

NENC ICB Involvement Strategy Review

NENC Healthwatch Network

February 2024

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About North East and North Cumbria (NENC) Healthwatch Network

Healthwatch is the health and social care champion for those who use GPs and hospitals, dentists, pharmacies, care homes or other support services. As an independent statutory body, we have the power to make sure NHS leaders and other decision makers listen to public feedback and improve standards of care.

We use feedback to better understand the challenges facing the NHS and other care providers locally, to make sure people's experiences improve health and care services for everyone.

We are here to listen to the issues that really matter to our local communities and to hear about people's experiences of using health and social care services.

We are entirely independent and impartial, and any information shared with us is confidential.

The North East and North Cumbria (NENC) Healthwatch Network is a collaboration of 13 autonomous Healthwatch who, when circumstances require it, work together to support, and promote the experiences of users of health and care services in the North East and North Cumbria. It comprises the following Healthwatch:

County Durham
Cumberland
Darlington
Gateshead

Hartlepool
Middlesbrough
Newcastle
North Tyneside
Northumberland

Redcar and Cleveland
South Tyneside
Stockton on Tees
Sunderland

Executive Summary

The North East and North Cumbria (NENC) Healthwatch Network wants to thank the NENC Integrated Care Board (ICB) for allowing us to share feedback. We look forward to working together to improve how people can be more involved in making decisions about health and care services in the North East.

Here are the main points from this feedback:

1. **Clear Communication:** Good communication is very important for public involvement. From the beginning to the end, we need to involve the right people and tell them how their input helps shape the changes. Communication should be simple and easy to understand, avoiding complex language.
2. **Turning Plans Into Actions:** People understand that we need plans and priorities, but they want to see these turn into real actions. These actions should come with deadlines and clear responsibility so people can see the changes happening.
3. **Supporting All Groups:** Groups that need special help to share their feedback often feel the ICB doesn't understand their needs well enough. It's important to talk with these groups to understand what support they need and how to involve them properly.
4. **Early and Meaningful Involvement:** People want to be included early in the process so they can really make a difference. They want to do more than just approve the final decisions. They want to see how their input helps make important choices.

We look forward to discussing these findings with the NENC ICB and agreeing how we can work together to achieve a culture of involvement that supports service improvement based on the needs of people who use the services.

Introduction

The North East and North Cumbria Integrated Care Board (ICB) is the largest in England and is responsible for the health services of more than three million people across urban, rural and coastal areas.

The ICB has a duty to listen, involve and engage with local residents and has created a 'Communities and People Involvement and Engagement Framework 2022-23' to realise their ambition to develop a consistent standard across the region.

"Involving and engaging partners, stakeholders and the public in planning, design and delivery of our services is essential if we are to get this right. Wherever, and whenever, possible we will include meaningful involvement as part of our work. We want people to help us design, develop and improve services by sharing their views and experiences. The people we listen to and involve need to reflect the communities we serve." (**Communities and People Involvement and Engagement Framework 2022-23**).

A year after publishing this framework, the ICB would like to understand what people think so far and will use this feedback to further develop their strategy, before engaging with organisations across the region.

The North East and North Cumbria (NENC) Healthwatch Network have been commissioned by the ICB to provide insights from members of the community.

The project scope has been developed in discussion with the ICB and reflects the needs of the Involvement Strategy review, likely interest in the project and capacity for delivery.

Methodology

Project coordination:

The North East and North Cumbria Healthwatch Network Operations Group identified Healthwatch Darlington as the project lead from the Healthwatch Network. Their role was to coordinate the project including providing each Healthwatch with appropriate resources to enable them to participate effectively, oversee timescales and delivery, undertake analysis, and develop the final report.

Delivery of focus groups:

The North East and North Cumbria region is split into four Integrated Care Partnerships (ICP):

1. North Cumbria
2. Central (County Durham, Sunderland and South Tyneside)
3. North (Gateshead, Newcastle, North Tyneside, Northumberland)
4. Tees Valley (Darlington, Hartlepool, Middlesbrough, Redcar and Cleveland and Stockton-on-Tees)

The Healthwatch Network asked local Healthwatch to come forward from each of the 4 Integrated Care Partnership (ICP) areas to attempt to achieve a rural and urban geographical spread. They were asked to speak to community volunteers, staff, and Board Members and/or to deliver a focus group from one of the following seldom heard communities:

- Young people
- Deaf/deafened
- LGBTQ+
- Asian/ethnic minorities

The key tasks were:

- Agree a detailed project plan including associated timescales.
- Understand and evaluate the feedback of local people including those from seldom heard communities.
- Provide feedback and recommendations to the ICB based on intelligence gathered.
- Complete engagement by 22nd January and report to ICB by early February.

Resources:

Each Healthwatch was provided by Healthwatch Darlington with a facilitators guide and presentation to help focus group discussions, as well as handouts, a recording template and equality and monitoring forms to capture the demographics of the individuals taking part in the discussion. No personal information was collected in the completion of these.

Participating Healthwatch:

Healthwatch	Activity	Attendees
Darlington	<ul style="list-style-type: none"> Project lead 	N/A
County Durham	<ul style="list-style-type: none"> Focus Group with Volunteers, staff, and Board 	11
Cumberland	<ul style="list-style-type: none"> Focus Group with Volunteers/Board Members 	7
	<ul style="list-style-type: none"> Focus Group with Seldom Heard Group (Children & Young People). 	11
	<ul style="list-style-type: none"> Focus Group with Seldom Heard Group (Deaf/Deafened Group) 	11
Hartlepool	<ul style="list-style-type: none"> Focus Group with Volunteers/Board Members 	7
	<ul style="list-style-type: none"> Focus Group with Seldom Heard Group (LGBTQ Community) 	26
North Tyneside	<ul style="list-style-type: none"> Focus Group with Staff & Volunteers 	5
Newcastle	<ul style="list-style-type: none"> Focus Group with Seldom Heard Group (Ethnically Marginalised/Asian Community) 	6
Independent Review	<ul style="list-style-type: none"> A local active 'patient voice' advocate from Cumberland spent time gathering people's views on the draft involvement strategy last year. (Appendix 8) 	7
Total participants		91

Governance:

- The Network provided the ICB with regular project updates.
- The Network met regularly to discuss progress, feedback issues and monitor project delivery.
- Internal project governance was accountable to the Healthwatch Network including to the Network's internal programme monitoring group to discuss progress, feedback issues and monitor project delivery.
- Project report to be presented to Executive Forums such as the Integrated Care Board, the Care Quality Commission and Healthwatch England.

Summary of feedback

Full feedback can be found in appendices one to five.

Focus group participants were asked for their feedback on five areas in the ICB Involvement Strategy: general approach, ICB's ambitions and priorities, developing consistency and how they plan to work.

General

Focus groups were posed a series of general questions about what is working well in involvement, what could work better and their concerns, what communities understood by the term 'place' and how they could tell involvement was working across the Integrated Care System (ICS). The ICS is the local partnership that brings health and care organisations together to develop shared plans and joined-up services. They are formed by NHS organisations and upper-tier local councils in the North East and North Cumbria and also include the voluntary sector, social care providers and other partners with a role in improving local health and wellbeing.

The intention to involve communities in strategic planning of NHS services was welcomed by all focus groups. Whilst examples were given where this was **working well**, the general feedback was that community involvement was not yet developed enough to have an impact on service change and make a recognisable difference. Many focus group participants did not feel sufficiently informed about what involvement opportunities exist to give a considered response to this question. Those who were aware felt there were limited opportunities to get involved, and many felt NHS staff were not aware and therefore did not communicate opportunities.

For the system to **work better** they suggested:

- Better promotion of opportunities to get involved.
- Simple and accessible ways to get involved – making it easy to participate.

- More timely involvement to get involved at the outset, rather than approving final decisions.
- Improved reporting of changes made as a result of community involvement, for example, along the lines of 'you said, we did' events.

It was clear that if the impact of involvement is not shown, then the importance of involvement is not understood by communities, and they don't get involved. Communication is key.

Concerns were raised about:

- Lack of promotion and poor visibility of opportunities (for some this exercise was the first opportunity to get involved).
- Appreciation by the ICB of the need to include and make adequate reasonable adjustments for groups such as the Deaf community.
- The size of the ICS area being too large to be truly representative of its residents (for example the needs of those living in urban areas is different to the needs of those in rural areas).

Some of the focus groups participants provided their interpretation of the **term 'place'** but many referred to it as an ICS term, or NHS jargon, which meant nothing to communities and caused confusion and created a barrier.

Focus groups felt **signs involvement is working** would include:

- Robust community feedback, with more communities talking about the ICB and its initiatives.
- Members of the public would know how to get involved and would be doing so, because they would know their input made a difference.
- Easy access to 'you said, we did' type of events so healthcare professionals and members of the public could easily see the impact of their input into service change.
- Having actual examples of involvement rather than asking for approval at the end of service change which looks like the decision was already made, and public input was tokenistic.

Ambitions

The framework outlining the ICB ambition to develop a consistent standard across the region was provided to each focus group (see Appendix two for details). We asked the focus groups if they thought these ambitions were right, what was missing, which are the most important and how the ambitions could be

summarised. We also asked if they have been involved in any ICB sessions over the past year and what feedback they had received on those sessions.

Group participants thought the **ambitions** sounded good but there were too many of them and were not specific enough to measure with outcomes and timeframes. The groups said that words mean little without the accompanying actions, and without evidence of actions, this could be seen as a box ticking exercise rather than promoting meaningful involvement.

The focus groups thought what was **missing** was:

- A short but meaningful action plan showing how these ambitions would be put into action now.
- Success factors indicating when the ambitions have been achieved.
- How the ambitions would be monitored.
- What steps have been taken to date to involve communities and the level of involvement which has taken place.
- Greater emphasis and awareness that different groups have different needs to ensure diverse involvement of those impacted by potential changes.

Across the groups, there was not one ambition that stood out as being more important than others – some individuals had their own personal favourite, and many said they were all equally important.

