NHS Long Term Plan
Engagement Report

Northumberland, Tyne and Wear and County Durham

what
would you do?
It's your NHS. Have your say.

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Executive summary

At a time of increasing pressure on NHS services and financial budgets, this research highlights how people want to be more involved in the management of their care and to make joint decisions with professionals. To do this they want better knowledge through well communicated information and more options through better access to primary care and more joined up working between services.

In line with this, people have frequently asked for more holistic community wellbeing support to prevent ill health and maintain good health. There was a demand for more local services, better transport to reach them or more support for care at home. More proactive listening to patients along with individualised care was also important. There were pros and cons to using technology for patients, but the value for professionals within services was highlighted.

Although the population is living longer, there is an increasing number of older people who are living with health conditions across the region. Alongside the decreasing funding of NHS services, an ageing population can increase pressures and strains on services. It is important that attention is given to the specific needs of this group of people in order to improve efficiency, effectiveness of their care, their care experiences and prevention of avoidable ill health.

In addition, prioritising young people's health and wellbeing could prevent people in our region from developing mental health problems later in life, by promoting health-supporting behaviours and services and by making young people more aware of symptoms and how to access treatment.

Reading this report, you will learn what the purpose and objectives are for the NHS as well as the Integrated Care System (ICS) and how the work carried out has an impact on local services. The report also summarises the findings of the engagement carried out by 7 local Healthwatch in the North of the ICS region as well as identifying what works well and what needs to be improved.

Each of the seven local Healthwatch in the region looked at existing evidence, received responses from the public using surveys and local focus groups and provided findings to the coordinating Healthwatch.

This report will be given to the Integrated Care System (ICS) team as well as the more local Integrated Care Partnership (ICP) teams to give them an insight into areas that currently need more attention and highlighting possible steps of prevention to reduce future pressures.

The NHS is expected to undertake its own public engagement work. The activity of local Healthwatch aims to complement and support this work. For example, by reaching out to specific communities or helping the NHS to get insight which they do not have.

We will work with them, as the independent local consumer champion for health and social care, as they develop services in the Long Term Plan's framework, to ensure that the voices and views of local people are part of the process.

This does not mean that the ICS can dictate to local Healthwatch the areas of focus, key lines of enquiry or our methodology. This has been clarified with the ICS through NHS England's communications but, by taking a partnership approach, together we can have a greater impact on the health and care of local people.

Michelle Thompson BEM
Chief Executive Officer, Healthwatch Darlington

On behalf of Healthwatch Northumberland, Healthwatch Newcastle, Healthwatch Gateshead, Healthwatch North Tyneside, Healthwatch South Tyneside, Healthwatch Sunderland and Healthwatch County Durham

Integrated Care System Response

Thank you all for your work on the NHS Long Term Plan engagement surveys and focus groups for the development of the North East and North Cumbria long term plans, and place-based plans for each of our localities. It is really positive to see that local Healthwatch colleagues have come together to give their thoughts on how their local priority areas for engagement such as mental health and GP access have aligned to priorities for our Integrated Care System (ICS). We look forward to reading the report findings.

Our ambition is to develop an outstanding ICS which is continuously improving health and care outcomes and delivering safe and sustainable services. Achieving this will be dependent on high quality engagement with the public, and colleagues across County Durham, Darlington, Teesside, Hambleton, Richmondshire and Whitby will find the report very useful when planning any further engagement work needed at a local level.

We will take forward the report findings which demonstrate that we have been able to involve patients and communities at the earliest stage possible when we talk about our plans and priorities. We will build upon your sound approach in seeking out and hearing the patient's voice, and working with a range of hard to reach and diverse groups.

Mark Adams
North ICP Lead

Ken Bremner MBE
Central ICP Lead

Dr Neil O'Brien
South ICP Lead

Background

Purpose

NHS England and NHS Improvement funded the Healthwatch network to carry out engagement with communities across the country to establish how the Long Term Plan (LTP) should be implemented locally.
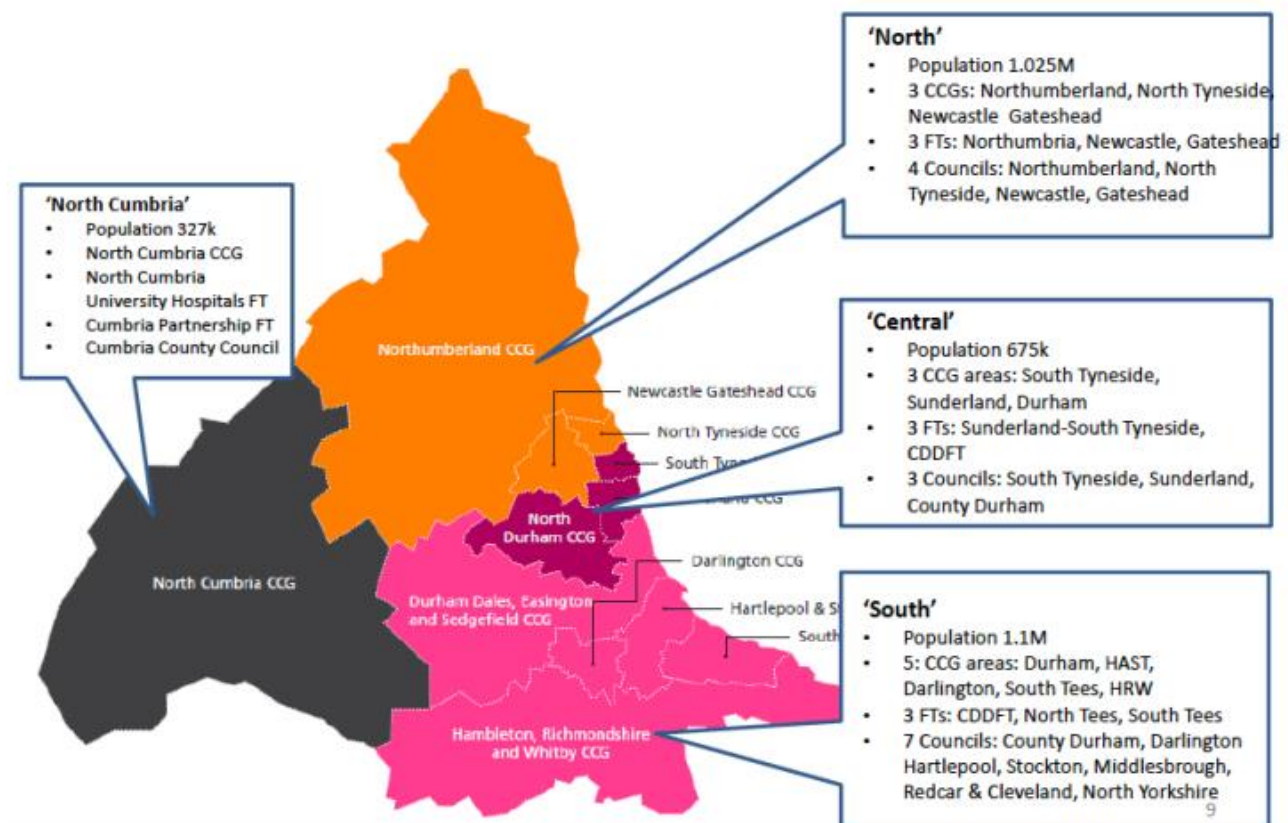
Local Healthwatch worked together to find out what local people think. What people told us will be shared with the NHS and will be used to help develop the plan for our area.

The coordinating Healthwatch for the North East is Healthwatch Darlington (HWD) and they agreed engagement priorities with Head of Communications and Engagement for our North East Integrated Care System (ICS) regarding the NHS Long Term Plan.

The area consists of four Integrated Care Partnerships (ICP) – North Cumbria, North, Central and South. For the purpose of this large scale engagement, North Cumbria ICP joined their Cumbria colleagues and the North, Central and South ICP's were split into two areas:

- Northumberland, Tyne and Wear and Durham
- Durham, Darlington, Teesside, Hambleton, Richmondshire and Whitby

Four Integrated Care Partnerships

'North Cumbria'
- Population 327k
- North Cumbria CCG
- North Cumbria University Hospitals FT
- Cumbria Partnership FT
- Cumbria County Council

'North'
- Population 1.025M
- 3 CCGs: Northumberland, North Tyneside, Newcastle Gateshead
- 3 FTs: Northumbria, Newcastle, Gateshead
- 4 Councils: Northumberland, North Tyneside, Newcastle, Gateshead

'Central'
- Population 675k
- 3 CCG areas: South Tyneside, Sunderland, Durham
- 3 FTs: Sunderland-South Tyneside, CDDFT
- 3 Councils: South Tyneside, Sunderland, County Durham

'South'
- Population 1.1M
- 5: CCG areas: Durham, HAST, Darlington, South Tees, HRW
- 3 FTs: CDDFT, North Tees, South Tees
- 7 Councils: County Durham, Darlington Hartlepool, Stockton, Middlesbrough, Redcar & Cleveland, North Yorkshire

Northumberland CCG
Newcastle Gateshead CCG
North Tyneside CCG
South Tyneside CCG
North Cumbria CCG
North Durham CCG
Darlington CCG
Durham Dales, Easington and Sedgefield CCG
Hartlepool & Stockton CCG
Hambleton, Richmondshire and Whitby CCG

HWD liaised and co-ordinated the engagement activities with Healthwatch colleagues and the ICS Head of Communications and Engagement in the relevant North and South ICS areas and produced two reports bringing together all the evidence and insight in the North and in the South gathered by each individual Healthwatch who were all contractually obliged to carry out this engagement work.

