com/r/SouthGrangeCSW>



Our survey is open from  
4 December 2023 –  
12 January 2024

#### Drop-in sessions:

South Grange Medical Group  
Practice, Trunk Road, Eston,  
Middlesbrough TS6 9QG  
Monday 4 December  
5:00 - 6:00pm

Coatham Health Village  
Coatham Road,  
Redcar TS10 1SR  
Wednesday 6 December  
12:30 - 1:30pm

South Grange Medical Group Practice and Coatham Surgery, based in Middlesbrough and Redcar and Cleveland, engaged with their patients to evaluate a cross-site working pilot they had undertaken.

The pilot's objectives were to promote efficient delivery of care by offering patients choice in where they accessed their appointment and providing access to a larger clinical team.

Working with the ICB, the practices launched a survey and hosted drop-in sessions to understand if their patients were aware of the pilot, if they had been offered appointments at alternative sites, whether they had accepted them, and their reasoning behind their decisions. Patients were also asked about their future preferences and their thoughts on whether the pilot would improve the care offered within the practices.

Over 880 patients shared their views and feedback will inform direction for the practices in relation to their cross-site working arrangements.

## St George and Riverside GP practice South Tyneside

Engagement with patients registered at St George and Riverside practice in South Tyneside was undertaken May to June 2023. Patients' views were important to understanding what is important to people in respect of location, travelling, and access to services. Engagement activities included a survey and drop-in events. An easy read version of the letter and FAQ document was created, and the ICB worked closely with Healthwatch to support the engagement.

Findings from the surveys and drop-in events, as well as other feedback provided was analysed and incorporated into an engagement report that was considered by the project team. This in turn helped to inform the new contract and supported the commissioning of a new provider.

## GP access, Sunderland - phase two

Following on from involvement work resulting in a [GP Access Report](#) in 2022, further work has been undertaken to explore GP access for groups facing greater health inequalities. The aim was to understand whether a different response is needed to address their needs. The work was jointly commissioned by the ICB and Sunderland City Council and designed collaboratively with Healthwatch. The involvement focussed involvement in areas of Sunderland that fall within the most deprived 20% of areas nationally, as measured by the Index of Multiple Deprivation or "Core20". Groups were mapped across Core20 areas to also get the views of some "PLUS" groups - population groups that tend to face greater health inequalities.

Specifically, we explored where people currently access health care, if and how they use their GP, whether they access preventative or routine appointments, and what makes it difficult for them to attend. There was also a focus on exploring whether more innovative or community-based approaches to delivering services could support better health access.



## Collaborative listening

### Always the Right Door – Children and Young People's Mental Health Summit

The 'Always the Right Door' Children and Young People's Mental Health Summit, held on 25 October 2023, brought together 250 people working in health and care from across the region all committed to bringing about the changes we need to give children and young people the best start in life. Young people, parents and carers who have navigated the complex landscape of accessing mental health services in the North East and North Cumbria shared their stories. This brought to light the challenges they've faced and the importance of finding "the right door" to support those in need.

The 250 attendees came from a wide spectrum of organisations, NHS, local authorities, social care, voluntary, community and social enterprise organisations all with a collective determination to make a difference.

Twenty five "World Café Stations" allowed an exchange of ideas and



best practice and there were some problem-solving activities where people got to vote on our top five 'big ideas' to take forward. What came out strongly was the need for integrated teams and posts across all sectors and that our young people should be involved in the commissioning and designing of services. A [post event report](#) is available on [Boost](#), where updates on progress will be shared.

## **Research Engagement Network (REN) Development programme**

Our REN development programme is a partnership focusing on increasing diversity in children and young people's participation in mental health research. National REN funding went to voluntary sector organisations across the North East and North Cumbria, who have trusted relationships with communities. The funding will be used to explore barriers and enablers to taking part research and to understand how best to engage to encourage future participation. Improving services for children and young people within mental health is a system-wide priority - research will influence decisions and services moving forward, leading to tangible improvements in healthcare outcomes and services.

We are working with representatives from across the voluntary, community and social enterprise (VCSE) sector, academics, researchers and health leaders, as well as children and young people from across the North East and North Cumbria, to help establish a new children and young people's health and wellbeing research network to promote and grow diverse community participation and involvement in research.