Advice from focus group participants in terms of **summarising** the ambitions was to use plain English, and the three top areas to maintain were:

- Communication
- Listening
- Experience

Some participants mentioned they have been **involved** in surveys, forums, and participated in PLACE assessments, but the general response was no they were not involved the past year. Sometimes papers were shared but they were too lengthy and did not feel like proper involvement. Likewise, focus group feedback was that forum participation and survey completion did not always feel like meaningful involvement.

This could be linked to only one or two participants receiving **feedback** from local Healthwatch teams, whilst others said they had not received any feedback or results from the ICB for sessions they were involved in.

Priorities

We shared the six priorities identified by the ICB from its original framework with the focus groups (**see Appendix three for full details of those priorities**). We asked participants if they thought the priorities were right, what was missing, if they still made sense, and were still appropriate, if they could be worded differently, and the key words.

When we asked focus group participants if they thought the priorities were **right**, their response was similar to when they considered the ambitions section – they were worthy priorities but too wordy and not realistic. Focus groups members would have liked to have seen some examples of how these priorities have been put into practice over the past year, rather than still being aspirational. There was a concern that having ambitions and priorities was too much duplication – too many words and intentions and not enough action. The need for both priorities and ambitions was not clear.

Participants shared what they felt was **missing** is what this actually means to the public, and how the priorities will be met, with visibility of a plan to achieve them and regular publishing of achievements.

When asked if the priorities still made **sense**, priority number 5* was highlighted more than once as difficult to understand or interpret its meaning. The general feeling was there were too many and they were not robust enough to make sense. Participants said that if they had to read it more than once, that was not a good sign. Plain English interpretation was needed.

**Priority Number 5. While our engagement and involvement will be targeted to meet local (neighbourhood) needs, we will be consistent in how we share and report the feedback through the NHS system both at place and at ICB level, with an ambition to build, enhance, learn, and improve – not reinvent.*

When asked if these were still **the right priorities**, the focus groups told us yes, they were. However, the priorities being **worded differently** would be very much welcomed. Language was thought to be too corporate with buzz words, too wordy and inaccessible. Involving appropriate communities on creating an Easy Read version would be a practical demonstration of commitment to the priorities.

The most popular responses for the **key words** in the priorities were:

- Meaningful involvement.
- Removing barriers.

- Listening to feedback.

Developing consistency

Focus groups were provided with statements from the ICB (see appendix four for full details) about what it would mean for the ICS to be more accessible and inclusive in their approach and make it easier for people to be involved. We asked the focus groups if they thought the statements were right, what was missing, what worked well and what could be better

The focus groups felt the statements provided on what developing consistency would look like covered the **right** areas. They felt that after one year this remained aspirational rather than discussing progress on achievements, and expressed concern around whether there was a full understanding at ICB level of the barriers to implement these intentions.

The focus groups felt that the **missing** areas were timescales, monitoring arrangements to build realistic expectations, an action plan to cover 'how', and accountability for the plan.

The groups felt that the session that created this feedback report was a good example of what was **working well**, but for many it was their first piece of involvement so were unable to provide further examples.

What could **be improved** included clarity of objectives. Ambitions and priorities are well intentioned, but communities need to hear specifics about what changes mean for them and how realistically they can get involved to influence change for the better.

How we plan to work

NENC ICB provided some statements around how they planned to work with local communities. We asked the groups if the list (provided in Appendix five) was right, what was missing, where it was working well and what could be improved.

The majority of focus group participants felt the list was **right**, and also that it was the clearest of all the lists provided in previous sections.

Areas **missing** were similar to previous questions, including timescales, an understanding of how actions and outcomes would be monitored. One of the groups also raised the importance of including staff in feedback exercises as they see hear and feel how the services are working on a day-to-day basis.

The groups generally fed back that examples of adherence to the principles outlined would be needed to provide examples of what was **working well**. One participant did have a specific example of the engagement on the Community Mental Health Transformation in North Tyneside where the NHS committed to involve people before making any decisions or spending any funds as an example of what had worked well and where people were actively involved in every decision made.

Where it could be **working better** is NHS services working better together, action on involvement rather than aspirational words, and honesty in communication of what was working and what was not.

Conclusion

The framework developed by the North East and North Cumbria Integrated Care Board was well received in terms of direction and intent.

Focus groups would have liked to see the ambitions and priorities further developed into actions and outcomes now that we are a year down the line and be assessing these against the framework.

The areas for attention are highlighted in our recommendations.

Recommendations

1. Improved communication of opportunities and outcomes.
2. Action plans published to indicate how the priorities and ambitions are planned to be met.
3. Make sure involvement activities are accessible to all communities.
4. Although the general content of the strategy is well received, it needs to be simplified.
5. Meaningful engagement methods ensuring input from communities does make a difference to health and care service decision making.

Response from North East and North Cumbria Integrated Care Board (NENC ICB)

"We would like to thank the North East and North Cumbria Healthwatch Network for facilitating the focus groups and all the people who took part and shared their insights.

As we refresh the ICB's Involvement Strategy we will keep what you have told us in the forefront of our minds.

Our next step will be to share a draft of our refreshed strategy and include what we hear on this draft in the final version.

Next steps

The insight gained from this engagement will be shared with the North East and North Cumbria Integrated Care Board to support the development of the strategy.

Acknowledgements

The North East and North Cumbria Healthwatch Network thanks all focus group participants who have helped us to gather this valuable feedback.

The information you have provided has been vital in helping us to ensure the voice of service users influence the improved delivery of health and care services and is greatly appreciated.

Appendix one: General questions and feedback

1. What works well about the way local NHS involvement currently works?

"You're asking now and that's a huge improvement".

"There seems to be a will to encourage and engage the public in the planning and strategy of the NHS and there are certainly much greater conversations and incidences of good practice where this is happening. There are requests for feedback in many centres of health and care and this is sometimes followed through with what has been changed".

"The direct face to face contact when Healthwatch Cumberland, with or without volunteers, attend patient support groups etc to gather views from patients and carers with lived experience, face to face contact, people gathering information is good, not keen on surveys and online. Trying to do some good work with people with learning experience but the introduction to this presentation can be mind boggling with all the abbreviations – also not always accessible to people, involvement still seems to be a tick box exercise".

"I know a lot about the NHS as my mam and dad are paramedics, I have to attend a lot of appointments".

"Don't really know a lot about involvement but understand it's a good thing to involve people in how services are ran."

"It is good to have a framework, as this makes sure that there is a focus on involvement, but it is not working effectively just yet. It feels like there is much more to do and more invest needs to be done. The framework highlights the desired direction, but it feels like the journey is still very new. Involvement of patients has not been done well in the past and there needs to be a lot of energy put in to change/shift people's perceptions (to make them feel that it is worthwhile)".

"The group felt that it was not working as well as it needs to be. As they felt that if the deaf community is ever consulted their feedback does not go anywhere. They also had not heard about the Involvement until Healthwatch approached them about providing feedback indicating that it has not reached enough people".

"Excellent to use specialist departments outside of our neighbourhood – but difficult for some people to access. May not be able to finance trip – also adds to anxiety because of travel times if very ill".

"Healthwatch works well – guided by staff on place assessment".

"Healthwatch is well involved but kept at arms – length when assessing e.g. no choice of what's assessed, questions asked, leadership of all NHS".

"If I feel that NHS involvement is being upgraded and people are being made aware of their capacity for involvement now than ever before, improving certainly but still needs more input from all communities!".

"It is improving, but still needs some work, especially the aftercare".

"NHS app, accessible, very friendly, repeat prescription, information, don't have to wait for results".

"An immediate halt to NHS cutbacks, avoiding robbing Peter to pay Paul solution, Tax those who can easily afford it to allow for what is described in this sentence".

"The fact that any of the current systems work at all in the current cash Strapped state".

"It's good that they want opinions of involvement. Puts mind at rest and opens minds. Broadens experiences"

"The one team I have spoken to previously listened well to me and were very empathetic".

"If issues are already made aware treatment/help is available. (Options are available)".

"Service delivery is fair".

"Some individual services do consult with their service users, which is positive as they are engaging with those who have lived experience of the service".

2. What could work better about how involvement currently works?

"First, we've heard of it. If it hadn't been for this exercise, we wouldn't have known involvement opportunities existed".

"Limited opportunity to be involved as CPN visits at home so never get the chance to know what's going on, other than Facebook or the occasional poster in a GP surgery waiting room".

"One stop shop needed as the atmosphere, and therefore opportunities, since Covid have changed".

“Those working for ICB (in this respect, Practice staff) need to be more aware and ‘upsell’ involvement opportunities when people attend for other things. Make service users more aware proactively rather waiting for them to ask reactively”.

“Sometimes major changes, e.g. closure of a surgery, are not communicated well bearing in mind the shift from general attendance at surgeries to more at-home visits”.

“Use pharmacy monitors more, i.e. increase the numbers of pharmacies with screens, insist on better positioning and that pharmacies actually switch them on”.

“Confusing messages and lack of consistency where involvement opportunities do filter through”.

“The capture and use of input from local residents has not changed since before the ICB existed”.

“Better representation from across all sections of communities and across the geographical spread of the county”.

“More timely involvement i.e. right at the outset of a piece of work”.

“Easier opportunities for involvement”.

“More flexible ways to access involvement opportunities”.

“In theory the establishment of patient involvement in General Practice should be viewed as an extremely important aspect of securing the patient view and just as importantly an understanding of the developments and pressures on the service. The development of Integration in the County should be supported and encouraged, i.e. further integration of patient involvement and a consistent approach across Place and patient involvement at PCN”.

“At present I am aware that not all groups representing patients are directly notified of local engagement opportunities with NHS bodies. I and others in the sight loss Third Sector only became aware of two very local events through the Cumberland “jungle drums”, which work quite well but meant attendance will be patchy due to short notice”!

“Are the ICB staff going into big employers to talk to working people? It seems involvement is targeted at the same groups, people still feeling excluded because a lot of things are still online. More public buildings should be used e.g. libraries, hospitals etc. People’s stories should be used as well as data, graphs and charts”.