Objectives

The ICS priorities across the North East include:

- Prevention - early detection and effective management of the biggest causes of premature death: cancer, cardiovascular (heart) and respiratory (lung) disease.
- Better lung health, with an ambition to achieve a smoke free generation
- More effective management of frailty to ensure no one is admitted to hospital that could have been cared for more effectively in their own home with the right personalised care, and doing more to tackle social isolation with our ICS partners.
- Improving the emotional wellbeing and mental health of infants, children and young people.
- Ensuring the best possible maternal health and early years outcomes.
- Improving outcomes for people who experience periods of poor mental health and specifically those with severe and enduring mental illness.
- Supporting and enabling everyone to have a good death and to be able to die in the place of their choice.

Discussions with individual Healthwatch colleagues revealed the following popular themes that they knew from their experience of listening to people locally, were likely to be important:

- Mental Health including dementia, young people and SEND
- Long Term Health Conditions
- Palliative Care
- Cancer Services
- GP services including primary care networks, self-care, community and technologies

After discussions with the ICS Head of Communications and Engagement it was agreed that all Healthwatch themes would be helpful across the region to help inform ICS priority areas.

What matters most to people in Northumberland, Tyne and Wear and North Durham?

The findings in this section are based on responses to the surveys designed by Healthwatch England. In total, there were 1337 surveys collected by local Healthwatch in the region. You can see the demographic information related to these responses in the methodology section of this paper. You can also see further details on what was said more specifically in each area by reading the individual local Healthwatch reports which are available on their respective websites.

There was also recognition that the NHS has to make difficult decisions around what resources are effective when managing costs against a limited amount of funding. There were also several positive comments across the region about NHS staff and services, which suggested there is little room for improvement. However most of the following summary is in relation to where services can be better

What is most important to you to help you live a healthy life?

We wanted to understand how local people felt they could be supported to live a healthy life. We asked people what element was the most important when considering a range of aspects regarding access to information and treatment to live healthily. Following analysis of the survey responses within each local Healthwatch area, the most important requirement for people when it comes to living a health life was "*Access to help and treatment I need when I want it*". Every local Healthwatch in the region reported that this was voted most important by their community. In County Durham, Gateshead, North Tyneside, South Tyneside and Sunderland the second most popular answer was "*professionals that listen to me when I speak about my concerns*" whereas in Newcastle and Northumberland "*Easy access to the information I need to help me make decisions about my health and care*" was noted as close second.

The importance of **access** was also reflected in some of the comments people made when asked if there was one more thing that could help them live a healthy lifestyle. For instance, at least 20% of all survey respondents in Sunderland commented at least once on their struggle to gain and access to GP appointments. People in Gateshead suggested improved access and **reduced waiting times** especially for GPs, but also mental health and learning disability services. While a key theme in Newcastle related to **timely** access. This theme covered a number of different services in primary and secondary care with a lot of comments relating to waiting for mental health assessment and support. GP appointments were mentioned by respondents in Northumberland with positive and negative sentiments about access by telephone, use of internet video calls, triage and 'call back' systems. In County Durham, they recognised that when they need help and it is not possible to see someone, and this can have an impact on accessing other services – i.e. where a referral needs to be made by the GP but the patient is unable to get an appointment for several weeks or more in some cases.

As the second most popular choice of response was around **being listened to**, further comments reflected this sentiment. The importance of staff manner was illustrated in several North Tyneside comments where the most common aspect people felt would help them live a healthy life was **prompt and consistent care** when needed.

"Having practitioners who listened to the full picture, one problem may be linked to another and need looking into more thoroughly instead of just being treated for each individual symptom" [North Tyneside resident]

"(I) Like to make choices myself and not told what to do or what will happen. It is most important that professionals listen to me when I speak to them about my concerns. When you get to a certain age nobody listens to you. I always feel rushed. Doctor never has time for you, that's when you get an appointment" [Northumberland resident]

In **Sunderland**, many people felt that when they are treated as an **individual**, in a **person centred manner** their care experience was much improved. Being recognised as an individual was also important to several respondents in **County Durham**, which could be seen in answers that related to **practical accessibility considerations** like the way in which services accommodate hearing loss or working hours. People in **North Tyneside** described a number of suggestions including access to a safe and personalised interpreting service; access to clear information; and difficulties in accessing local services, particularly pertinent, again, to GP appointments. This need for individualisations reflects common issues local people raise with their Healthwatch.

"I cannot use 111 service as I have a hearing loss" [County Durham resident]

"Appointments outside office hours (when people are working)" [County Durham resident]

"A GP who actually has time to listen and get to know their patients, and not to be treat like a timed number." [Gateshead resident]

"Be able to make appointment to see doctor, being told to phone up first thing in the morning is difficult when you are at work." [Gateshead resident]

"You should always have access to the same doctors at your own doctors or someone from their team" [North Tyneside resident]

A few other key themes emerged across the region about **community health and wellbeing support**. In **Sunderland**, a significant number of survey respondents stated they would benefit from resources on how to stay healthy, good nutrition and where they can access exercise as a means to keeping themselves happy and healthy. This was also reflected in **Gateshead** where a number of respondents suggested that affordable and accessible healthy lifestyle choices would help them. Whilst knowledge to prevent ill health and advice on how to stay well was important to people in **Newcastle**, specifically around diet and healthy food choices. Some survey respondents indicated that they would like to have access to complementary therapies such as mindfulness, yoga and massage. Further comments included requests help with the costs of maintaining health for things such as nutritious food, gym membership and exercise classes. Several people in **North Tyneside** discussed the importance of prevention and lifestyle factors that would help them to live healthily including exercise, nutrition information, stopping smoking and banning high percentage alcohol. Accordingly, a reoccurring theme in the feedback given to **County Durham** was the importance of *"easy access to services which promote a healthy life"*. People there wanted more options to be available in their local and immediate areas, which didn't require excessive travel or unreasonable delays. They recounted the benefits mutual aid can have in reducing social isolation, predominantly in rural areas. Some of these suggestions may be outside the NHS' remit but could be achievable through joint work with other services and organisations at a local level.

"Time from work to be able to keep fit, shop for healthy food, cook and being able to sleep without worrying what tomorrow will bring" [Newcastle resident]

"Easier and cheaper access to healthier food choices" [Gateshead resident]

"*More information and support on local activities to improve health*" [County Durham resident]

"*Referrals for more complementary therapies, e.g. acupuncture, physiotherapy, sports massage*" [County Durham resident]

"*The offer of a fairly full health checks every year to try to get ahead of emerging problems and offer personalized advice on issues and referral to nutrition or physiotherapy specialists as needed*" [North Tyneside resident]

What is most important to you to help Sunderland live a healthy life?
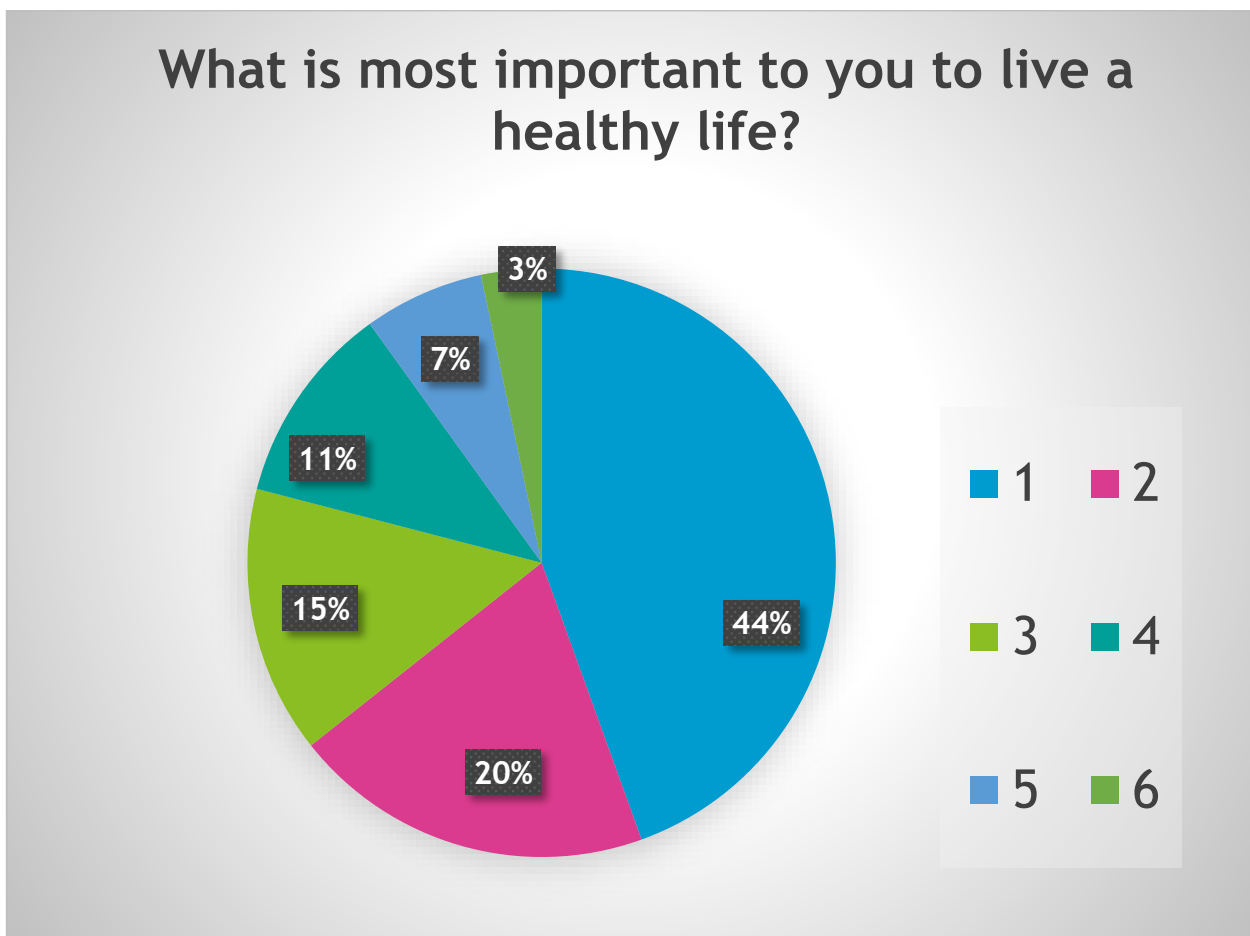
KEY

1   Access to the help and treatment I need when I want it
2   Professionals that listen to me when I speak to them about my concerns
3   The knowledge to help me to do what I can to prevent ill health
4   Easy access to the information I need to help me make decisions about my health and care
5   No response
6   For every interaction with health and care service to count; my time is value

What is most important to you to help you manage and choose support?