In the coming months there will be a shared learning event with our REN Development partners which will also provide an opportunity to shape the network as a legacy of this work.

## **Northern Cancer Alliance oncology service review**

We are supporting public involvement in a review of oncology services across the North East and North Cumbria by the Northern Cancer Alliance. The Alliance includes representation from all trusts. The aim of the review is to develop a sustainable clinical model for oncology services which aims to



address the current issues being experienced within the existing service delivery model: a national shortage of oncology workforce and increasing demands on oncology services.

While this oncology service review has been taking place, and due to a shortage of oncologists within the service provided by Newcastle Hospitals NHS Foundation Trust the rapid implementation of temporary changes was needed within the north of the Integrated Care System region. Whilst most patient care has continued to happen locally within the initial diagnostic pathway, for a relatively small number of patients (estimated to be 114 patients a week out of 630 cancer patient contacts) their first face-to-face outpatient appointment with the consultant oncologist, and for any necessary face-to-face follow up appointments with the consultant oncologist during their chemotherapy treatment, has been taking place at another unit than historically would have been the case. The service is also offering and maximising the use of virtual appointments where this is appropriate.

To understand the impact that these temporary changes have had on patients accessing the oncology service, a four-week piece of engagement was undertaken with patients in July

2023. Patients attending an oncology appointment were given a survey to complete, either on paper or online. This work was followed up with a focus group and phone interviews.

Valuable insight was gained from patients to inform the new model across the North East and North Cumbria including around travel and virtual appointments. We are building on this work with focus groups and interviews with people from ethnically marginalised groups and disabled people.

## **Continuing healthcare and domiciliary care specifications – regional**

Identified as a piece of work across the North East and North Cumbria, there was a desire to review the Continuing Healthcare (CHC) and domiciliary care (both standard and complex) specifications.

This opportunity to listen was to understand what is working well in relation to these services and any aspects of the care and support that could be improved. There was also the opportunity to consider people's perceptions around what 'good quality' and relevant 'outcomes' were in relation to these services.

Involvement activity included the distribution of survey questions through a range of existing points of contact and communication channels. These focussed on electronic points of contact as part of established follow ups/ interactions that already existed with people using these services. A specific set of questions were produced and circulated for staff working in these services to be able to capture some of their perspectives too.

The information was collected throughout December in order to align with the required timelines of the wider project. The information collected across staff, service users and family members was then collated at the start of January 2024 and presented back to the project team leading this work to help inform elements of the future specifications.

## **Rapid response palliative care - County Durham and Darlington**

Commissioners across Durham and Darlington came together to look at their respective rapid response palliative care services. This opportunity to listen to families' views and experiences of these services was undertaken as part of the re-procurement processes.

This provided an opportunity to engage, as sensitively as possible, with the families of people who have used this service to understand what they valued in the current service, as well as where this type of support might be able to improve in the future.

The involvement activity undertaken needed to be completed to align with the timescales of the wider re-procurement exercise. A set of questions were developed together with the relevant commissioning and clinical leads for this piece of work.

Working jointly with the two existing service providers, paper copies of the questions were printed and distributed to the providers directly. During the involvement period, paper copies of the questions, along with freepost return envelopes were left with each of the contacts that the providers had. Providing the family members time and space to complete their feedback anonymously when they were able.



The findings from the involvement recognised the high-quality care and personal support that staff delivering this service provide. There was a high regard for the compassion and caring nature of the staff by the family members too.

The full feedback obtained was provided to commissioners for them to consider as part of future contract specifications as part of the re-procurement exercise. At the time of producing this report, the re-procurement process was still live.

## Secure Data Environment

People tell us they have concerns about their health and care data being used for research. Secure Data Environments (SDEs) are a way to address public concerns about the safe use of patient data. Data linked to each person would be used in a secure server and only for agreed purposes. The ICB has one of eleven SDEs in England, working with healthcare and academic partners.

From the beginning we have put patient and public involvement at the heart of the SDE work. We have developed an involvement and communications strategy which puts listening and learning the centre. To build trust we must be open that previous national programmes have not placed public involvement as being important. We must show that lessons are being learned and actively using this in new public involvement work. We are focusing on listening, checking understanding and showing how insight and feedback is being used to and inform decisions.