“Involve more young people, we will be using the NHS for a long time”.

“Include more people and share the feedback. There is a need to inform who you have involved and what they have said – this needs to be shared far and wide, otherwise it

feels like it is not really happening (who are you involving? Who are these people and what are they saying?)”.

“Promote how people can get involved, it feels like it is just a luck of a draw if you get the chance to be involved. Making it feel like a token gesture and not something that the NHS actually values”.

“Involvement could work better if the communication was strengthened. Better listening to the constructive criticism that is being provided but also better feedback given on what has happened with what they are being told”.

“More help to reach locations, especially if having treatment and not well before or after journey”.

“More transparency about place assessment and more involvement”.

“Better transport, getting response from GP surgeries about health, getting appts at GP surgeries – appt process – availability of out of hours. Information from GP practitioner service”.

“GP surgeries talk to hospitals more”.

“If our input as people was actually heeded upon and avoid unfulfilled promises”.

“Lack of communications, response times after showing interest in involvement”

“Communication generally”.

“Communication between GP`s and hospitals could be improvement. Healthcare professionals need to establish clear time lines for things like test results and keep in contact with patients. Make sure certain medical things are easier to understand and work on accessibility”.

“Not sure it does work that well; seems to me information has to be sought”.

“I don't feel involved at all, GPs could actually talk to the hospitals and clinics when dealing with certain tests, results or appts. They don't know how to interact with anxious or Autistic patients”.

“Never know how to find people to talk to or consult with”.

“Initial assessments almost seem to expect the service user to know their problem and with mental health specifically (not exclusively) that isn't always the case. Conversations around home life and such provide more information than a generic questionnaire which people aren't likely to be truthful. Medication shouldn't be a primary treatment to mental health instead it should be more moderated”.

“Improvement on the way appts are taken”.

“Much more advertising and creating awareness about NHS involvement, as people had not heard of NHS Involvement, aside from where individual services send out requests for feedback”

“Greater awareness about how to get involved and the processes of being involved in NHS research”.

“Showing the impact of involvement and why it’s important”.

“Clarity for service providers about when and how they should be involving service users, families, carers, and residents. Some providers appear to do this much better than others”.

“Very hard for the group to think of involvement in the wider system on universal services (GPs etc) and at regional levels as the size is too big”.

3. Are there any concerns about involvement at a regional level (across the North East and North Cumbria).

“There has been only this opportunity to input and even then, there has been no recognition of the amount of work needed to engage with a requested seldom-heard group: deaf and deafened community (i.e. the need for signing and the time the exercise would have taken was neither appreciated nor funded adequately) – a great opportunity for “ask, don’t tell” missed”.

“I am still aware of issues where people’s residency postcodes cross alternative identified boundaries”.

“Having seen how difficult it can be to ensure equitable representation across one large county, the scale of this across the NENC region makes this seem very aspirational at best”.

“There is a need for more inclusivity and involvement as well as increased visibility of the involvement of patients and carers, followed up by published outcomes”.

“This starts with leadership and must be championed at all levels of the organisation and operation of the NHS. The huge challenges within the NHS mean that it has become fragmented with health care professionals working extremely hard under very difficult circumstances to care for people. However, they seem to lack the support that would enable them to take a wider patient perspective. We know that the public do prioritise the continuation of the NHS very highly but there is still widespread dissatisfaction that has accumulated over the past 10 years or so. There is no easy answer but the gap that there is between the NHS and patients seems to be widening with voices of patients not being reflected in the developing operation and management of the NHS. That gap needs to be bridged through moving involvement and engagement much higher in the priorities that are attached to all levels of

operation. It needs to be simplified, creative, concise, meaningful and easy for people to engage. It should move fast, and value increased, shorter involvement”.

“Yes(!) Pre-Covid involvement as a patient rep covering sight loss issues with the regional Eye Health Network (LEHN) meant travelling to the NE for an evening meeting. Since Covid the Group appears to have ceased to exist! An online forum would be good and secure much greater involvement”.

“Not enough local people involved, no communication about any involvement opportunities, don’t feel enough vulnerable people’s voices are heard, too much jargon and abbreviations”.

“Don’t really know the difference, NHS is just hospitals and doctors to us”.

“Our area feels very large, and that does not feel entirely fair. What people experience in Newcastle (North East) compared to Carlisle is drastically different. I know this because I have had family members who get sent to Newcastle for treatment or for a specialised follow up – it can’t be done in Carlisle meaning we have different needs from the NHS currently. We are not at the same point nor receive the same quality of care at our doorstep”.

The barriers and challenges across the region are too different, and therefore involvement needs to cover right across, I don’t think someone in the North East can speak on my behalf, they do not have the same experiences”.

“Cumbria always gets forgotten, it gets left behind – we have got used to this, and often just accept it (probably wrongly). Maybe if we felt that the NHS invested in us, we would invest more as well – we would feedback and fight for the quality we deserve. I suppose being asked this questions show that there is some care being taken”.

“Concerns is that Involvement at a regional level is not making a big enough impact at local level. For example, spoke about accessibility laws and equality laws not actually making a difference”.

“Don’t know enough about what is happening at a regional level to comment”.

“The staff are not listened to on a regular basis, hence strike action”.

“Not sufficiently aware of situation to answer”.

“Just don’t know they exist”.

“In cases where there is just a focus on individual or localised services, this does not enable those who require region wide services, or who use multiple different services, to give their feedback in full. E.g. a survey for a local GP will only give feedback about the GP service and not the person’s entire journey through the healthcare system”.

“Focusing on just one service, rather than the person as a whole and their entire healthcare plan is a weakness. Multiple organisations involved in a person’s healthcare should work together, e.g. different NHS trusts and the local council (social care). Partnership working should seek to understand a person’s entire care needs, not just their use of one particular service”.

“Need to think about scale and proportionality of the issue or service and ensuring this research is set at the appropriate scale, e.g. for a region wide service, research engagement should also be region wide, not just in one local place, involving the people affected or likely to be reflected by the service etc”.

“To some it feels that current sample sizes are too small and that a small number of people are just consulted to ‘tick a box’ and show that consultation has happened. Instead, there should be consultation with a fixed proportion of service users and a number which is large enough to be statistically significant or a more representative sample”.

“Alternatively, research could sample people where difficulties have been identified in order to explore and overcome barriers to a good service.”

4. What does the term 'place' mean to stakeholders (for example, local authority level, or smaller neighbourhoods and communities).

“Nothing until it was explained today”.

“It’s a term that’s used in more than one situation, as is “neighbourhood” so can be misinterpreted”.

“Confusion as other developments title themselves as ‘Place’?!”

“The term ‘place’ means nothing to the vast majority of the public – it is an ICS term understood by people involved in relevant organisations. And, as the term is now to be dropped, the question has become irrelevant.”

“The perception of place usually refers to a local community or social grouping”.

“I don’t think it is well understood by the average patient or the public”.

“‘Place’, for me, means the area in which the medical services relevant to me are provided e.g. firstly, the catchment for “my” GP Surgery and related primary care services and secondly the area covered by my District General Hospital. Local Authorities don’t provide direct health care so don’t seem relevant to me”.

“Where we live and work”.

“Where we live, neighbours and friends”.

“Place’ sounds like a reference to where we live. But the health boundaries are confusing and seem to be over complicated. I cannot always tell the difference and I do not know if I need to know”.

“Terms like these seem to only matter if you are part of the system”

“Felt that the levels should be (smallest to largest)”:

1. GP
2. Hospital
3. North Cumbria
4. North Cumbria and North East.

“Place meant to them ‘where they live’, their town or village. Whatever they would refer to as their area of residence is what they assumed was what ‘place’ was referring to”.

“Place; your own specified area, used more often by patients’ needs to be efficient and available weather working or not, wealthy or not”.

“Hartlepool, the services in different areas of the town”.

“A place where they are expected to deliver their services at any cost”.

“Local authority level”

“For most people this relates to the common sense meaning of the word and their neighbourhood or local authority area, to others, this is just NHS jargon that doesn’t mean anything to local people.”

“Many residents see the NHS as one organisation and think services should be much better connected”

“For lots of people they just want to know that they can access care when they need it and that it will be high quality care”.

“Only some ‘nerdy’ folk are interested in being involved in governance”

5. How would we know involvement was working well across the ICB.

“You’ll only know if you receive robust feedback. We’ll only know if we’re told: at an individual level, we are not involved in Regional changes, unless they hit the news service”.

“More people would be talking about the ICB and its initiatives”.

“People would be more aware of the ICB (changes from the old CCG’s) and be talking more about it. ICB has not become common parlance yet”.

“General public would have some understanding of how they could be involved, and what their involvement could achieve”.

“Public communications about the impact that involvement has had, and publicising future opportunities for involvement”.

“A good range of ways for people to get involved, appealing to different audiences”.

“Evidence of representation from different communities”.

“Regular, published information across existing forums, delivered to ‘Place’ of involvement, including achievements and future opportunities”.

“There would be a seamless service of health and social care provision available to all, with the complexities of the totality of individual service provision being navigated through the differing provision by health and social care professionals. The influence of patient and public involvement would be active and continuing, with patients feeling that they were fully supported and cared about. This would be continually monitored, in a variety of different ways to ensure that at all levels there is continuous dialogue. The encouragement of this collaborative approach would do much to repair the damage to the trust that needs to exist between patients and the NHS”.

“I would say when all the relevant Third Sector groups for a particular health need are engaging and contributing to a particular Project, Consultation in their area of interest. Obviously, involvement of the general public is needed but by definition very few of them will have informed opinions”.

“Only going to know its good if we are aware of what the comments are and if they have been acted upon, “you said we did” have to be fairly systematic to be of any value, very simply any feedback we give we should know what has happened on the back of that”.

“If we could find out what affects us, hard to get GP appointments”.

“Excellent involvement would be that you could stop people on the street, and they could tell you correctly where to find the information about involvement (how to get involved, what is happening and the feedback received)”.