We also asked people about factors that are most important when it comes to managing and choosing the support they need. Across all areas people felt that *"Choosing the right treatment is a joint decision between me and the relevant health and care professional"* was the most essential option offered.

While the second most popular option for **South Tyneside** and **Sunderland** was *"I should be offered care and support in other areas if my local area can't see me in a timely manner"*. This was in contrast to the other localities in the region who raised issues about travel to their current local support. For example, **County Durham** where people mentioned the difficulty around access, from shortfalls in the local transport networks that prevented travel to certain sites or the difficulty in centralising clinics at hospitals that had poor options for car parking, either through costs or limited spaces.

The value of **communication** and **listening** was highlighted as another key theme. **Gateshead** residents felt clear explanations, being listened to and treated as whole person was important for them to manage and choose support. Comments were also made on the **poor communication between services** resulting in patients having to repeat information or, in some cases, in delays and errors. **Newcastle** participants highlighted the need for better information for patients and the need to listen to patients. Responses about clear communication were significant in **North Tyneside** when managing and choosing their support and they told us that this is an area where improvements needed to be made. In **Sunderland**, many people cited that when professionals actively listen and information is given in an easy to understand format, they have had much better care experience. However, many people also commented that professionals often don't speak in a simple language and/or don't give them enough time to understand what is being said. People in **County Durham** shared their personal experiences about when communication between health care professionals did not meet the standard that should be reasonably expected. It led to delays from referral to diagnosis, for the patient to be kept waiting on results due to delays between departments, and feeling marginalised or dismissed by professionals who should be a source of help. Any failure in communication prevents people from managing how the NHS supports them and also means that they are unable to make informed choices about what is right for them.

This theme of access came up again in **Newcastle** where people identified better **access to GP services**. Further suggestions from **Gateshead** when it comes to managing and choosing support included improved access to services and testing, particularly improved GP access.
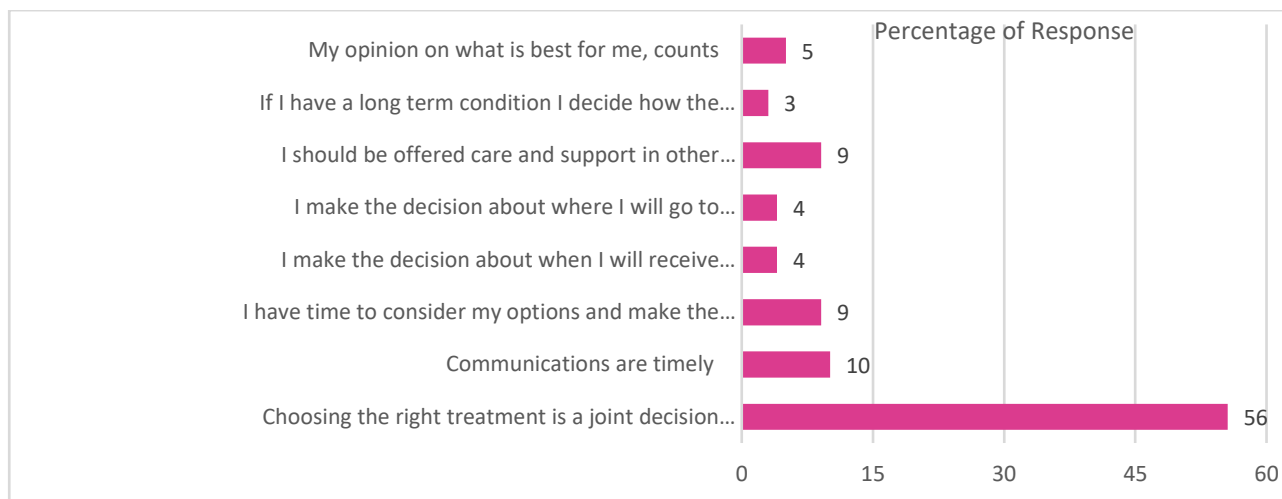
For patients to be involved in a joint decision it seems that having the **knowledge** and **information** to make choices, as well as **multiple options** of care or treatment to choose from were important. Knowing what services are available locally and being informed to make decision about their own treatment were recurring themes in **North Tyneside**, particularly in relation to **accessing primary care** and having open discussions about the range of treatment options available locally. The community in **County Durham** reiterated the importance of sharing information on local services that are already available. A key theme for the community of **Newcastle** was the importance of having time to consider the treatment and care options. In **Gateshead**, they also valued having a choice of time and location.

"Access to a health advocate who could guide you through options about your care/treatment (but who is not your doctor so they are independent but medically qualified)". [Northumberland resident]

People in **County Durham** have shared concerns in a number of areas, including specific references to local service changes and hospital sites. Proposed changes to service provision at Bishop

Auckland General Hospital have been well publicised over the last six months and engagement activity is currently looking into what will happen for the future of Shotley Bridge Hospital. Residents in these areas are passionate about their local resources and fear losing what they have ("*reopen Bishop Auckland Hospital again*").

What is most important to you to help North Tyneside manage and choose support?

Percentage of Response

Response	Value
My opinion on what is best for me, counts	5
If I have a long term condition I decide how the…	3
I should be offered care and support in other…	9
I make the decision about where I will go to…	4
I make the decision about when I will receive…	4
I have time to consider my options and make the…	9
Communications are timely	10
Choosing the right treatment is a joint decision…	56

What is most important to you to help you retain your independence and live healthily for as long as possible?

Looking at the quantitative data analysis across all localities in the region, the most important thing when it comes to keeping independence and aging healthily was "*I want to be able to stay in my own home for as long as it is safe to do so*", apart from in Northumberland where the most important option was "*I want there to be convenient ways for me to travel to health and care services when I need to*". County Durham, Gateshead, North Tyneside, South Tyneside and Sunderland all reported that "*I want my family to feel supported at the end of life*" were the second most important options in their respective communities.

This idea of travel and transport links being important was also picked up in County Durham, Northumberland and Newcastle. Some suggested that more local community support would be useful to reduce isolation due to lack of transport. A frequent concern in Newcastle was about services being too far from patients which causes access problems due to the lack of and cost of transport. There was a suggestion that '*community hubs*' might help with this but also that home care is there when it is needed would help. A number of people in North Tyneside commented on the importance of '*care at home*' and the importance of consistent and reliable support to enable people to stay in their homes and promote independence. There was some suggestion of better community provision in Gateshead but more respondents suggested that advice and support from NHS professionals were important. They felt that in most cases services should be local enough to be easily accessed by public transport.
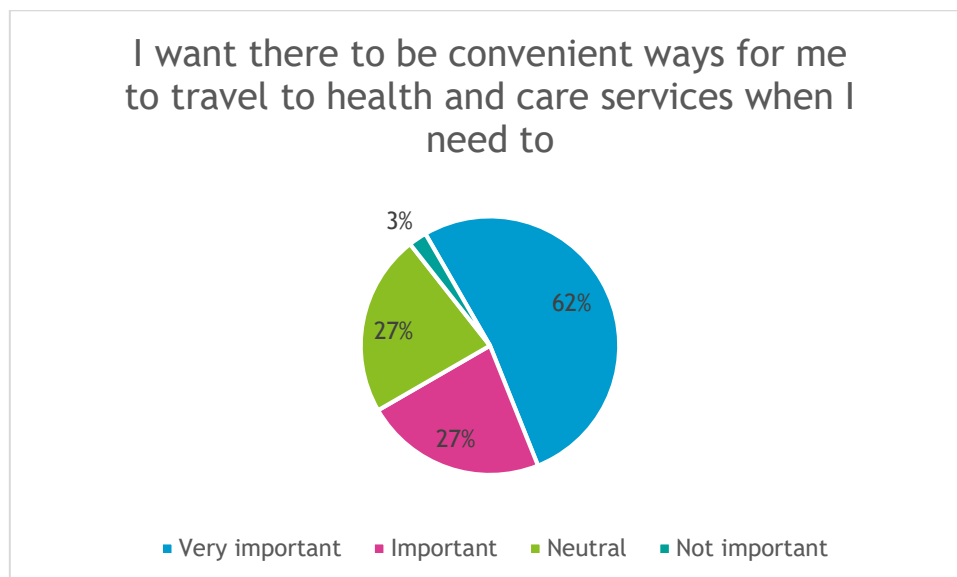
People's answers in **County Durham** on what it meant to be independent considered what was available to them in terms of accommodation, transport, affordable care and ways to reduce social isolation, which is a risk when getting older.