### 1. We have built on what we have learned from previous work around data, including from public insight.

We looked at the NHS data opt-out programme we learned that

- the North East is in general more open to data sharing than the rest of the country

- the opt-out rate is higher among women, the most affluent, the most educated, and people aged 30 to 59.

We developed a survey with the public members of the programme. We asked people on street what they thought about sharing health data. We made sure we had good representation of the population across County Durham, Cumbria, Gateshead, Newcastle, Northumberland, Sunderland, and Teesside. 405 people took part.

People have told us:

- they would like to have access to data about them, both to see what is said about them and to add additional information like donor preferences.
- they expected communication and decision-making about data sharing to be accessible to all regardless of class, education and literacy, disability, ethnicity or capacity.
- they want a say in how data is used about them, by whom and for what purposes. Control of information use and access was not only an individual issue, citizens expected to be involved in the oversight and governance of information sharing.

Barriers were identified to the SDE programme:

- Concerns about uses of the data and data privacy protections
- Uncertainty about how the NHS is using the data it collects and how it would be used for secondary purposes, including the processes involved
- Low satisfaction about sharing data organisations outside of the NHS (specifically universities, care agencies, pharmaceutical companies and local councils). Particularly for people who are in the 35-44 year old age group
- Misinformation
- Use of different words and abbreviations (i.e. SDE / TRE / Safe Havens)
- Explaining technical information simply
- Lack of awareness about ethics practices used in academia- data safeguards
- GPs influence.

Public involvement is central in all SDE work, promoting reciprocity, fairness, agency, privacy, transparency and trust. We are involving people from all parts of the population, and focusing on people who have more concerns with sharing their data.

We are using the [five safes framework](#) as the basis for communicating with the public about SDEs. Our public information campaign has two main goals;

- Highlighting the benefits of using data
- Addressing concerns such as data security and confidentiality

## **2. Included members of the public in governance of the programme**

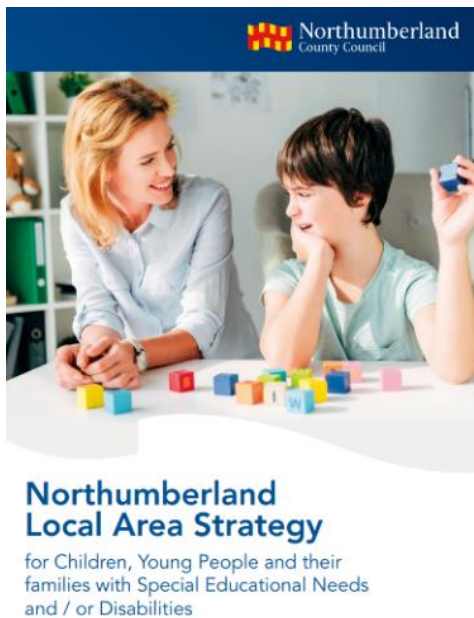
The aim is to provide a broad perspective to the Secure Data Environment's thinking and support the different governance groups on the programme. We recruited 16 people who reflect the population of the North East and North Cumbria. We value the understanding they have of what matters most for people using health and care services. They offer a different point of view from other people on a committee who are usually healthcare professionals such as clinicians, researchers or managers and academics.

Our public members have developed evaluation criteria that will be used to test applications to access data in the SDE in the North East and North Cumbria:

- a. Transparency, accountability, and public involvement
- b. Data management, security, and ethics
- c. Sustainability and strategic alignment with NHS and public health policy

We are now refreshing the public involvement strategy based on what we have learned. Read more about public involvement in the [Secure Data Environment](#) work.

## Co-production with parent carers of children and young people with SEND - Northumberland



A refreshed Northumberland's Special Educational Needs and Disabilities (SEND) strategy is being co-produced with children, young people and their parents and carers with the support of Healthwatch Northumberland. A steering group has been established and is developing surveys and discussion groups. The refreshed strategy will be launched late 2024. The survey will run in May.

## Involving on our strategies

### Integrated Care Strategy

Last year, the NHS, local authorities and the community, voluntary and social enterprise sectors (VCSE) came together to develop the [Better Health and Wellbeing for All](#) plan to improve health and care in the North East and North Cumbria.

There was the opportunity for stakeholders, partners, and members of the public to help shape this strategy through an online survey and by submitting a direct response. The [engagement findings report](#) is available on the ICB website and this feedback was used to help finalise the strategy.