“Could do more social media campaigns, website pages dedicated, radio, tv, go into schools and colleges”.

“Share stats, we spoke to X number of people etc”.

“The group shared that if they heard about changes and impact, then they would know that the involvement was working well across the ICB. This includes social media campaigns, via radio and TV as well as posters and information via local health services”.

“Being given regular updates – via Healthwatch and other emails etc”.

“Very good for Healthwatch – bulletin etc”.

“Communication from Healthwatch is good, public don’t get to know, many don’t know what Healthwatch is or how it works – perhaps a poster regularly in GP surgeries to say how well ICB has worked on particular issues over 3 months”.

"By feedback given to us via Healthwatch and other communities via information being passed on".

"Feedback, updates, people more informed and aware of health services and what is available".

"Less strikes/shorter waiting lists, happier staff/patients".

"Communicate better, inform public".

"We see the change we ask for at ground level"

"If involvement is actually meaningful. In other words, if the involvement actually influences decisions that are made, rather than just involvement for involvement's sake. Not tokenistic".

"Knowing that there is a way to get involved. Or rather different ways for different people to get involved in a way that are appropriate to them".

"That involvement reaches a diverse range of people. As the ICB covers geographically diverse communities e.g. both rural and urban areas. Ensuring each community has chance to be heard".

"If local voices are heard and can be seen to be involved".

"If it was possible to see evidence as to how engagement with people has shaped the decisions being made".

"Properly researched engagements with large statistically significant sample size".

"If there were a range of methods being used, e.g. digital, face to face, consultation with voluntary sector".

"Allocating a level of funding to involvement which shows that it is valued. Rather than just the bare minimum level. Having skilled staff to manage/coordinate involvement across the region with strong local links".

"Consistent involvement at all stages of the decision-making process, rather than just seeking 'approval' by involving people at the final stage when decisions have already largely been made".

Ethnically Marginalised/Asian Community

(Participants needed support filling in equalities forms here. Most conflated the terms NHS/ICB together).

"NHS voluntary sector: declined application for me to volunteer; I just wanted to learn the system here. There are a lot of issues and barriers e.g. needing specific paperwork you can be here [in the country] before you are given a chance."

"Equality: don't feel like it's there."

"Job opportunities: NHS makes it difficult to accept people."

"I feel as if the NHS needs to welcome people more [like The Comfrey Project]."

"I am not sure where to go to get the response I need."

"NHS service is excellent [in comparison to where I am from], e.g. surgery."

"We hope the NHS can provide and deliver talks/outreach events/work colleagues can let people know more."

Appendix two: Ambition questions and feedback

This framework outlines our ambition to develop a consistent standard across the region for our Integrated Care Board (ICB). We will do this by...

Our ambition

1. Building on what we do well and valuing local relationships
2. Going to where people are – and knowing we have to try harder to reach some people we don't hear from well enough
3. Supporting people to be meaningfully involved
4. Being open about the challenges and opportunities we face – being transparent with the people who run and use our services
5. Ensuring the recent, relevant lived experience of people using our services (and their families and carers) can help to inform service change and improvement
6. When people give up their time to share their input, we should provide timely feedback about the impact it has had – you said, we did (or weren't able to do because...)
7. Use a range of engagement approaches
8. Ensure involvement is part of all business case development and implementation
9. Take opportunities to innovate – including exploring the creation of a NENC Citizens' Panel
10. Make information and opportunities to engage accessible to everyone in our community

Ambition Questions

1. Are these ambitions, right?

"Yes, the ambitions sound really good but there are too many and not they're not

SMART. It's more of a manifesto, a 'gold standard' and, as such, needs to be broken down and picked off one by one. It needs measurable objectives with timeframes".

"Based on the above, there is scant evidence, so far, of any requirement for MEANINGFUL involvement. It's in danger of being regarded as a bit of a 'box ticking exercise', which is a shame as the ambitions are laudable".

"Seems to be an impact assessment from the public on the strategy".

"It's top down led rather than being co-produced".

"Absolutely! But they must be translated into action, and I think that often we are not creative enough about how this can be done. It is not seen as being a real driver for change and improvement. The current fashion for accountability (blame!) does not encourage an environment of collaboration where there can be a positive working together to make real improvements, both small and large".

"Ambitions do seem to be right but there needs to be a life cycle built in, from being born to the end, build engagement that way".

"Keep it really simple, list of ambitions is too long and complicated".

"Too many big words we don't understand, they sound good enough".

"They are broad, but they are probably the right ambitions in relation to involvement. Need to involve people (especially those who don't get heard often), need to maintain and value these relationships, timely feedback is very important".

"Transparency is very key; it isn't something that is often shouted about but honesty especially around the difficulties can help build relationships".

"They are probably right, but the group felt that there are too many. They questioned about how people would know when these ambitions have been achieved".

"Yes, to variety of engagement processes including social media".

"Ambitions are right and ongoing".

"They are right to a point, but more detail needs to be given with regards to the groups that will be focused on".

"Yes, ambitions look good".

"Yes, they seem to be about building on what works and engaging with various diversities".

"Yes, making sure to involve different communities".

"Yes, but it means nothing if we don't see it in action. Also, the first point – it's great to build on success but more important to recognise and fix failures".

"Yes, I agree".

"Yes, they are as ambitions however they feel "woolly". There is no sense as to how these will actually be achieved. There needs to be a "roadmap" and "tools" added to these so there is a way they will be achieved. SMART. 'You can't really disagree with them'. 'Motherhood and apple pie'"

2. Have we missed anything?

"A way of checking ambitions are being met. Being clear about what CANNOT be met and why".

"A Focus on transparency, what steps have been taken to involve people, and what level of involvement has taken place".

"The structure/organisation of how the achievement of one ambition will lead on to the next".

"Although the ICB has been established for over twelve months there is little published information regarding the involvement, experience and value of existing, or the future intended, involvement of people".

"Visibility and demonstration of the meaningful contributions that have been taken into account".

"I am sure that there are plans to support these ambitions. Is there real commitment at the right levels? Are there the skills available and the partner organisations on board to translate the ambitions and plans. I think the challenge is huge but not unachievable!".

"Too many ambitions".

"Don't know"

"Maybe the timeframe? Like say you are going to include people from the beginning and continue these relationships throughout".

"Which groups are you wanting to talk to? How many?"

"Something about effective listening/communication?"

"The group felt that there was nothing missing. Questioned about timeframe and what order things would be implemented".

"No".

"To specifically engage with teenagers/young people".

"Information in different format and languages is not always available, not enough on Health inequalities and addressing causes of inequality".

"Probably, but nothing drastic comes to mind".

"Making sure all staff know how to engage with people who need help".

"Knowing that different people need different help when communicating needs or concerns".

"Diversity across the board – inclusion".

"Supporting people's involvement".

"I think all is said and done".

"Using accessible language which can easily be understood by everyone".

"The ways and methods to get people involved. How this will happen. One suggestion is to use time people are in waiting rooms waiting for appointments or in 'discharge hubs' to involve people then, when they have the free time available".

"Include people who don't access services too. Particularly people who would be potential service users, find out why they are not using the service".

"A range of effective engagement approaches".

"Effective thoroughly considered research methodology to be set out. With a research question trying to be answered. Who do we need to ask about this? What are the most effective methods to engage with the people we need to talk too?" "Appropriate scale and scope".

"Hearing from service users, families, carers and potential service users"

3. Which of these ambitions do you think are most important?

"Being "Accessible" is a fundamental requirement".

"That the strategy is 'open to challenge'".

"Valuing local relationships/ recent, relevant lived experience of people using our services (and their families and carers) can help to inform service change".

"They need to be implemented as a whole to be effective".

"They are all of equal importance".

"It is difficult to prioritise, they are all important because they are all part of a bigger picture, but: - "Ensure involvement is part of all business case development and operation" is the one that is the closest. I think it needs to contain some reference about being led from the top of each level of organisation and operation to ensure that it becomes embedded and is working throughout".

"Take opportunities to innovate – including exploring the creation of a citizens panel".

"We will make it easier for all people to get involved, remove barriers from preventing people to get involved and meet people where they are".

"Get out and talk to people in plain language so we can understand".

"The ones relating to transparency, feedback and valuing relationships".

"Ensuring the recent, relevant lived experience of people using our services can help to inform service change and improvement."

"Take opportunities to innovate – including exploring the creation of a NENC Citizens panel".

"The group expressed a desire to be involved or at least to have voices from the deaf community involved in the discussions".

"Constant communication".

"Info and opportunities to engage accessible".

"All ambitions are important".

"All ambitions are important. If you take one out the rest will fail to work as well".

"Going where people live, trying harder to hear more from seldom heard groups, timely feedback – you said – we did"

"Supporting people, making hard to reach communities are being heard. Timely feedback"

"Being open and honest about why things can or can't be done".

"Lived experience".

"Ensuring lived experience informs the service".

"When people give their time to give their input and feedback".

4. If we needed to summarise an ambition into a sentence or short paragraph, which words, concepts, or phrases do you think we should include?

"Word – "Listening", e.g. ICB are here to listen to everyone (and mean it)".

"Concept – actual, effective, communication"

"Concept – simplify communication (take some words out, use plain English) use mental pictures".

"Concept – multi-channel opportunities to inform and receive input"

"Concept – positive communication with a positive, conclusive output".

"Not sure I understand this question".

"For example, I might precis "Ensuring the recent, relevant lived experience of people using our services (and their families and carers) can help to inform service change and improvement" to "making sure people who have recently experienced services can inform and improve them".

"They should already be summarised".

"Speak to more young people".

"Effective communication".

"Valuing relationships".

"Honesty"

"Very important to acknowledge good practice as the NHS employees need to know we are aware often things go well".

"Listening Eye".

"Giving a voice to users of the NHS"

"Open, transparent, honest"

"Listening is fine, but action need to be taken with regards to what people's opinions are (deeds not words)"

"Openness, willingness, transparency"

"Inclusion/diversity/commitment"

"The word "meaningful" was discussed as being important. To make sure there is a purpose for involvement and that it makes a difference".