One person's experience and views overlapped several other individual comments: "*Confidence that I can manage myself, but that the help was there when I ultimately couldn't do that myself. I am a very strong independent person; I only ask for assistance and help with anything if I totally have to. I try my best to ease my own pain and bother no one. My experiences of hospital and doctors' care at the moment makes me very reluctant to ask for help. I need the confidence to know what's available, and truly accessible if needed*" [County Durham resident]

Another respondent reflected the importance of family support and end of life care:

"*Palliative Care beds in hospitals with caring professionals looking after me and taking the strain off my family. Some do not have fit and able family to care for us….leaving us at home can mean a lonely death*" [Northumberland resident]

What is most important to you to help **Gateshead** retain independence and live healthily for as long as possible?

I want there to be convenient ways for me to travel to health and care services when I need to

3%
27%
27%
62%

■ Very important   ■ Important   ■ Neutral   ■ Not important

What is most important to you when interacting with the NHS?

There was far more variance in responses to this line of questioning than any other, especially when rating levels of importance as the answer seemed to be different when ranking a single most important option. "*I can talk to my doctor or other health professional where I am*" was most important in **County Durham**, **Sunderland** and **Northumberland**. **Northumberland** also had "*I have absolute confidence that my personal data is managed well and kept secure*" as their most prominent response, which was the same for **Newcastle**, **South Tyneside** and **Gateshead**. **Gateshead** also had "*Any results are communicated to me quickly making best use of technology*" which was also a priority in **North Tyneside**. Although in a different ranking orders, the top 3

responses in each locality were similar so perhaps it better to consider all these elements are of importance across the ICS/STP region.

While it was important for data to be secure, there were some suggestion to share information between health services. For example, many answers in County Durham related to how services should be joined up, enabling patients and other professionals involved in their care to be able to access the same records. Lack of communication between healthcare professionals was raised by people in Gateshead who said that the patient was expected to keep contacting each department and to inform them of what was going on. A Northumberland resident also had a similar suggestion:
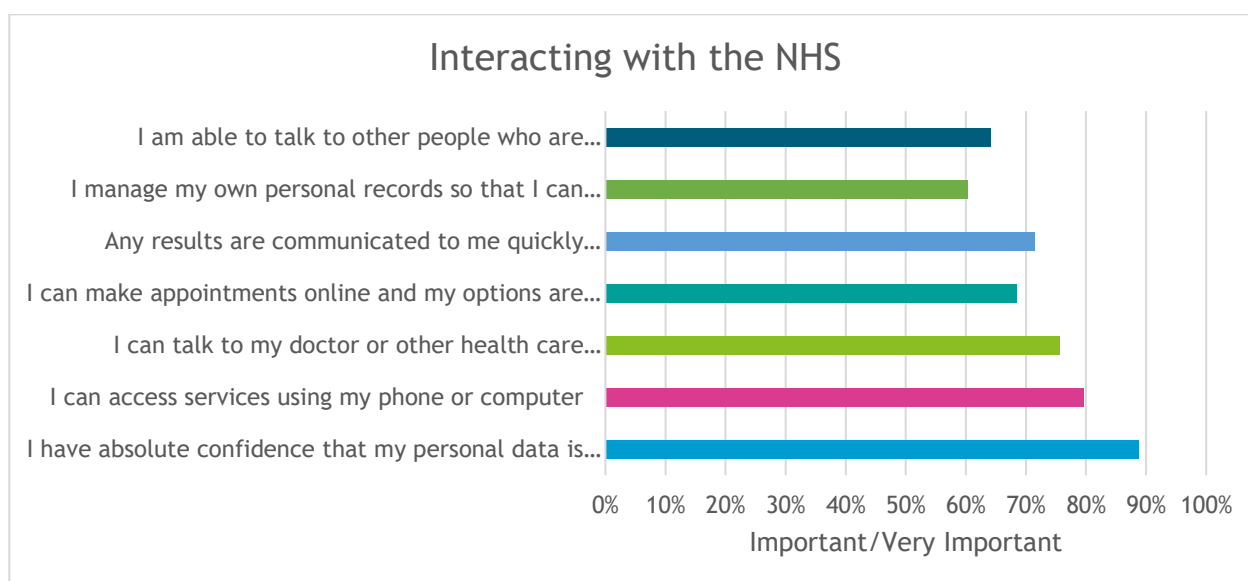
"My up to date records are available in every health centre or hospital I may attend" [Northumberland resident]

In Newcastle there were suggestions of health and wellbeing support and advice hubs and being able to talk to other people who are experiencing similar challenges. In Gateshead, some of the suggestions put forward as most important when interacting with the NHS were about extended and improved access, support for self-management and less dependence on technology.

Survey respondents in Newcastle felt that there should be a greater use of technology including email, although views did vary. Some felt that technology is good for repeat prescriptions and administrative issues but that it wouldn't work well if you were trying to get a diagnosis or showing a GP a problem. Sunderland resident shared experiences when they have used technology available to them to help improve their experiences within Primary Care including text reminders, booking appointments on line and ordering prescriptions. However, the level of understanding of technology and the access to IT equipment was a significant issue in County Durham as some people stated their access needs would be by telephone or other offline means. Feedback over the forms of technology available and choices around level of communication depended greatly on personal preference. One person addressed this:

"All of the statements in this question are important but they should be enhancements to what we have now not replacements, e.g. technology is fine if you can use it confidently but many people can't and they should have access to the same information and services through established traditional methods." [County Durham resident]

What is most important to you to help Newcastle when interacting with the NHS?

Interacting with the NHS

- I am able to talk to other people who are…
- I manage my own personal records so that I can…
- Any results are communicated to me quickly…
- I can make appointments online and my options are…
- I can talk to my doctor or other health care…
- I can access services using my phone or computer
- I have absolute confidence that my personal data is…

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%
Important/Very Important

healthwatch

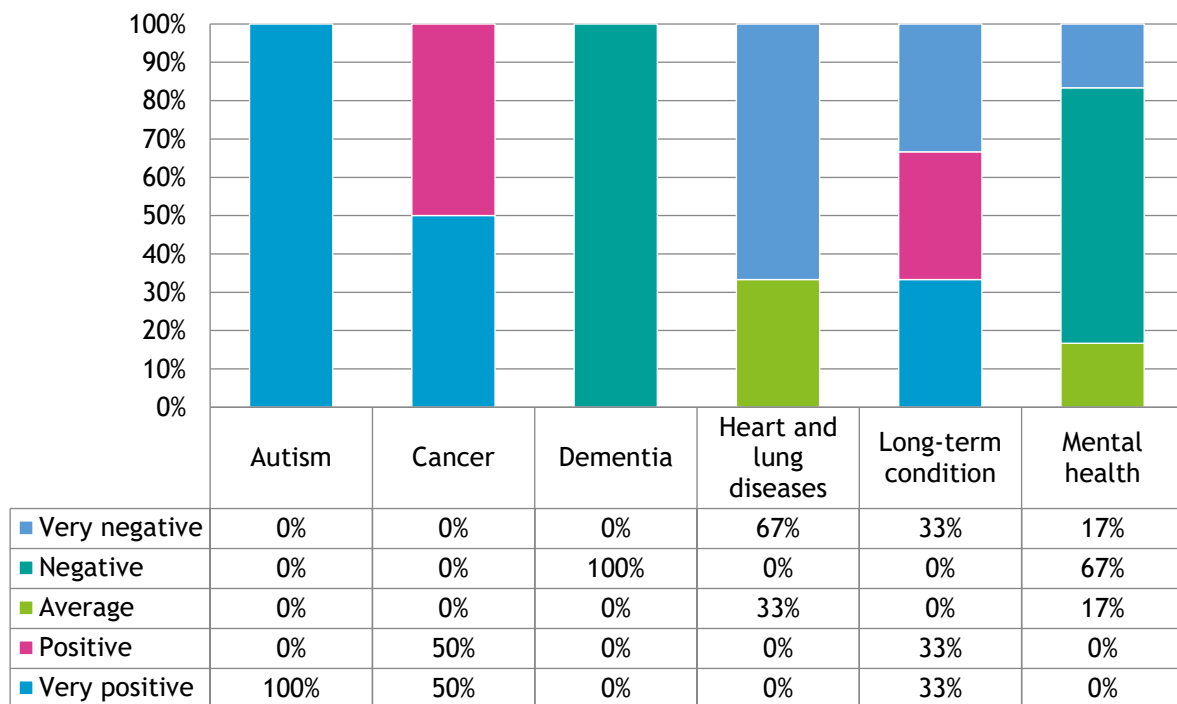# Long term conditions specific survey

In addition to the general survey, Healthwatch **Northumberland** and Healthwatch **South Tyneside** used the specific conditions based survey produced by Healthwatch England to find out more about care support for those with long term conditions. Here's what they found:

In Northumberland

The specific health conditions which people told us bout were cancer, autism, heart and lung diseases, mental health and long term conditions. The chart below shows how they described their overall experience of getting help with their condition.

People with cancer and autism reported the most positive experiences and those experiencing dementia and mental health services, the most negative.

Overall Satisfaction

|	Autism	Cancer	Dementia	Heart and lung diseases	Long-term condition	Mental health
■ Very negative	0%	0%	0%	67%	33%	17%
■ Negative	0%	0%	100%	0%	0%	67%
■ Average	0%	0%	0%	33%	0%	17%
■ Positive	0%	50%	0%	0%	33%	0%
■ Very positive	100%	50%	0%	0%	33%	0%

Of this group of respondents 62% felt the support they received when they first tried to access help did not meet their needs, 23% felt it did meet their needs and 15% thought it met their needs "somewhat".