We are continuing to listen about the strategy and will take on board feedback we receive at [Better health and wellbeing for all survey](#).

### Joint Forward Plan

Following the publication of our Integrated Care Strategy, Better Health and Wellbeing for all, we worked closely with our partner organisations to produce our Joint Forward Plan. The Forward Plan is a delivery plan for the parts of our strategy related particularly to NHS delivered or commissioned services, but within the broader partnership context.



In the summer we asked our system partners and communities for their thoughts on the [draft Joint Forward Plan](#), for 2023-2028. We used the feedback people gave us to [finalise the Joint Forward Plan](#), which will be the framework for our work for until 2028, with revisions each March. This is the [easy read version of the Joint Forward Plan](#).

## Involvement strategy

The ICB's first [involvement strategy](#) was developed through co-production with partner organisations and through conversations with stakeholders to understand what has worked well for involvement, what could work better, and how the ICB can deliver excellence through involvement across the North East and North Cumbria.

Our strategy, based on the five themes below, is built upon these conversations and a shared commitment to continue to involve patients, public, carers, and wider stakeholders in shaping, evaluating, and improving the services we commission. This strategy ensures that we have a clear plan to meet legal duties to engage and consult the public and also the pledges set out in the NHS constitution. The strategy was also produced as an [easy read version](#).

We are reviewing the involvement strategy and will engage with people to ensure this is further informed by feedback. This work has started and Healthwatch, on behalf of the ICB, is engaging with people across the North East and North Cumbria, including people who are seldom heard, to understand what people think of the strategy so far and how this can be strengthened.

## Working with our communities

### Working with Healthwatch

The ICB is committed to listening to local communities, and to work with community-based organisations to help support these two-way conversations.



One of the ways we will do this is through close partnership working with Healthwatch, who are a health and social care champion in ensuring people's feedback is used to improve standards of care. Healthwatch plays an important role in representing the views of patients across the region and are present at many forums and groups. Funding has been secured to work alongside Healthwatch across our region, to support the ICB to embed engagement and involvement in everything we do.

We also work with a wide range of other local voluntary community organisations across the region to support these two-way conversations. This helps us to reach and involve our wide and diverse populations in shaping local health services.



## Working with Haref to improve cultural awareness and health messages



Regular updates from local community groups are a key part of how we remain informed about new and emerging community health issues, and we are committed to nurturing closer links with all parts of our communities.

In Newcastle and Gateshead, we work closely with the Haref charity, who facilitate links with ethnically marginalised communities to identify their key issues around health and improve the health information available to them. As well as attending regular meetings with Haref, in February 2024 we worked with Haref and other health and community partners to develop and distribute a [Ramadan Calendar](#). The calendar was distributed via local mosques as well as to local GP practices, and provided health advice on healthy eating and managing health conditions, whilst

observing religious fasting customs during Ramadan. Haref has also provided Cultural Competency training for our NHS staff across both Newcastle and Gateshead.

## Listening forums

### Health and Care Engagement Forum in County Durham

The County Durham [Health and Care Engagement Forum](#) brings together, public representatives, VCS organisations, commissioners and providers. It was established in July 2022.



At the start of this financial year a process of public recruitment was undertaken. There were four public member vacancies, out of a total of 12 positions available. Following an article in the County Durham News publication (distributed to residents across the whole County) 17 applicants came forward for these positions. A series of informal interviews were undertaken with those applicants ahead of appointing public members to the current vacancies.

Members from the engagement forum have contributed to a range of projects that have been undertaken locally. These cross over between both health and care services as well as work within the public health remit locally.

Topics they have contributed to include: urgent community response, children's community nursing, community services, care in later life, sexual health strategy, community engagement review, and the involvement forward plan.

In January 2024, the members of the forum benefitted from the partnership working that is in place with Durham University. Staff from the school of Social Justice and Community Action delivered an introductory workshop about participatory Action research. Members found this

an extremely beneficial opportunity to consider this type of approach further and how it might be able to be applied to future involvement activities.

The engagement forum exists to provide local assurance and guidance to staff in the County Durham Integrated Commissioning team around developing, implementing, and monitoring their involvement activities. The forum is part of the local governance arrangements, sitting underneath the County Durham Care Partnership and connected to the three main workstreams of Starting Well, Living Well and Ageing Well.