5. Have you engaged in any involvement over the last year?

Statement: question answered in respect of involvement with ICB strategy:

"No".

(A staff member commented....) "Received snippets of information via the Board but no involvement".

"Sight of particular documents but have not had time or too lengthy, to read and so have not been involved".

"As a member of the public, rather than as staff, I have taken part in various consultations and completed surveys".

"Participated in forum – but not necessarily encouraged that my contributions have been valued. There has been no opportunity to contribute to service developments".

"Yes".

"Yes, but felt it wasn't really meaningful, too many surveys and not enough info back".

"No".

"None of the individuals have been approached before the discussion to give their feedback or knew how to get involved".

"Everyone expressed that they would like to be more involved, but they would be worried about it being time consuming or made difficult to do so. If there was flexibility, then that would work for them".

"None of the members have been involved in the last year, but some members have been involved in the past in regard to NHS consultations".

"World Mental Health Day, College of Further Education event in Hartlepool – NEAS, Pharmacy".

"Yes – place assessment of 4 wards at North Tees Hospital, Access to Primary Care event hosted by Healthwatch Hartlepool at Hartlepool College of Further Education".

"Waiting Well, Integrated Care Strategy, all that Healthwatch Hartlepool has been involved in – this is ongoing".

"Yes – place visits, various events and activities"

"I've had a few appointments with various medical professionals. Steps should be taken to recognise foreign medical qualifications in this country, possibly though a system of refresher courses, theoretical/practical exams".

"We have been approached by patient involvement team and invited to meetings".

"Only on personal matters at GP"

"Sort of! Here at Hart Gables another organisation came to listen".

"Friends & family test".

"One participant had engaged in a questionnaire sent by the CNTW NHS Trust Adult Autism Diagnosis Service, as a service user with lived experience of the service. This questionnaire was mainly focused on the appointments themselves rather than other aspects such as waiting time and support on discharge, so seemed fairly narrow in focus".

6. If you have been involved, how did you receive feedback/results?

Statement: question answered in respect of involvement with ICB strategy:

"Board recently involved in HW network feedback but nothing springs to mind. However, papers have been received but feedback was not accepted".

"Via my Line Manager and involved Board member".

"I don't recall receiving any feedback or results".

"No didn't receive any feedback".

"N/A".

"Not applicable as they have not been involved".

"But hypothetically they would like to receive feedback direct and preferably digitally – for example via an email".

N/A

"Feedback received via Healthwatch meetings – information disseminated through the Healthwatch website and news bulletin".

"Haven't as yet from place visit which took place in October 2023".

"I didn't"

"For the Adult Autism Service survey mentioned above, there was no feedback or results shared once completing the questionnaire".

Ethnic Minorities

"Not happy-not very good. E.g. NHS attempting to contact local community".

"Try to encourage NHS about their services – there are many barriers in the communities; the local authorities need to sort this out."

"[It is] OK – different mindsets of people, depending on respective countries." (In reference to bullet point no. 3 in list of ambitions). (3. Supporting people to be meaningfully involved)

"We have not tried to get information from NHS – there is a language barrier, refugees listen to and support each other, rather than going to the NHS." (in reference to bullet point no.4 in list of ambitions). (4. Being open about the challenges and opportunities we face – being transparent with the people who run and use our services)

"[Bullet point] no.10 is most important." (10. Make information and opportunities to engage accessible to everyone in our community)

***Addition information:**

"Bad experience with GP: my daughter had a chest infection, but interpreters told me this was a lung infection. Interpreters are not always perfect. Some won't use interpreters and appointments can be delayed."

"Today it is impossible – method of communication/translation."

"Doctor may give 3 options, but if person doesn't understand I just agree; less hassle/let's just move on."

"Mental health problems not easy to solve. Body can be checked, but mental health cannot [physically]."

"Translating services should be provided in different languages, even by zoom."

Appendix three: Priorities questions and feedback

When we developed our original framework, we asked people to help us shape our priorities. Through listening, we identified the below six priorities. We have highlighted what we feel are key words in these priorities.

Our Priorities

1. Listening and involving the communities that we serve through open conversations, to truly make a difference together with the aim of reducing inequalities, will be at the heart of our integrated care system.
2. We value trusted, transparent and ongoing relationships with the communities we serve at all levels of our Integrated Care Board (ICB) – neighbourhood, place and ICB – to improve and shape our services for better outcomes for all.
3. We will make it easier for all people to get involved, remove barriers from preventing people getting involved and meet people where they are.
4. We aspire to better demonstrate how this feedback and involvement has influenced the way services are planned and delivered.
5. While our engagement and involvement will be targeted to meet local (neighbourhood) needs, we will be consistent in how we share and report the feedback through the NHS system both at place and at ICB level, with an ambition to build, enhance, learn, and improve – not reinvent.
6. We have heard from our communities and partners they want to have the opportunity for meaningful involvement in service improvement and change. We will build the need to evidence the involvement of people in any service change.

Our Priority Questions

1. Do you think we got these priorities right?

“Yes”.

“Worthy priorities but not realistic at this juncture: we need to make meaningful changes at a lower level first and build confidence.”

“There’s no way to tell as it’s too wordy and actual intentions are not clear. However, what WAS clear was that phrases like “aspire to” don’t provide clarity of intention or confidence in ability. Either just commit to doing it or don’t mention it”.

"Who was it that was consulted in setting the priorities and were they asked what was needed or told what had been decided? (We think Health and Wellbeing Board plus agencies were involved; were any PRP's or PPG's?)".

"They are laudable but one year in there is little support to suggest achievement of the ambitions".

"Yes broadly, there has been consultation and a good deal of listening! But I am not convinced by the relevance of no.5". (5. While our engagement and involvement will be targeted to meet local (neighbourhood) needs, we will be consistent in how we share and report the feedback through the NHS system both at place and at ICB level, with an ambition to build, enhance, learn, and improve - not reinvent).

"Priorities seem to be the same as the ambitions, is it necessary to have so many, it just over complicates having so many, too much for people to consider. Ambitions should not be tokenistic; this list feels like it's been put together as a wish list rather than something to be actively working towards".

"Framework is comprehensive and promises a lot".

"Too many big words we don't really understand".

"They feel very wordy but overall, yes, they are right".

"The group did not understand what some of the priorities were specifically meaning. But they did agree that involving communities should be a priority and that there should not be barriers in doing this. All communities should be able to get involved if they wanted to be".

"Yes".

"Difficult to tell – probably fine but could be better worded, meaning is lost in some cases".

"Priorities appear to be right at this stage".

"Yes, but shorter and punchier".

"Sounds like a tick box exercise on a list of buzz words".

"In a similar way to ambitions, there are no issues with the priorities themselves but there needs to be a much clearer roadmap as to how they will be achieved.

They are too focused on the NHS, what about integration and taking a holistic approach to people's experience and their care? Need to consider social care, inequalities, and public health".

2. Do you think there is anything missing?

"Yes, the means to make these priorities realisable: getting out there and meeting people".

"Will there be a scrutiny panel?"

"Some form of co-production with those affected".

"Is there a continuity plan in case the structure of "ICB/Place/ Neighbourhood" changes in the future?"

"How will these priorities be met, though? They appear to be aspirational, with no detail about the actual plans, even in broad-brush terms, for achieving them".

"A review mechanism for understanding whether the priorities selected were delivered. ICB need to publish the process for people responding to Strategy releases that they don't understand or where understood plans are achieved".

"The plan and its visibility".

"What happened to 'no decision about me without me' – can that be demonstrated and independently evaluated in contracting?"

"Yes, the commitment to involvement and engagement being led from the top, with authenticity and passion".

"Ambitions and priorities seem to repeat each other".

"Don't know".

"Nothing really came to mind to the individuals, though timescales were once again mentioned and questioned."

"There was a discussion about the need to change the current narrative and maybe that should be a priority? Establish that feedback is worth giving and that the NHS are listening".

"The group felt that it was hard to comment as they were not sure if they fully understand the priorities, but they felt that involving communities and reducing barriers are necessary and must have inclusions".

"Priority is to make people feel they have a voice in shaping the direction of the NHS".

"No".

"Listening is all well and good but actually hearing people and making changes is more important".

"Action".

"Concerns that individual services / NHS Trusts only look out for themselves. There needs to be a more holistic approach where a person's entire healthcare needs are

considered together, considering the person and their health as a whole, not as split between services. This will involve partnership working with multiple different NHS organisations, local council services (such as social care) and possibly private care providers. People should be questioned on their full relationship with healthcare services, not just use of one specific service”.

3. Do they still make sense?

“They make sense but feel like ‘pipe dreams”.

“I appreciate the ‘meeting people where they are’-this is important. ‘Barriers’ are difficult now, especially because of cost-of-living pressures, and public travel is both expensive and unreliable”.

“They would if there were Place and neighbourhood co developed plans to support their delivery”.

“Yes, apart from no 5”. (5. While our engagement and involvement will be targeted to meet local (neighbourhood) needs, we will be consistent in how we share and report the feedback through the NHS system both at place and at ICB level, with an ambition to build, enhance, learn, and improve - not reinvent.)

“Too many on the list and not robust enough”.

“Don’t really make sense and there is too much information for us to understand, too many questions”.

“They felt wordy and that meant that for some individuals they had to read it a couple of times before they felt that they understood what they meant. There was a discussion about making them clearer and then they would appear to make more sense on a fundamental level but on a contextual level they do make sense in relation to the ambitions previously discussed”.

“Not fully”.

“Very long winded”.

“Needs better English”.

“Yes, but needs re- wording, simple and easier to understand – plain English”.

“No – it should be easy to understand and in the universal priorities for all the community, compassion, empathy, inclusion, a complete lack of judgement, accepting each other’s realities”.

“Yes, however there are some uncertainties, e.g. who does the ICB have ‘trusted transparent’ relationships with in the local area. It is unclear who the people / organisations involved in these relationships”.