17% described the waiting time to receive an **initial diagnosis** as "fast" with 63% rating it as "slow or "very slow". Those with mental health conditions were the most dissatisfied with the speed of being referred to a **specialist**, cancer was the only condition where the referral rate was said to be 'fast'.

People with specific conditions show a preference for diagnostic services to be within an hour travel time. This is especially marked for those with mental health problems.

Travelling for diagnosis
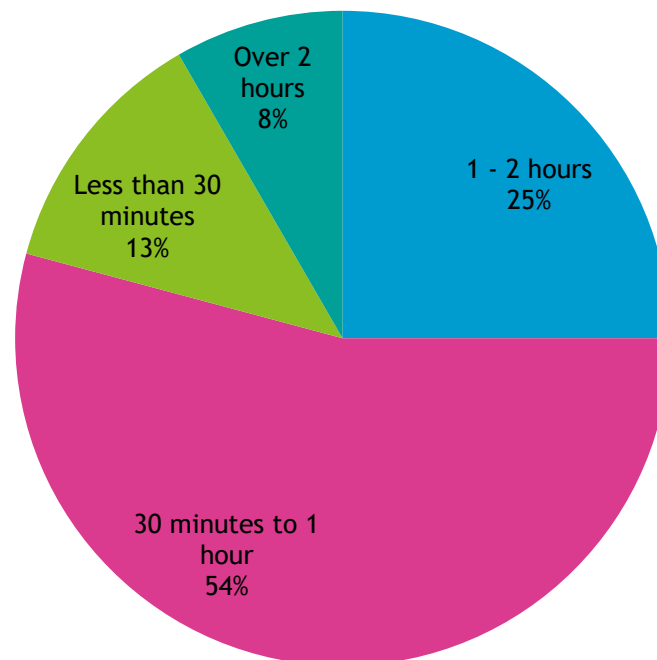
71% of respondents in this category used a car as their way of travelling. As a large rural county an hour's travel time is important as it has different implications for those who can drive to appointments and those who rely on public transport or be driven by friends and family.

Those with dementia reported using a taxi and carers pointed out the difficulty of driving with a person with dementia. The difficulty of accessing alternative or planned transport – either NHS or charitable was noted as dementia is not routinely an automatic qualifying condition, as is cancer.

People with specific conditions showed a higher preference for services up to one hour travelling time but were prepared to travel further.

In focus

Northumberland is a large, rural area with dispersed populations. Travel and transport are key factors in providing services in Northumberland as an issue of fairness and equity. Particular concern for those on fixed incomes or who do not drive due to age or other restrictions and where distances and weather can affect the ability of people to access services or for service providers to maintain a level of service in sparsely populated rural areas and more urban communities.

In South Tyneside

7 specific surveys were completed in South Tyneside. The most interesting findings from these were about their expectations at each stage of care and who it is most important for them to see. As the below table demonstrate, most respondents felt it was important to see the health professional they normally see at every stage, despite a potential wait. This was important regardless of what condition the respondent had, though for some people with mental health conditions they didn't mind during the initial seeking of help or diagnosis stage.

Mental Health x 4 Surveys	Seeing a health professional you normally see but you may have to wait	Seeing any medically appropriate health professional who is free immediately	Don't mind
When first seeking help	2 x Mental health conditions 1 x Dementia 1 x Heart and Lung 1 x Long term condition	0 x Mental health conditions	2 x Mental health conditions
When you first received a diagnosis and explanation of treatment or support options	3 x Mental health conditions 1 x Dementia 1 x Heart and Lung 1 x Long term condition	0 x Mental health conditions	1 x Mental health conditions
During your initial treatment or support	4 x Mental health conditions 1 x Dementia 1 x Heart and Lung 1 x Long term condition	0 x Mental health conditions	0 x Mental health conditions
During your long term support	4 x Mental health conditions 1 x Dementia 1 x Heart and Lung 1 x Long term condition	0 x Mental health conditions	0 x Mental health conditions

In focus

In South Tyneside, young people identified that people aged 16-18 fall between children's and adult services. They said it was difficult to know what service they fitted into and suggested that separate 16-18 year old services could be offered.

In focus

Personal experiences featured in some of the comments that were shared in the Healthwatch County Durham survey responses and during the focus groups we held. People spoke about contact they had with services and the outcomes, some of which were better than others. It does seem as though there may be gaps where services do not meet the needs of individuals or promote the opportunities widely enough so that members of the public are aware of them.

Accessibility issues have been raised with us, including:

- "I cannot use 111 service as I have a hearing loss "
- "I have had several jaw surgeries, and have difficulty speaking much of the time - I need to have the confidence to be able to access a doctor face to face"
- "Reasonable adjustments to services, e.g. services coming to see my son rather than in clinic. CAMHS did this but it all changed when he transitioned to adult services"
- "I need the confidence to know what's available, and truly accessible if needed"
- "In my experience the walk-in service is not that accessible"

Patient transport needs also factor into this issue; people have been allocated appointments or surgery but are unable to access it due to the lack of public transport at the required times, inability to stay overnight in hospital for surgery the next morning, or being unable to meet the cost of taxis. One person also said they would like to see: "*community support services for transport that me and my carer can get to appointments together and get home together. It does not work if we have to make our way to an appointment separately.*"

North Tyneside Existing Insights:

What Matters to You?

North Tyneside heard from 531 people in our 2018/2019 'What Matters to You?' annual survey. This included children, young people and adults from across the borough who told us about experiences of using several services. A key element local people frequently told us about was around access to services when you needed them. We identified frequent experience of inconsistent access to:

Both routine and emergency GP appointments particularly for those with work and childcare commitments and a lack of awareness around extended hour primary care services.

Mental health crisis services when you are experiencing a mental health crisis, particularly if you are over 65 years old whereby no out-of-hours provision is available for older people's mental health.

Mental health services such as talking therapies whereby waiting times are significantly high.

Emergency and Urgent Care has also been identified as a key issue based on local people's feedback about knowing where to go when they are unwell and lack of clarity about emergency and urgent care services.

Care at Home

People have told us mixed experiences about the support offered in North Tyneside to live at home independently. Positive experiences were largely characterised by the quality of care received.

"Overall care within the community with the provider is second to none"

"I feel safe, secure, settled and carers are marvellous"

Care Plus continues to be one of our overall highest rated services on our online feedback centre. Care Plus staff are utilising feedback forms to gather this feedback and have received significant positive feedback about the support offered and delivered in a comprehensive and coordinated way – "I couldn't have wished for better care".

Focus Groups and Events

In addition to the surveys, all local Healthwatch held focus groups and events based on the NHS Long Term Plan priorities using Healthwatch England discussion guides.

Healthwatch Gateshead

GP services

Generally, people spoke about the information and advice they'd like to receive about their care. They said that they wanted to make the right choices for them; about their lifestyle, about their treatment options and that the right information and advice was vital to support them to do this. Waiting times and difficulties accessing GP services was raised repeatedly and seen as a barrier to getting good care.

"Being able to access a GP. Lack of appointments and difficulty obtaining an appointment mean that many people, myself included, put off trying to seek medical advice on symptoms."

Assessment, diagnosis and treatment
People commented on the need for clear, accessible information in different formats, designed for the patient and not for the healthcare provider.

"To be given as much information as possible on consultation and not to use medical terminology, that is confusing."
This next comment was not exclusively about GP services, however, focus group attendees also said that they would like a range of methods to be assessed, e.g. telephone, video, face to face, and that they would like to receive a written care plan that they could refer to.

The provision of ongoing care and support
Focus group attendees said that they wanted some continuity of healthcare professional so that the person would get to know them and their health needs.
There was a suggestion that having one, medically trained professional, who could coordinate all of their health needs would be helpful.

RECEPTION

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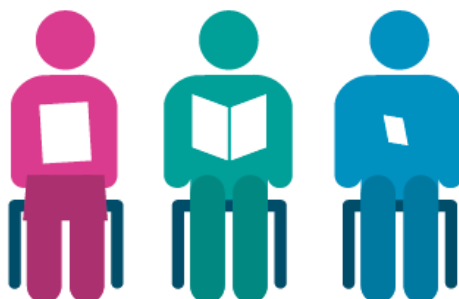
Healthwatch Newcastle and Healthwatch Gateshead

Mental Health Services – Young People

We held a separate focus group for young people looking at mental health. As with the responses to the main surveys, the young people expressed concerns about long waiting times and difficulties accessing the services. They also described the stigma that exists around mental ill health and how this can cause barriers to people seeking treatment as well as make existing mental health conditions worse.

Assessment, diagnosis and treatment

1. *Access*

   Young people felt that:
   - the responsibility currently falls on the individual to reach out to the service
   - there are long waiting lists for existing services because there are no specialised counselling services in the community
   - waiting times make people feel like they aren't important enough and feel forgotten about
   - there can be problems when people have to travel to services as this can depend on the person's mental health severity; some people won't travel far, especially if they are lacking motivation. Some young people also have money issues that can make travelling difficult.

2. *Diagnosis*

   One survey responded told us: "Almost nothing whatsoever is available to help eating disorders. Very, very poor. Long term conditions are not taken into account. Unless you are at severe risk, there is no help available. After a suicide attempt which resulted in three days of intensive care and intubation, discharge home immediately with absolutely no support at all is unacceptable. Then waiting 5 weeks for a first appointment."