### **Epilepsy awareness training- Newcastle and Gateshead**

In November 2023, we facilitated a public epilepsy awareness training session, in partnership with the national charity, Epilepsy Action. Members of the public, as well as representatives from the local voluntary and community sectors, and health and social care staff learnt about different types of seizure and appropriate first aid, including how to help someone having a tonic-clonic seizure. The session also included information on supporting people in the workplace with a predisposition for seizures, as well as how children and young people can be affected by different types of seizure. After the session, working with Epilepsy Action, we provided further [links to support and a toolkit](#) to attendees.



### **County-wide Patient Reference Group - County Durham**

Dedicated public representatives have continued to actively participate in the regular meetings of this group. This group has carried over the connections out to local practice patient groups in the County. Providing a space that brings together patient representatives to look at wider issues across the local population.

During the last year this has included topics such as: drug and alcohol services as well as the family hub development from public health and cholesterol/ lipids with medicines optimisation.

The members have also continued to capture a broad range of patient experiences that the patient representatives have been made aware of. This has included the complaints procedures at County Durham and Darlington NHS Foundation Trust. A direct dialogue with staff from the Trust was able to take place in January 2024. Providing the patient representatives with a direct route to share the experiences they have collected, as well as hearing about the developments the trust has implemented since the end of 2023 in recognition of changes that were needed.



There have also been a series of three focussed workshop sessions during quarter three of 2023/24. These sessions provided dedicated time and space for all involved to consider and review the role and function of the group in the emerging landscape locally and regionally.

A pilot of the agreed new approach will be implemented from April 2024 for 12 months. This will see the group hold eight meetings a year. Half of these will be open, information/experience gathering sessions to look at important and emerging themes from the wider patient groups and networks that members connect to. Efforts are also continuing to establish a routine dialogue with the Public Health Community Champions, Area Action Partnership 'local networks', and even Parish Councils as part of this revised approach too. Helping to expand the range of opportunities to connect and draw upon local experiences.

The other half of their meetings will be dedicated spaces with service providers relevant to the identified themes to be able to respond to the experiences shared directly.

### **Sunderland and South Tyneside Involvement Partnership (SSTIP)**

The Sunderland and South Tyneside Involvement Partnership continue to meet every six weeks to better co-ordinate involvement activity. Existing responsibilities, were to:

- Share examples of best practice.
- Make best use of resources.
- Provide updates on involvement activities.
- Discuss how the SSTIP can support partner involvement activities.
- Reduce health inequalities and ensure inclusion is considered in our work for Sunderland and South Tyneside residents.

Following review of the partnership in 2023/4, the group also agreed that they would have themed meetings to support projects and strengthen assurance. They also agreed they would share the outcome of involvement activity to support more coordinated insights.

### **North Tyneside Patient Forum**

The North Tyneside Patient Forum is made up of residents, GP practice patient participation group (PPG) members, and ICB colleagues. Its aim is to encourage members to be involved in engagement processes and act as a critical friend to the ICB.

Agenda items for the forum are a mixture of North Tyneside Place areas for discussion and member-led issues, ensuring two-way engagement between the ICB and local patients. As well as the forum, there are a series of smaller working groups which enable more in-depth discussion on specific subjects. These include end-of-life, mental health, and communications working groups.

All working groups and related topics were decided by forum members and are compatible with strategic plans and priorities in North Tyneside. In addition, all groups also have a watchful eye on carers, children and young people, mental health, and self-care.

Topics this year have been wide ranging. They've looked at:

- diabetes services on offer
- new pharmacy information campaigns
- research in care homes looking to improve post-pandemic
- changes to the ICB operating model

- primary care access review and recovery plan for North Tyneside, particularly looking at electronic repeat prescriptions, pharmacies undertraining additional roles and employing trainee GPs.
- involvement in research around safe transition from hospitals to care homes.

## Community Forums in North Cumbria

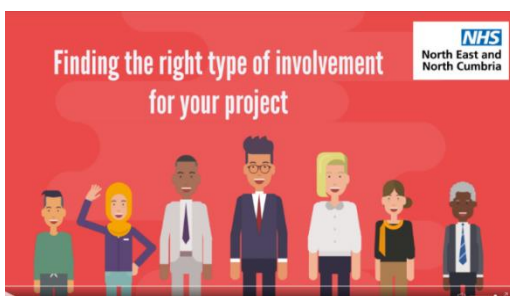


Community Forums, facilitated by Healthwatch across North Cumbria have been well attended, and rotate around West Cumbria, Eden and Carlisle. The ICB North Cumbria involvement lead attends these forums regularly.