4. Do you think these are still priorities for us?

"Yes"

"There is no harm in having them, but they are end goals with no apparent means of getting there".

"I think they SHOULD still be priorities; whether they are or not is difficult to assess, as there appears to be limited evidence to support them".

"Without doubt, and there ought to be discernible evidence to put to Neighbourhoods of what has been achieved."

"Absolutely why would you doubt this"?

"Depends on how well you have delivered the priorities in the last year".

"Yes, we think so".

"Yes, they felt that they have not been fully achieved and therefore they should keep pushing for success in these areas. They should be a priority constantly, even if success is achieved as then they should be maintaining this".

"They feel that the priorities are most likely still priorities, as they have not heard about what has changed or improved".

"Yes. Punchier e.g. Consistency in how engagement and involvement is targeted to meet local needs and how feedback is improved".

"Yes, with the recognition that it is the delivering on these that is important. Not simply having them as priorities on a page but actually making them happen. Recognition that if these priorities do happen, this will be a positive".

5. Can they be worded differently?

"Definitely".

"Yes, the language is too high level; it needs to be brought down to 'easy speak' – what about the Plain English Campaign"!

"Also, and maybe a bit more to the point, reduce the word count for clarity, to encourage people to stay engaged".

"More clear, plain language could be used".

"They could certainly be less wordy, so probably more accessible".

"Some of these priorities are almost "mealy mouthed", not robust enough, very public sector language".

"Shorter sentences without big words"

"Yes, shorter, more direct and simpler".

"NHS is known for jargon and using terms that over complicate the basics".

"Makes it feel like there is something to hide or allows for room to not do it as it is not clear".

"Should be very basic language that everyone can understand".

"Simplicity removes the issues of ambiguity".

"The group felt that there could be less jargon and that they could be worded to be more direct. Use shorter simpler sentences as this will cause less confusion".

"It was pointed out that they should be written in a way that the majority of the population should be able to understand what they mean".

"Needs to be more compacted".

"Listening, involvement, ongoing".

"Affirmative texts for people with learning difficulties, simple short and sweet"

"Talk in smaller words, people shouldn't need a medical degree to understand what you are talking about".

"Yes, language that suggests we will try to achieve the priorities should be replaced with language that suggests they will happen. E.g. not using the word 'aspire', instead saying 'this will be achieved'. Certain language in the priorities needs to be made more direct. E.g. 'Aspire' to achieve suggests 'try to achieve'. The priorities should be more firm e.g. 'we will achieve' as opposed to try / aspire to achieve. There was concern that the way the priorities were phrased lets people off doing anything. Write them in a way which makes people accountable".

6. What are the key words which stand out for each priority for you?

"Listening and involving".

"Ongoing".

"Remove barriers (make reasonable adjustments to allow)".

"Feedback"

"Remove – "not reinvent"; finish at ...'improve'".

"Demonstrate transparency – and be open about how that feedback has been used".

"Listening and involving/ at the heart of/ improve and shape/ where they are/ demonstrate how/ not reinvent (why not re-invent?)".

"Meaningful involvement, listening and involving, consistent, remove barriers".

"Meaningful improvement in service; Learn and Improvement; Removing barriers to get involved; Making it easier to get involved (is that demonstrable one year in?); Listening and Involvement."

"Listening, involving".

"Trusted relationships".

"Removing Barriers".

"Demonstrate influence (and remove aspire, this is not an aspiration. It must be done!)"

"I am not convinced by this priority".

"I think this is not necessary as it is covered elsewhere".

"Remove barriers, meaningful involvement in service improvement".

"Listening and involving, trusted, remove barriers, influenced, targeted".

"Transparent and Trust".

"Feedback".

"Consistent".

"Meaningful involvement".

"Listening".

"Remove barriers".

"Involvement".

"Reduce inequalities, listening, remove barriers, targeted to meet local neighbourhood needs". "meaningful involvement, ambition to build, enhance and improve and then share this information across the 14 places".

"Yes".

"Listening – involvement – improve and shape our services".

"Meaningful involvement, targeted needs – locally, transparent and ongoing relationships, evidence involvement of people".

"Listening, truthful, transparent involving".

"meaningful" "there does not seem to be enough about how you will listen and involve. Number 2 is not a priority, it's a statement".

"Listening, remove barriers, feedback, local, evidence".

“As above, ‘meaningful’ was mentioned, along with having ‘influence’ and ensuring that involvement includes proper research methods”.

Ethnic Minorities

(Issues with participants understanding nature of focus group; misunderstood aim, discussing personal NHS experiences instead).

“Being provided paracetamol is a ‘normal answer’ in the UK.” (Respondent gave comparison of how medication is prescribed in their respective country, i.e. provided with a Medi-pack/assortment of medication).

“Agrees with GPs in UK to allow body to sort issue out on its own.”

“Feel there are differences between British community and refugees. Feel disparity – British people looked at more carefully to see what is wrong.”

“Different in Turkey to England.”

“Would prefer to go and see a doctor out of area if they are able to speak the same language as me. This should be allowed”.

“ICB team need to collaborate more; more work needed.”

“Didn’t know about ICB partnership [before this focus group].”

“Working as a teacher back in my country we used to watch behaviour and character of children by resolving issues with a game of football. NHS [ICB] should develop activities like that to understand needs of community.”

***One respondent’s story of being a new father to highlight if priorities are correct**

“Baby crying all night; not taking milk; feeling distressed. I have Universal Credit problems; GP can be alright – needed medication for migraine, but why do I have to contact every month for this, why can I not have automatically on repeat. Sometimes waiting 2 weeks for authorisation of medication.”

“Communication is very hard; being asked problems over again, takes one month for action. In end, I go walk-in centre.”

“No, not listened to [priorities not met].”

Appendix four: Developing consistency questions and feedback

Whilst there is excellent work across the region at a local level, we must establish a mechanism to ensure the ICB can both:

- hear the voice of our communities when setting priorities and making decisions
- ensure our communities know about the issues facing the NHS and partners.

We will continue to listen to the voice, views, ideas and lived experiences of our communities at a local level by developing a culture of continual involvement and engagement embedded in our commissioning and service improvement processes. We have heard that NHS organisations should do more to be accessible and inclusive in our approaches and we will work harder to make it easier for people to be involved. We have heard this should mean:

How we will develop consistency

1. Spend time nurturing relationships with people at a local level – including groups and forums.
2. Build understanding and commitment from leaders to embed a culture of involvement as a key priority at every level.
3. Work across the whole of the health and social care sector, including voluntary, community, third sector groups, local authorities and Healthwatch.
4. Establish a formal mechanism for sharing that feedback and intelligence between placed-based partnerships and the ICB. This should be embedded in our governance and reporting structures to provide assurance.
5. Improve feedback to patients and the public – closing the loop to show ‘you said, we heard, and we did’.
6. Creatively highlight the impact of lived experience.
7. We will ensure more diverse views are shared into the ICB decision making and assurance.

8. Explore the development of an inclusive, accessible, regional Citizen's Panel/Assembly.

Developing Consistency Questions

1. Do you think this list is right?

"Yes".

"Can't argue with it, definitely would be a huge improvement".

"Ensure our communities know about the issues facing the NHS and partners" is one of the most important aspects to me, if people have an understanding of any constraints and where they come from they will be more willing to be involved with what CAN be achieved".

"Yes. However, one year in there should be demonstrable evidence of those ambitions being achieved".

"It is very aspirational. Is there a real understanding of how this will be achieved? It seems to imply that having these priorities will in some way mean that there will be a difference in organisational behaviour. My experience tells me otherwise! This needs much more focus on raising engagement and involvement throughout the organisation and creating an enthusiasm that may only be with some individuals. They need supporting and encouraging through training, discussion and experimenting alongside strong organisational expectations".

"What has happened in the last year with progress on the list"?

"It is simpler than the other lists".

"It is right but is it achievable. Will it not be dropped when things get busy? How do you ensure involvement always is and remains a priority".

"Having the people who actually have the power to make decisions listen directly to the people is so necessary, nothing is more powerful than having those share their stories and experiences – but they won't make the time to go along (not everyone but should go to some)".

"The group felt that the list is probably right. Though felt that it could be said simpler or more straightforward".

Yes, but needs to be applied at all times but not selectively".

"Yes, and it is positive that this does have more suggestion as to how these will be achieved".

2. Have we missed anything?

"Negotiate rather than consult. Ask and respond rather than say, "we've worked it out and this is the answer, what do you think?"

"Published timescales and how changes are to be monitored to enable building realistic expectations".

"Still no "how".

"Tell us who's going to be on the Citizens' Panel, e.g. professionals, VCS, volunteers etc".

"A transparent approach to rectifying issues when things go wrong. The plan and progress towards achievements and impact at local level with a levelling up of services".

"Of course, it would be naïve to expect otherwise but the process of engaging in this will help to identify and shape the way that this is achieved."

"No".

"Nurturing relationships with people, creatively highlight the impact of lived experience, doctors don't speak directly to us they only talk to our parents".

"Consistency across geographical areas? Not just different levels of the system".

"Timescales?"

"The group could not think of anything else that should be added".

"Lived experience is very important in shaping strategies".

"Inclusivity, - Learning disabilities, Autism, simple plain language, translation accessible, information, lots of important info, not accessible and readily available to all communities".

"Leaders should be held accountable with regards to following the needs of the staff/patients".

3. Is there anything you think we do well?

"You've asked, and provided the opportunity, for honest feedback here today".

"No".

"Don't know enough to answer this question".

"Hard to judge as this is first experience of providing feedback or being included".

"Having an independent party support in giving feedback is good, there should be a mix of NHS direct and independent party support. Feels safer and less likely to get backlash as it is anonymous."

"Felt that there was a lot of room for improvement. Felt that this consultation was something, but it was questioned 'what next?' and felt that it was a 'tick box' exercise".

"Excellent communications, engaging with the public, sharing information on Facebook and media".

"Getting better, more updates and info made available, but often website based, more info should be going out through press and other media sources.

"I feel though they are always helpful, there for me" "I've always felt involved in my care, my opinion, thoughts matter".