   Another said: "After many attempts at suicide only after getting clean of drugs was my mental health listened to. Many of my friends & loved ones did not make it after sadly not being listened to."

3. *Treatment*

   Young people described being in a kind of loop where one was removed from treatment because they failed to attend an appointment due to their mental health condition. They suggested:
   - that people should be initially offered therapy at home for those with issues that make it hard for them to leave the house. This could change once the condition began to improve
   - the as counselling sessions usually last an hour, an online method such as Skype could be used for the initial session
   - that the current limit on the number of sessions available is a barrier to recovery as it takes a while to build up relationships and all the work is lost after sessions end
   - that mental health services should be attached to GP services and embedded in the community

   Young people also told us that they feel that medication is given to easily as a cheaper option. One participant told us that when they were 15 years old, they were told that their condition wasn't severe enough for medication and that healthcare professional don't like to give children medication. Once they turned 18 the medication was 'thrown' at them.

A survey respondent said: "The support actually caused me more harm than good... To me, my local mental health services destroyed my life, but because the injuries aren't physical it is denied... It could easily have been improved had they listened at any point, acknowledged the harm they caused and weren't so obsessed with labels."

The provision of ongoing care and support

1. *Family support*
   The young people felt that services should reach out to the families of young people with mental ill health to support them with strategies on how to handle their relative as well as to try to change attitudes towards mental health.

2. *Support offered whilst on the waiting list*
   The young people explained that there is no follow up with people while they are on a waiting list and they felt that this needed to be improved. This is a common factor that we have heard across our work on mental health. People describe the challenges they face while waiting for care.

   'The waiting list felt quite long considering the extent of my depression'

   Another answer suggested that they had been put on a waiting list for Cognitive Behaviour Therapy (CBT) treatment and in the meantime put on medication by their GP; 10 months later when they were seen by the CBT specialist they decided that it was not the right type of treatment which then meant more referrals and a longer waiting time before they were able to get help for the diagnoses. The student said that they felt like giving up trying to get help.[1] The young people in the focus group had previously researched recommended apps called therapy bites and they found 85% of young people found them helpful. They see them as a good alternative therapy to use whilst waiting for other treatment.

3. *Support in education*
   Focus group participants described positive experiences of support from the school nurse, however, they also stated that there is no support for young people in sixth form. They expressed concern about teachers taking on counselling responsibilities when this was not their role. They identified that the counselling within a university setting is quite good, however, our report on student mental health[2] indicates that there are still issues in our university settings.

4. *Peer support*
   Whilst the young people identified that they got support from their peers, they felt that this put the individuals providing support under a lot of pressure. They suggested that mental health first aid should be taught at a young age to help with this.

5. *Lack of coordination*
   The young people described how lots of different health professionals and other workers can be involved in a person's care. They explained how they can often have different views and standpoints and suggested that this needed better coordination and communication.

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[1] Student experiences of local mental health services https://www.healthwatchnewcastle.org.uk/wp-content/uploads/2019/04/mental-health-report-student-community.pdf

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Prevention and/or early intervention

1. *Stigma and lack of knowledge*
   The young people told us that there is still a lot of stigma around mental ill health. This is especially the case for young men where mental health and wellbeing is less likely to be discussed. The young people felt that there should be more publicity focused on talking about mental health.

   The group generally agreed that there needed to be education around mental health and that schools should be involved in this. They suggested that all professionals should have training in identifying the symptoms of mental ill health and that education of children should start, in an age appropriate manner, in primary school.

   For young people in particular, the use of online media to education and share information was highlighted. They told us that they could then use their phone to look at sensitive and personal information. They also felt that this would help the information to reach a bigger audience: "can't share a poster but can share a post."
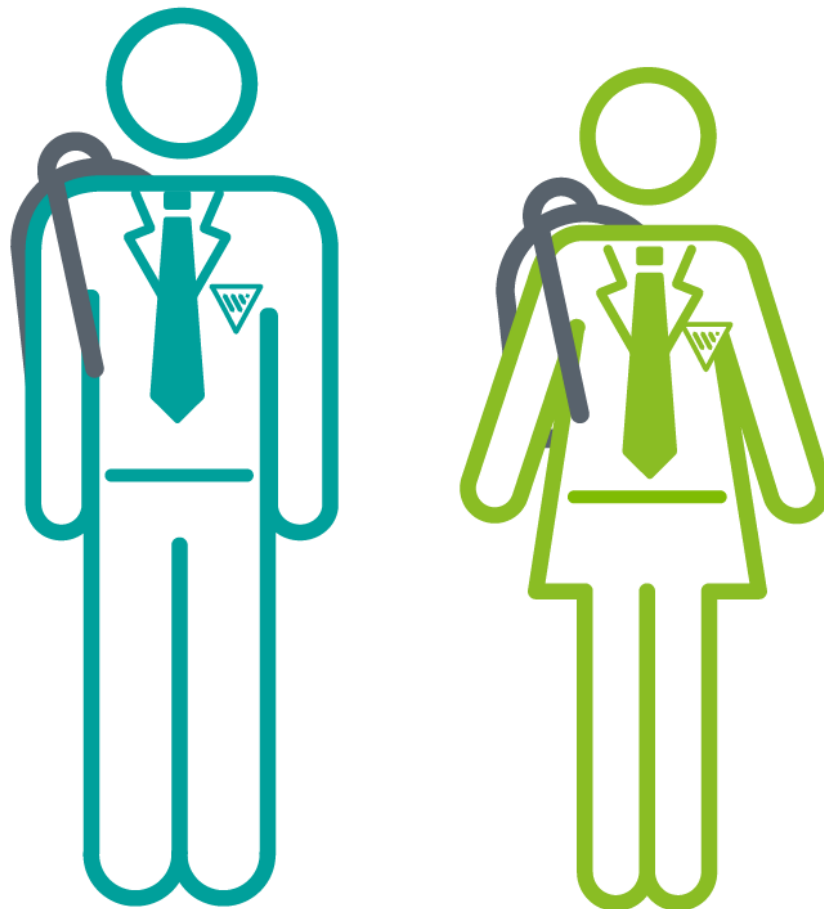
Healthwatch County Durham

Overview of care & support in County Durham

There was a mixed response when people were asked if having multiple conditions made it easier or harder to get support. Some people indicated that already being known by services made a difference, perhaps in terms of asking or receiving advice about what to do or who to speak to, but there were others that felt it made no difference or made it more difficult to seek support for a second condition.

How would you describe the experience of seeking support for more than one condition at a time?
75 people identified that they had multiple conditions and almost half of those (35 people, 47%) said it made no difference. People answered as follows:

It made getting support easier	7	**9%**
No difference	35	**47%**
It made getting support harder	24	**32%**
I don't know	4	**4%**
Not applicable or did not answer	5	**7%**

Across the three stages of the care journey, the survey responses indicated that people have different experiences around the timescales that are involved. Accessing services and making the initial appointment, for example with a GP, can involve delays as people commented on. This has an impact on how quickly people can then be diagnosed and treated. Ongoing care and support in some areas can be positive; such as when people are able to see health care professionals who they are familiar with or they are able to access regular check-ups to monitor their condition.

People are receptive to work that supports the prevention and/or early intervention to illnesses or other conditions. With some help and encouragement, people want to improve their general health and wellbeing. They were happy about the level of support they currently receive or had suggestions about what would help:

- "Just to maintain the level of care and support I am receiving now."
- "A fairly regular set of appointments to monitor progress or otherwise."
- "Have more support groups and easy access to services."
- "To continue with appointments for check-ups on a regular basis and not change appointments."
- "Regular health checks for recognised conditions."
- "There should certainly be more emphasis on staying healthy and provision of exercise plans and dietary help."
- "Provide information and tips on how to maintain a healthy lifestyle."
- "I feel continuity of service is key as well as appointments being long enough to discuss issues thoroughly so nothing is missed and assumptions not made."

Assessment, diagnosis and treatment

From our work into mental health services, the main concerns surrounding service access appears to be how long it takes for people to seek help, how long it then takes to start therapy, and the time it takes for mental health to improve once therapies have started. Many people we spoke to said they reached 'breaking point' before admitting they needed help. We found that over 75% of referrals were made by a health care professional, such as a GP. (*Source: Healthwatch County Durham - Report into "Your views about mental health services in County Durham" April 2019*)

This survey also shows similar issues for assessment and diagnosis. Patients struggle to receive a diagnosis or experience difficulties during the process:

- "I've never had a clear diagnosis. Told three different conditions by three different psychiatrists."
- "I saw my GP in January and I have a referral letter. I have researched and chosen a particular endocrinologist I wish to see but, as yet, two months later, the hospital have not been in touch to provide a date for the appointment. Do not know how long I will be expected to wait."
- "The time was not the issue. It would have been faster had the GP used the correct tests at the outset. It was only on consulting a charity that I discovered that the wrong blood tests had been carried out initially."
- "My GP suggested CBT to cope with pain. After several planned calls not happening, they have now sent me a questionnaire. I waited for the planned phone calls, but they never came."
- "The time between diagnosis and treatment was ok, but there was a lack of support."

It is apparent from the feedback we have been given that patients have had issues while accessing services. We would suggest that the key areas that would benefit patients in County Durham are quicker access to health care professionals when first seeking help and also accurate levels of communication during the stages that follow.

The provision of ongoing care and support

From the people who did access ongoing care and support, there were a number of aspects that worked very well, from the inpatient and outpatient services at hospitals to the involvement of other agencies & organisations. There was some feedback that where services were time-limited then having the option to extend this would have been useful.