## Supporting staff to involve people

### Involvement toolkit

The [ICB has produced an involvement toolkit](#), which is a practical guide to help colleagues in the North East and North Cumbria to involve people in their work. The easy-to-follow guide includes advice, techniques and templates that can be used with a variety of audiences and topics to engage meaningfully and improve the quality of services. The toolkit includes two animations to help increase awareness of involvement to ICB staff:



- [Team introduction](#)
- [Types of involvement](#)

The people and communities we serve should be involved in all parts of the commissioning cycle to ensure we make the right decisions when it comes to the future of the health and care services they use.

The toolkit details engagement, when the ICB is developing relationships and partnerships so that the voice of local people and partners is heard, and consultation, which refers to the statutory duty for NHS organisations to consult with overview and scrutiny committees (OSCs), patients, the public and stakeholders when considering proposals for a substantial variation of how local health services are provided.

ICB staff work alongside members of the involvement team to plan, research, engage, analyse, monitor and report back on involvement projects, with full transparency. On our website you can find details of our past and current engagements to see examples of the work we deliver.

We promote a range of engagement methods when involving local people, including surveys, focus groups, co-production events, public meetings and events, pop up stalls, working with people with lived experience, community outreach and interviews.

# Boost

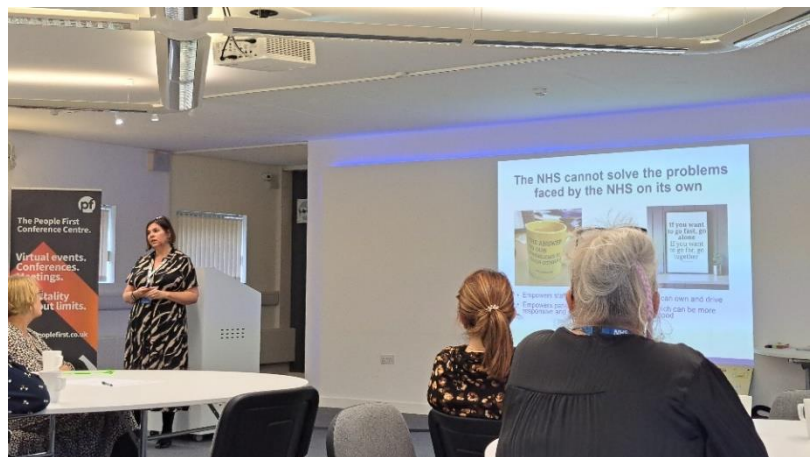


Our aspiration is to 'be the best at getting better' and so it is essential that the North East and North Cumbria is a place where continuous improvement and learning is at the heart of all we do and the way in which we work. We have therefore established a [Learning and Improvement Community Network with a focus on quality improvement: Boost](#).

The involvement toolkit is a mechanism for ensuring staff strive for excellence and can feedback learning through the Learning and Improvement Community Network. This enables our staff to lead, persuade and move forward, with the patient voice at the heart of what we do, so that improvement becomes a value and not just a behaviour.

## Co-production

Co-production is a way of working with people and communities in equal partnership. It is an approach to decision making and service design, rather than a specific method of engagement. It stems from the recognition that if organisations are to deliver successful services, they must understand the needs of their users and work closely with them in the design and delivery of those services. Co-production offers the opportunity for professionals and citizens to work together to ensure that service delivery connects to lived experiences and is therefore meaningful and effective.



The ICB is committed to working with people and communities at the earliest stages of potential change, acknowledging that people with lived experience, carers, and community stakeholders are expertly placed to advise on what support and services will make a positive difference to their lives and what is needed for their communities. We champion this way of working and are leading this way of working as an ICB.

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For example, we have been working with people and communities in Workington, North Cumbria, to encourage an [asset-based approach](#) to building a thriving community. We aim to build an ethos that will encourage health and care professionals to work with communities to

help generate capability and a sense of agency within Workington community and to drive change.