"Emergency medical attention when it's needed, notwithstanding unacceptable delays in those referred from A &E needing a bed, meaning delays in paramedics returning to answer 999 calls. Beds being occupied by patients fit enough to be discharged but their personal circumstances won't allow it. These two aspects require liaising between various government departments".

"Partnership working – The way the NHS works with key partners, including Healthwatch and the wider voluntary sector."

"In specific cases where the NHS has committed to not make any decisions, or spend any funding, until involvement has occurred, this works best and ensures involvement influences decisions. Rather than decisions being made and involvement just to seek approval"

4. Is there anything you think we could do better?

"Wordsmithing"!

"Layered explanation of how, e.g.

- *Top level: where we are to where we want to be, and when;*
- *Next level: dated milestones to get there.*
- *Next level: individual steps to achieve milestones etc".*

"This audience is educated, engaged and informed and we're struggling"!

"Further down the line, "show" rather than "tell" us the changes you've made in response to this feedback".

"Take responsibility and apologise when things aren't good enough".

"See above: where are the improvements across all of the initiatives commenced, and how have they been published in Place for reassurance that the service is consistent, and that there has been both inclusion and enhanced service development".

"I am not so closely involved to be able to comment on either of these questions".

"Telling people how we have used what they have told us to change things".

"Let us know how we can be involved; this is the first time anyone has spoken to us".

"Are asking for feedback right now, but is it true feedback? How many people are you speaking to? Has it been rushed or has the right investment gone in? is it honestly not yet another 'tick box' exercise?"

"Felt that the deaf community does not get engaged with enough and that there is no strong connections or relationships between them and decision makers. Felt that there is a disconnect and that feedback is not communicated efficiently".

"Feedback, which is essential for constant growth and communication outside our neighbourhood".

"Complete exercises and look back to see if it is efficient or proved successful, revisit ,share reasons and adjust accordingly".

"Not sure about a citizens panel – more feedback to more groups – more frequently. Groups don't always disseminate information successfully".

"Point 3 about working with other health organisations could be done better, multi organisational approach is good". (3. We will make it easier for all people to get involved, remove barriers from preventing people getting involved and meet people where they are)

"Actually, have a schedule for updating patients in a timely manner".

"In my experience the NHS doesn't know the word consistency".

"The work across the wider NHS. To my knowledge, is generally outstanding. I personally felt the main issue is with general Practice both with the expectations of them as well as the service they provide. I feel they are expected to deal with too much and this leads to delays in people receiving proper treatment. I don't blame the service for this, however I definitely do believe it is easier to engage with other services. I believe the main detriment to the value of care given is the volume of service needed to provide"

"Clear plan on what needs to proactively involve people – service design etc – and clear plan for how people can be involved on a day-to-day basis".

"Not just asking what organisations themselves think, but rather using the organisations as a way to connect with their network, so it the opinion of service users rather than the organisation itself".

"Actual plans to implement, rather than just ambitions".

“Most knowledge of the whole problem exists nationally and is hard to get from local organisations. Local groups can only see some parts of the problem, rather than the entire national problem. Finding a way to use knowledge from the national level to make decisions about and changes too local services, rather than just local knowledge”.

Ethnic Minorities

“List is ‘right’.”

“Experience talking about NHS services, i.e. Community Bridgebuilders.”

“General first feelings: health system is good, need to try and sent people to the right place.”

“same problems/same questions asked; still going on, not much improvement.”

“Need more action/less talk”

“[ICB] need to take action, not just NHS services”

“Refugee communities – try to get people to stand on two feet. Culture needs to be fed back.”

“NHS Need to get directly into community.”

“I feel opinions have been taken from us, but what is going to happen with that feedback?”

“Could do something better/do something with feedback. Communicate it better, what happens with it. Would like to see actions/responses.” (In reference to bullet point no.4 in list of Our Priorities).

“Focus group should transpire into something more than obtain more ‘truthful responses’ and see change driven from that.”

Appendix five: How we plan to work

As an Integrated Care Board, we look after the health needs of lots of people in the North East and North Cumbria. To make sure we are doing a good job, we want to hear from people about how we work and our plans to involve. We want to make sure our plans to do this are the same across the whole region. We plan to do this by:

How we plan to work

1. Working with local people
2. Going and talking to and hearing from as many different people as we can
3. Getting people to take part in our work
4. Telling the truth about us and our plans to people who work for us or use our services
5. Making sure we hear from people who use our services so we can learn from them about our services
6. Telling people how we have used what they have told us to change things.
Telling people why we have not used what they have told us to change things
7. Use lots of different ways to make sure people can tell us what they think of us and our plans

How we plan to work questions

1. Do you think this list is right?

"Yes, it is good as a starter, but it needs to be iterative as more ways of engagement and involvement are experimented with and real experience in working in this way is gained".

"Yes".

"Don't know".

"This list feels the best, it is the clearest and simplest".

"It feels like it is right and corresponds with the other lists".

"The group felt that this list was right, and the clearest. Just want to see a timeline of action and see actual actions".

"The list is right".

"Yes"

"Yes, although as with the ambitions, it appears to lack clarity on how it will be achieved. A plan to ensure this happens".

2. Have we missed anything?

"The route and means of travel to achieve end goals".

"Acknowledgement of the different needs of the various Hard-to-reach groups that result in inclusory 'justice'".

"Level of proportional universality in the delivery of support in making the plan work".

"Making sure you hear from people who use (AND STAFF THAT RUN) our services, so you can learn from them about your services"-don't forget staff see, hear and understand what works and what doesn't- but they need to feel confident that they can speak up without any negative come-back!"

"Where is the plan and achievements to date at Place"?

"No".

"Don't know".

"Just once again timescales, is it a 1 yr, 5 yr 10 yr plan?"

"Will it change and when would that be? "

"What are the success criteria, how do you measure that you have done what you said you are going to do".

"Group felt that there was enough in the list to work on and to do".

"No".

"significant lack of communication about personal and mental health measures that can be adopted to alleviate problems on later life (or earlier) This should start in schools from age 5. It would save NHS billions in years to come. Educate people".

"Proportionality, speaking to a certain percent of people who will be impacted by service change".

"Working in partnership should be recognised more in this list, as it has been in the ambitions".

"Clarity on the use of the term 'we' does this mean we as in the ICB, or in the NHS as a whole, and its multiple organisations".

3. Is there anything you think we do well?

"End goals are good".

"To be determined at Place".

"Encouraging participation at this stage is great".

"No".

"Don't know".

"Feel that still at the start of the journey, but it looks promising if manage to deliver what has been detailed out".

"Sounds like Healthwatch could play a good role in providing constant feedback – so co-production with other organisations also appears to be working at the moment and could be further developed".

"There is a lot of room for improvement. Felt if it was happening it is not effective as no one had really any evidence that it is happening".

"Involve local people and appreciate their help".

"Communication and sign posting to other organisations".

"What we do when done well can make a great difference to peoples lives".

"The plan would help if it was implemented as suggested here. Turning this plan into actions would be positive".

"Engagement on the Community Mental Health Transformation in North Tyneside was an example where the NHS committed to involve people before making any decisions or spending any funds. Therefore, people were actively involved in every decision made".

4. Is there anything you think we could do better?

"Services should be talking to each other as there's a lot of customer feedback required on a multitude of topics. Is there any way we can coordinate and condense this to reduce the opportunity for left-hand/right-hand. Shouldn't NENC co-ordinate (not control) all customer-facing surveys".

"Does the current budgetary provision enable this strategy to be delivered? (It would be appreciated if it wasn't a "yes/no" answer)".

"Commit to actions based on input/feedback".

"Communicate how the plan is going to be reviewed (at interim stage completion, using milestones or key dates, at the end) and communicate the results of those reviews as they happen".

"Don't be afraid to share failures and recovery plans: it helps build confidence".

“Work more through third party support including charitable local projects, who already have the trust and confidence of local people. Really think creatively and ‘out of the box’ when looking at how to reach/involve people more effectively”.

“Link the involvement, feedback and experiences of different organisations – health & care is very rarely confined to one service, and the experience of one, impacts on others”.

“Increase the use of independently gathered feedback and the voice from the VCSE sector who generally have a more trusted role within communities”.

“Enhance the role of involvement at PCN, build the bridge between PPG and PCN to improve communications. Enhance the role of Healthwatch or have an independent ‘external’ organisation independently verify that ICB ambitions are being both met and measured”.

“Display performance against target for each of the key measures of success for ICB”.

“Ensure that there is much more active, widespread and time limited ways to involve more patients to nurture a sense of ownership between patients and the NHS”.

“Going and talking to and hearing from as many different people as you can”.

“Telling the truth about us and our plans to people who work for us and use our service – this is all very well but there needs to be more candour about what is going wrong quicker, no good waiting until things are in crisis”.

“Talk to more people with disabilities”.

“Feedback on what is happening”.

“Share how to get involved so people are more aware of what is going on”.

“Engage with more people”.

“Could get people involved better, people with lived experience need to be involved from the beginning and need to be listened too”.

“Needs to be better communication about what is happening and what has been done. Feedback needs to be shared from the top to the bottom”.

“Make sure they get feedback after the event to encourage further involvement”.

“Making it easier for folks to have their experiences with the NHS and feedback given”.

“Following up with multiple visits”.

“Working with partners to view a person’s health as a whole. E.g. working with local council Public Health teams, more upstream working”.

"Invest and involve people in more preventative health measures, rather than just reactionary".

"Language 'telling the truth' could be replaced by 'honesty'"

"Basic project planning, include aims and objectives".

Ethnic Minorities

"Lots of information gathering."

"Many NHS groups not linked up."

"Where are the information groups? Where does information go? Where is all information used? Is it joined to see change?"

"Co-production/link together."

"Ethnic minority groups not involved."

"Different rules in the UK."

"7 years working on translation issues/nothing resolved. Keep going around in circles."

"Language barriers; not involving refugee/asylum seeker community enough to understand this barrier/ ones that are most needed to assist, are not involved."