What worked well

- "Hospital care, both outpatient and inpatient, was excellent, including follow up appointments with the oncology nurse specialist."
- "I have been referred to Talking Changes - for my weight. It is s marvellous idea and think this should be throughout the Country. I have also done the 4 weeks that explains about the brain, how it can sabotage our thinking and why. A truly great course. I still go weekly to my support group for weight. Far better than slimming groups."
- "Coming out to my home where family could take a more positive part in the assessment making them more aware of what the next steps were for my care."

What could have been improved

- "The physio gave my mother a sheet of exercises to do. That was pretty much it."
- "The fitness and motivation side of recovery but it is only 6 to 8 weeks long."
- "Treatment is fine but process too slow."

One person said: *"CAMHS offer help and support but there is very little. If anything we were signposted to voluntary and charity help as there is very little funding in this area."*

We are frequently seeing the inclusion of the voluntary sector as being able to address the gap or limitations in service provision for long-term support. A number of other comments also reflected on the invaluable help and support that nurses from Macmillan Cancer Support have provided for the patient and the wider family.

Regular health checks can provide a reassuring level of input from health care professionals. It gives the patient access to someone who can offer advice and support, the opportunity to ask any questions, and have long-term conditions monitored.

Prevention and/or early intervention

There was less said about this in the survey but it is recognised that national campaigns also reach people at a local level. Work is ongoing in County Durham to address the top five risk factors identified by the "Global burden of disease study" in The Lancet: *smoking, poor diet, high blood pressure, obesity, and alcohol and drug use*. The NHS will be able to play a role in the work on prevention and members of the public are receptive to the opportunities that will be presented to them. A number of comments in our survey also shared the view that individuals must do more to help themselves with resources that can be made available.

Healthwatch North Tyneside

Implementing Cancer Services

We spoke to a group of local people with experiences of using cancer services to understand what currently works, what areas should be improved and understand how cancer services should be implemented locally in the future.

What Works Well?

People told us about a range of positive experiences when using cancer services. Every person we spoke to was very positive about the care they had received and acknowledged that '[they] wouldn't, be here without it'. It's important to note how grateful people felt for the care they received.

> "Particularly lucky to have excellent hospitals and university working together on improving treatment, it's a terrific place to be ill"

"The Bobby Robson is Magic, Brilliant, I didn't want to leave"

"Maggie's centre is great although the centre manager is very busy and not as focused on local services now, she manages other places too"

"The specialist nurse's phone line is available 24/7 and that's really important"

People told us about the importance of having continued support from specialist services and the positive impact peer support could have both during and after treatment.

"What really helped me was talking to someone who had been through it whilst I was having my treatment"

What could be improved?

People also discussed a range of areas they felt could be improved based on their experiences of using services.

1. *Early Identification* was a key issue that several people raised, this was deemed as particularly pertinent for males who felt fearful of reaching out for support and did not prioritise screening.

   "If you don't feel ill then you don't prioritise"

   "I thought I was just getting old"

   "Blokes are particularly good at ignoring things"

   Not identifying cancer early had a significant impact on people's experiences of diagnosis, treatment and support and therefore people suggested that awareness around screening and what to do post-screening was an area which needed increased improvement.

   "When the screening showed there might be an issue to check out, I didn't realise how serious it was"

   "Some people are so 'shit scared' that they don't want to know more"

2. *Access to GPs* was also identified as a challenge for people being diagnosed and treated. People discussed GP availability being a factor in delayed diagnosis.

   "Difficult to book an appointment and that was partly why my diagnosis was delayed. I'd had a PSA test as part of a check-up at work through Nuffield, they identified my levels were very high and said I needed to get a GP appointment, but I was working away, and it was difficult to get an appointment that worked for me. I didn't appreciate how important it was until Nuffield began calling me to check if I'd seen my GP"

   "Post treatment was GP is first port of call, but they are hard to get appointments with"

3. *Communications at Key Points* were described as being difficult to hear and understand, meaning that often people weren't able to absorb the information or treatment options available to them.

   "But you are in the zone [reacting] so not hearing"

People discussed the value of taking another person to appointments with you, to listen and take notes, or making sure information was relayed in a way that meant you could revisit it at a later point.

Positive experiences of consultants listening to patients who had done their own research into the cancer and treatment options were described. The participants also said that they knew people who 'just wanted to be told what to do' and relied on the professionals to make decisions. This confirms that the level of involvement or control of treatment different people wants varies.

People also told us about feeling like they did not know what to expect, further demonstrating the importance of peer support and continuity of care.

4. *Patient Transport* was also noted as 'a real issue' for a number of people who often needed support to get to their treatment. This is a particular concern for those travelling from other areas to access treatment.

   "[I am] lucky to live close to the Freeman [hospital] but for people traveling from Northumberland or other places it's a massive issue"

5. *Support for carers and family* was indicated as a major issue as their experiences showed it was vertically nonexistent. This was a key concern for patients who felt their families were not supported and felt more signposting to support groups and local charities such as the carers centre would be incredibly beneficial.

   "emotional support and impact of seeing someone you love suffering and dying isn't thought though in the NHS…[they] need to do a better job"

Suggestions for Improvement

Through discussions, patients highlighted and crafted key actions that would help improve future provision of cancer services in North Tyneside. These included:

- Improving ways to find out about access to support for patients.
- Significant development in the way that carers and families are supported, involved and signposted to further services for further support.
- Supporting people to understand the treatment options and support available to them, whilst understanding that each person may want different levels and types of support to suit their needs.
- Improving awareness about screening and post screening actions to ensure people take the actions they need to. Additional support for those who are too worried about being screened or seeking further investigation to engage with services early.
- Increased support with practical issues that change post-treatment. For example, how you can manage your waterworks.
- Increasing support for peer support networks to ensure that people have the opportunity to discuss their lived experience with someone who has experienced cancer too.

Implementing Mental Health Services

We also spoke to people with experiences of using services to support their mental health needs. We discussed what currently works, what areas should be improved and how mental health services should be implemented locally in the future.

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What Works Well?

People talked to us about positive experiences of mental health being discussed within schools and schools now referring students directly to CAMHS. Similarly, one person discussed the support offered to their child at university as being 'life transforming'. In this particular case, a student with autism was assigned a tutor with autism to support their needs most effectively.

A number of people also commented on the positive experiences of the provision of mental health support delivered through the voluntary sector. The Newcastle Recovery College (ReCoCo) was highlighted for its good practice and the user led approach adopted. People noted that pharmacies were helpful and often took the time to describe and explain medication thoroughly.

The Crisis Resolution and Home Treatment team and Talking Therapies were both described as helpful but only once people were able to access the service which was a significant issue for most people who felt access was incredibly challenging and the amount of support was often time limited and restrictive. This issue is reflective of the views we continue to hear about mental health services through our general engagement activity.

Existing Insights: Supporting People in Crisis

In 2018, we carried out research to understand local people's experiences of accessing support when they were experiencing a mental health crisis. We spoke to 215 service users, carers and mental health staff through various research methods to gather a range of experiences and challenges people face.

We found that:

- 82% of respondents discussed long waiting times to access mental health services in a crisis. They discussed long waits for call backs from the crisis team, waiting for talking therapies and to see their GP.
- People found the experience of receiving care as positive, although often raised concerns about staff approach to mental health.
- People had largely poor experiences of transitioning and discharge from services. They talked about the process being 'disjointed', self-led and the follow up support following discharge being very short-term.
- Full report: https://healthwatchnorthtyneside.co.uk/your-issues/mental-health/

What could be improved?

People discussed a range of poor experiences and areas that could be improved when delivering mental health services.

1. *Waiting times* to receive support is a key issue. This includes waits between GP referrals to Talking Therapies, waiting for specialist services and many other services. The long waits to receive treatment often meant people's mental health worsened and they required higher support by the time they began treatment.

2. *Rationing and time-limiting* of services meant that often interventions tended to be too short causing increased anxiety and what was often felt as premature discharge

3. *People discussed the binary options of treatment being offered.* These options were often CBT or medication. The use of CBT or medication which were often not helpful and did not

meet the person's needs. People perceived these options to be available because they were 'easy' options and 'cheap'.

4. *Access* was reinforced as one of the most pertinent issues for people engaging with mental health services. People felt that suicide intention is often seen as a measure of need. People have to 'act out' a certain role or say certain words to be eligible for support. This was noted as 'a game' that is played to slow down the process which can look good for mental health services stats but is extremely detrimental to the patients waiting for support. Access was even more difficult for people with multiple conditions or substance use issues.

5. *Support for both mental and physical health* was challenging as either one or the other is dealt with and they often influence each other. Such physical health issues can also be exacerbated by medications.

6. *Information sharing* was identified as a complex issue. People felt they should have the choice and control over their information, although processes should be in place to share information effectively between services when people consent to sharing their information to streamline support from services and stop people from having to repeatedly explain their issues.

7. *Support for older people* was a primary concern as currently in North Tyneside there is no out of hours support for over 65s mental health meaning there is no access to 'crisis' support.

8. *Staff approach* and the relationship between staff and service user was also noted as challenging. People discussed experiences of appointments being changed by professionals without consideration to the service users personal commitments. However, that flexibility was not allowed for those waiting for the service. Staff also sometimes made assumptions on behalf of the service user about when they would want support. One person described not being offered appointment for Christmas Eve due to the assumption that they would not want to attend – person stated that they would rather attend to start the journey of support after waiting so long to access.