## Co-production training and toolkit

We commissioned independent experts to develop bespoke co-production training for staff and wider partner organisations. The main objective was to develop a co-production training toolkit which is practical, easily understood, and accessible for staff and stakeholders to use. The work had the following key objectives:

- Understand thinking about co-production, any barriers that may exist and how they would like training to be delivered.
- Develop and deliver initial training based on findings, working to overcome any barriers.
- Evaluate this training to understand how it could be improved.
- Develop and evaluate the [final co-production toolkit](#). This is a stand-alone resource for co-production that can be further developed by staff to reflect their learning as co-production becomes embedded in routine practice.

## Co-production survey and conversation

Our Healthwatch partners in North Cumbria led a survey to consider people's experiences of co-production, to help improve working between the system and citizens. The survey highlighted that people would like to get involved in the future development and improvement of services, even though many had not previously been involved. People wanted to know how to get involved and they wanted to know how what they said had made a difference.

We followed the survey up with a conversation with partners to reflect on what is working well with co-production and identify areas for improvement. This included local authorities, NHS, Healthwatch, the voluntary sector, education and local citizens.

From the two pieces of work it was concluded that we could strengthen working together by:

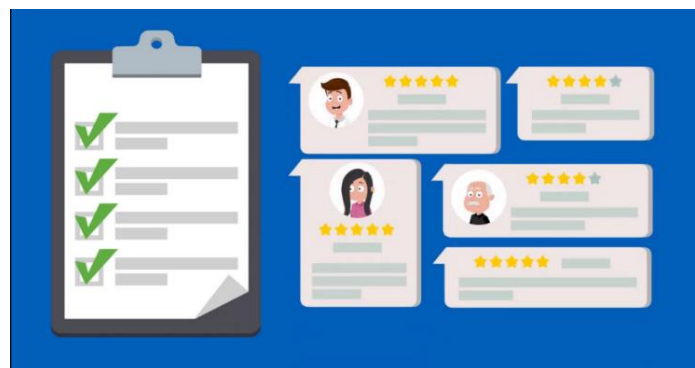
- supporting staff to work more closely with our communities. [Boost](#), our learning and improvement team, is committed to training staff in co-production methods.
- making it clearer how citizens can get involved.

The involvement team is developing how we develop and share ways for people to get involved.

## Real-life storyteller process

Across the ICB, there has remained the desire to hear the lived experiences of patients, families, and staff in relation to the breadth of services we commission.

The involvement team has been implementing an approach that has enabled these experiences to be directly shared with senior leaders across the organisation. During the past year we have been able to highlight specific experiences that relate to topics and issues such as:





- Cancer patient - missed opportunities and breakdowns in communication
- Carers experiences – needing to navigate multiple teams, organisations and support for loved one
- Elderly patient - admitted without family's knowledge during the night.

There is recognition within the involvement team of always wanting to be reach out to our communities and ensure we are listening sufficiently. We continue to collaborate with provider organisations, community partners and many others to be able to ensure voices from across the whole of our geography can be heard.

## **Lived Experience Board**

The ICB's Associate Director of Lived Experience brings a lived experience perspective into the ICB's mental health transformation portfolio and how we can develop an infrastructure to support meaningful co-production that leads to change.

We have been mapping the rich and diverse participation happening across mental health care in our region. This included significant involvement and engagement structures within our two mental health trusts alongside lived experience leadership posts, a growing peer support workforce both inside and outside NHS services, a range of user led and VCSE organisations and networks, a number of recovery colleges and examples of co-production across place-based commissioning. The mapping work identified that there are many ways for patients and families to be heard about their experiences of mental health services and to be part of improvement work but also identified some key recommendations to improve this agenda.

Following the mapping report, the Lived Experience Board for Mental Health was established and is a group of 25 people with lived experience, many of whom work in either the NHS or a VCSE organisation in lived experience roles. The board meets monthly with the aspiration of influencing the mental health transformation portfolio. Each member has links back to broader patient/service user communities whether it is via involvement banks, peer workforces or community lived experience forums. Members of the board are involved with each of the mental health transformation priorities including suicide prevention, inpatient transformation and community transformation. Our aim to ensure that all the significant pieces of work are happening in partnership with people who have lived experience.

In addition, the board is currently co-creating a lived experience strategy to ensure the aspiration for co-production within mental health becomes embedded at system level and this will be an addendum to the ICB's involvement strategy.

Find out more about how we work to involve people on the [ICB website](#).