"There is a problem somewhere but knowing how to communicate this."

"Found being part of Community Bridgebuilders more helpful to gather information/ This is working better. Need to collaborate more like this."

"E.g. Africa is not 'one'; there are several communities and many different languages."

"How does the NHS transform these? Culture doesn't allow people to do x and y, NHS doesn't get this."

Appendix six: General Feedback from ethnically marginalised focus group

- High rates of attrition: started off with 6 participants ended up with 2 who stayed until the end. Participants dropped in and out of focus group fluidly, therefore responses did not capture much of discussion accurately.
- Materials not tailored to this seldom heard community (Ethnically marginalised): too much information, leading to misconception about aim of focus group. E.g. participants kept talking about NHS services, and not ICB agenda.
- No prior knowledge of ICB (and other acronyms), despite having read aloud statement and definitions, therefore hard to engage as participants did not know what was being delivered.
- Participants only provided answers on what they perceived they were being asked, hence answers mainly depict lived experiences of NHS services.
- Too long/lengthy duration: evidence of participants lacking engagement, experiencing focus group fatigue due to not understanding aim and nature of discussion. Having 15 minutes per section to ask up to 6 questions without leading the conversation, clarifying meaning, and recording responses was extremely difficult/unrealistic. Focus group took a total of 4 hours to complete.
- Participants' views, highlighted failings and challenged the points listed in the strategy.
- Signs of discernment in understanding amongst group.

Appendix seven: demographics

Involvement Strategy North East and North Cumbria

Equalities questions

1. What is your postcode?

CA2	NE9 6RN	TS17 7EG	TS26 0AQ
CA2 5EH	SR1 1XB	TS19 8UD	TS26 0HT
DL3 6NJ	TS19 85W	TS23 2HG	TS26 9LY
NE10 0BA	TS1 4EE	TS24 0UF	TS3 6PR
NE33 5EX	TS1 4JJ	TS25 1AL	TS3 9NS
NE6 202	TS1 4RR	TS25 4EQ	TS4 2HP
NE81 1QD	TS1 8JH	TS25 5NJ	TS5 6BB
NE9 6B5	TS10	TS26	TS5 6JR

2. How old are you?

16 – 17	18 – 24	25 – 34	35 – 44	45 - 54	55 – 64	65 – 74	75 or older	Prefer not to say
2	13	8	9	7	8	12	3	

3. What is your sex?

Male	Female	Prefer not to say
18	25	4

4. Is the gender you identify with the same as your sex registered at birth?

Yes	No	Prefer not to say
38	4	3

5. Are you currently...?

Single (never married or in a civil partnership)	13	Separated (but still legally married or in a civil partnership)	1
Cohabiting	2	Divorced or civil partnership dissolved	2

Married	12	Widowed or a surviving partner from a civil partnership	
In a civil partnership	1	Prefer not to say	14

6. Do you look after, or give any help or support to, anyone because they have long-term physical or mental health conditions or illness, or problems related to old age? (Please exclude anything you do as part of your paid employment)

Yes	No	Prefer not to say
8	23	15

7. What is your ethnic group?

White Includes British, Northern Irish, Gypsy, Irish Traveller, Roma or any other white background	40
Mixed or Multiple ethnic groups Includes White and Black Caribbean, White and Black African, White and Asian or any other Mixed or Multiple background	
Asian or Asian British Includes Indian, Pakistani, Bangladeshi, Chinese or any other Asian background	
Black, Black British Caribbean or African Includes Black British Caribbean, African or any other Black background	8
Prefer not to say	
Other (Turkish x 1 Kurdish x 1)	3

8. Which of the following terms best describes your sexual orientation?

Heterosexual or straight	Gay / lesbian	Bi/bisexual	Other	Prefer not to say
15	7	6	2	14

9. What do you consider your religion to be?

No religion	Christianity	Buddhist	Hindu	Jewish	Muslim	Sikh	Other	Prefer not to say
13	12				6			14

Appendix eight – Independent Review

I asked 6 other patients/service users and they very kindly went through the document, highlighting queries and making suggestions, and I then met with each of them F2F to summarise. In the table below are some general points and then specifics to document pages. In the group, there were apologies for sounding negative, or for simply wondering who the document was for. I felt that this was all valid.

MOVING ON Suggestions

The group felt that we had been on this road a few times before. Is there much more we can learn about communicating better with patients/service users? When you read patient feedback, there are so many repeats about the experience, but communication figures high up on the list, as does feeling that you are being passed around. Does anything new come up?

More active co-production and communication between patients/service users and professionals - not papers to read. Focus groups, face to face or on- line with very specific agendas, asking patient for examples of what worked and what didn't, what they would suggest. Follow up with "you said, we did" and then "we said, we did".

Cumbria CLIC did some "Rapid ward/dept Improvement projects" which were effective because they gave staff time to think OFF the treadmill, so they could analyse their processes to see exactly what it was which made a poor experience for patients, and ALSO a frustrating experience for staff. They had patients in the group.

Back to my own starting point for this. I feel there should be an independent member of the public at Integrated Care Board level, for the reasons we discussed before and below. I would be concerned, if Integrated Care gained such traction and success that we were left behind.

	GENERAL POINTS / members of group clearly needed to say.
	List of Integrated Care Board members ... where is an independent patient with lived experience? There will be patients who want the opportunity to tell their story, and for whom moving beyond this is really difficult, and we understand that you can't have patients just telling their story at every meeting, but the group who have read and responded to this document, and who do have lived experience, are taking a wider view – practice populations/public health and so on.
	The term "HEARD" - it can mean so much.....including heard but not listened. This was a long read but <u>who</u> is it intended for? Would patients/members of the public read this? What about HOW things will be achieved? The whole felt jumbled/ cut and paste-ish.

	<p>Need improved communication from GP to the practice population – there is good practice but it is patchy and inconsistent – e.g. a sudden change of GP. Who had any idea what a CCG was and what it did? GP APP - expected to travel to another surgery and to a doctor who may not know your context. NHS still struggling with joined up records/digitisation when so many organisations we deal with don't seem to have problems e.g. banks. The lack of joined up, is part of the problem of delays/length of stay/waiting for medications. Some in the group have learnt to keep their own printed copies of their records – they just don't trust that people in the system will have the information to hand. Primary to Secondary care records --just not joined up.</p>
	<p>Acronyms too many "I just don't understand what they mean by this" – quoted several times and with an absolutely unnecessary feeling of embarrassment at saying it.</p>
	<p>We have heard all this before.</p>
	<p>Would time be better spent by professionals here, on NHS waiting lists? Workforce?</p>
	<p>Heartfelt comment about keeping people alive/going on – for not a good continuing experience. Quote from a husband of someone given a defibrillator at 84 – "<i>She is not <u>able</u> to die</i>" - never heard it put this way.</p>
	<p>Existing deferential behaviour which can underlie bullying and lack of teamwork, but probably more important, can mean that decisions don't get challenged. This has to change – from top to bottom. The patient/family are sometimes there to witness this deferential behaviour and bullying.</p>
PAGE	Specific points
1	<p>The language of "Maybe", "whenever possible" - too vague, too easy NOT to do.</p>
2	<p>Draft strategy discussed and approved by NECS ICS Development and Transition Programme board. Who were they? June 6th, 2022. We were unclear who were involved in drawing up this document. We are unclear what these roles mean. Someone commented about marking your own homework.</p>
3	<p>"Has there been? Does there need to be Patient /public involvement?" We thought there might be practical matters – buying equipment, for instance, but could think of little where there would <u>not be</u> patient/public involvement. Reach out to patients for feedback. Go to them</p>
4	<p>A Patient Experience Team" may focus only on the Acute experience, and this may stop at the exit door of the hospital. Patient experience is the whole journey across primary/secondary/community/social care and beyond. If there is silo working here, this is absolutely what does not work for patients.</p>
5	<p>What is meant by patient groups? Surveys? Actual conversations? The term "keen to involve" - admirable but does it have teeth?</p>
6	<p>Unclear which year we mean. <i>Citizens Panel scoping</i>. Unclear about this model. A colleague suggested including the following for such a group: parent of child/young adult/patient with chronic condition/ patient in care home, and there will be other representative people.</p>

	Is there a budget for this process? There are ways volunteers can be paid without it affecting their benefits
9	How will the new unitary authorities work? Volunteers (patients and members of the public) should have opportunities to meet with clinicians/professionals, and eventually with support, those same volunteers would feel trusted and confident enough to speak directly where there are clinicians/professionals. Volunteer may need help of mentor/buddy to start.
12	Para 6 “ambition to embed-everything we do”. WHY are views not sought? Or Ignored?
15	The time to listen must be made as part of the therapy – to understand the patient’s context. Quote from a patient with recent time in acute ward “We’re too old for them to bother. They don’t care” Add to this the current “thinking” around the normalising of continence pads (Panorama programme) and hospital life for some would look pretty grim. We have learnt/we have heard --but what was the learning here?
16	Consultation. This paragraph points out that there are different connotations for NHS and local government. So why does my heart sink? The term “ as appropriate ”- <u>we have to stop using this term</u> , because it offers too many options NOT to engage - time, opportunity, someone can’t see the point of having a patient’s view, whose job is it, and so on. It feels like the “get out of jail free card.
17	Follow up services not always timely. Especially the move into social care services – carers sometimes left to just get on with it and feel as if any control has been wrenched from them. It just has to be joined up across all the sectors, The common denominator here IS the patient.
18	Poor graphic, too small to read, not adequate contrast
21	Section 2 Community Voices. Where are the Patient Participation groups?
24	“We are all patients”- we hear this all the time. We looked askance at this term
25	Which year do these dates refer to? “Citizens’ Panel Scoping” May to September WHO are you talking with?
28	The section on “insight” the bullet points are too vague. As a group we did look at the Gunning principles – these seemed to have real teeth.
32	The graphic idea is great particularly because of the plain speaking and accessible language. However, this does not translate as a good PPT slide and would be difficult for some in an audience to read.



healthwatch

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