9. *Additional issues* were noted around the impact of austerity on people's mental wellbeing, the decommissioning of crisis bed provision in the borough and the lack of effective signposting offered by medical professionals to support services.

What Should Support Look Like?

To understand how issues could be resolved and changes could be implemented locally we asked people what support should look like in the future. To break this down we considered 'who' should provide support, 'where' support should be provided and 'when'.

Who?
- There should be a choice of which people should be involved and support needs to be delivered in a coordinated approach whereby professionals work together and share information accurately so that they can see the whole picture.
- The person should have the time and skills to listen to you and work decisions out together and staffing should be consistent and someone you can develop a rapport with.
- NHS 111 was not viewed as the right place for a single point of access.
- Specific roles identified included: school nurses, health visitors, community support, someone who understands mental health, physical health and other related issues.

Where?

- Within the community, especially for people with eating disorders who usually must travel further afield.
- Home visits should be offered, especially for people experiencing anxiety or agoraphobia.
- Walk in centres with trained nurses and pharmacies or local clinics.
- Person should be able to nominate their primary point of contact that suits their individual needs.
- The idea of crisis cafes is good or safe spaces within local services, this could be helpful for people with other needs such as homeless people.
- The Northumbria Specialist Emergency Care hospital is not appropriate due to how far away it is and lack of appropriate transport in place.

When?

- Person described historical experience of getting mental health care quickly after a criminal event and questioned if it worked then, why not now?
- The individual knows how urgent they feel they need to be seen, they will be giving an honest response, and this should be listened to but is often not.
- The annual medication review is very important, especially for older people and those with limited interaction with services.
- Prevention and early intervention are important, there needs to be an earlier way of reaching people before they hit crisis point. The lack of this support will no doubt lead to exacerbation of mental health needs.

Access, Information and Digital Solutions

Digital solutions are an increasingly utilised way of providing health care and have a key focus within the NHS Long Term Plan. We discussed both the benefits and issues utilising digital solutions may have when supporting people with their mental health needs.

A key issue was raised about a number of services where the requirement is telephone centred access (such as talking therapies). This is a significant barrier for people with limited verbal communication and for people who are not confident.

The group also discussed how an online chat service is common on most websites and this would be useful for people experiencing mental health issues and their carers who may require informal support. This could be used as a helpful way of navigating the system and finding out the most appropriate service to access. FRANK was noted as a useful resource for support and could provide a useful model for a mental health support too.

It was noted that GP and hospital appointments are beginning to be delivered via skype, however, they often cost. This would need to be offered free to limit financial barriers to support.

Healthwatch Northumberland

Dementia Services

Healthwatch Northumberland held a focus group to discuss the Long Term Plan with eight people with a personal experience of dementia as a carer or professional supporting families living with dementia. Dementia services were identified as a priority by residents in the 2018 and 2019 Healthwatch Northumberland Annual Survey.

The most prevalent issue expressed was the lack of information, advice and support following diagnosis. This was summarised by one participant who cares for their partner with dementia as:

"I can't think of any other illness where someone is just sent home and the family has to deal with it with so little information and support."

Prevention and/or early intervention

What works well?
The group were unable to identify from their own experiences positive examples of prevention or early intervention.

What could be better?
The group identified the use of screening and early diagnosis to help to keep people with dementia independent for longer.

Assessment, diagnosis and treatment

What works well?
There was positive feedback about NHS Community Mental Health Teams. There was experience of regular (6-weekly) meetings with Community Psychiatric Nurses and help during diagnosis.

What could be better?
The need for support and information with the priorities as:

- Admiral Nurse (for carer) or similar to meet with the person with dementia and carer on the same day as diagnosis in line with Macmillan support at a cancer diagnosis.

- Named individual within GP practice "to take ownership" and develop a care plan with patient and carer and to provide signposting and referrals to information and support services.

- Letters or communications about the diagnosis to be in plain English

Ongoing care and support

What works well?
Services provided by **voluntary and community sector organisations,** specifically for carers were mentioned for practical and emotional support including training sessions for carers on how to maintain good mental health, peer support on how to deal with challenging behaviour and for maintaining a sense of individuality. However it was noted that that securing long term funding is a problem for these organisations resulting in a lack of continuity.

What could be better?
Information, advice and training. The group identified a need for well-coordinated post diagnosis information and support with key priorities as:

- Training and practical advice for carers on how to manage relationships, behaviours and what to expect at the different stages of dementia journey. This to be funded and promoted (although not necessarily delivered) by NHS as the 'trusted brand'.

Also training for NHS and healthcare staff on how to work in partnership with carers by recognising their knowledge and expertise about the person with dementia.

- GP practice to be the central co-coordinating point with designated leads for patients and carers for all services and information. Including flags on patient and carer records, following up on patient and carer care plans.

- Dementia diagnosis and practical information from carer flagged on all records for all services prominently. This would help forward planning for transition between services before a crisis point (eg hospital admission) and improve quality of care with regards to giving medicines, pain management, eating and toilet arrangements.

- A wider recognition by NHS services that people with dementia and carers require more time and support to access appointments, especially those not related directly to the dementia eg health screening appointments. The latter being important to overall health and wellbeing.

Suggested practical changes to services as:

- Automatic longer GP appointments for people with dementia and their carers.

- All NHS services to communicate with carer to arrange appropriate time and length of appointment and support that might be needed.

In focus

The most prevalent issue expressed about dementia services was the lack of information, advice and support following diagnosis. This was summarised by a focus group participant who cares for their partner with dementia as:

"I can't think of any other illness where someone is just sent home and the family has to deal with it with so little information and support."

Mental Health Services

Healthwatch Northumberland held a focus group of nine people with a personal experience of mental health problems, as a carer or professional supporting families or individuals and received written responses from two people who care or cared for relatives with long term mental health conditions. Mental Health Services have been the top priority identified by residents in the 2018 and 2019 Healthwatch Northumberland Annual Survey.

Inequality of access to services due to the geography and population distribution of the county means there are perceived "hotspots of support" in the more populated areas. Barriers to accessing services can be both physical, due to poor broadband/mobile signals and mental – it can be hard to phone up for yourself if you are suffering from anxiety or paranoia and individuals may not want to be identified in their small local community – this may prevent access to local services.

Lack of funding or ending of short term funding of both statutory and voluntary sector services was mentioned as an issue which can lead to problems of accessing services and providing continuity of care.

Prevention and/or early intervention

What works well?

The service areas that were identified as working well were:

- Voluntary and community sector services including work in schools although it was noted that access varies creating a "postcode lottery"

- Northumbria Police, described as "fantastic but it's not what they should be doing and is potentially stigmatising". Also noted a voluntary police project specifically for mental health

- Two High Schools which have a buddy/peer support programme

- Northumberland Tyne & Wear NHSF Trust services:

  Involvement strategy to promote the active involvement of patients and families through a 'service-user and carer reference group'

  The crisis team which has improved over time but noted the need to wait until next day for contact and police number given during wait.

What could be better?

- Crisis Team availability in rural areas

- Respite care for those caring for loved ones with mental health problems, some of whom also have a range of long-term chronic conditions

- Support for carers with lived experience to provide support

- Crisis moments have resulted in inconsistent care and support, e.g. perceived poor care from 111 and excellent care from ambulance services. Lack of joined up working means repeating story over and over –technology/digital improvements may be able to help with this

- More information about support planning which is a service available through Northumberland County Council's 'One Call' contact centre.

- Recognition by service providers (statutory and voluntary) that telephone contact may not be appropriate for everyone

A bereaved parent reported:

"The support for a bereaved parent with anxiety, depression panic attacks and PTSD, is very hard to find and the waiting list for treatment is ridiculously long. Having suffered a sudden traumatic loss I like many others struggle to use the phone and yet (provider) do all their initial assessments by phone"

In 2018 Healthwatch Northumberland listened to young people and about their experiences of finding help and support for concerns about their own or others mental health. Our findings were that routes into universal services were less clearly signposted to community than targeted/specialist mental health support. The majority of places young people would seek help were not in professional realm and that young people appeared motivated to seek help on line and adopt a "self-help" approach.

Priorities identified as:

- Consideration of how to equalise access to crisis services across the county

- Promotion of Support Planning service by NHS and local authority

Assessment, diagnosis and treatment

What works well?
- Positive experience of inpatient Recovery College at St George's Hospital

- Eating Disorder children and young people's intensive community treatment

- The dedicated mental health team at the Northumbria Specialist Emergency Care Hospital, which may be accessed just by walking in.

- Booking GP appointments online

What could be better?
- Training and support for front line staff including GP receptionists to have more of an awareness of mental health issues.

- A more responsive service based on an individual's support plan

- Co-ordination and joining up of services between emergency mental health liaison team, primary and community mental health team with for people going in and out of services eg avoiding 18 week waiting time

- Waiting lists, especially for under 18s are long and there is an absence of anything while waiting.

- NHS procurement system which leaves providers uncertain about future of services and therefore at risk of losing staff and continuity of service.

Priorities for development identified as;
- Front line staff in NHS and local authority services to be able to access mental health training in work time, developed and delivered by people with personal experiences as patients and carers.

- Active management of waiting lists by contacting those waiting weekly to reduce isolation or to signpost to a support group. This would not have to be a clinician. Impact measured via contract management process.

- Review of referral pathways for people who re-enter services from emergency services.

- Review of procurement process to include consideration of impact of short term contract on quality of care.

Ongoing care and support

What works well?
Services provided by voluntary and community sector organisations were identified as providing important and varied support but subject to limited funding.

What could be better?
- Provision of a Recovery College in Northumberland.

- More referrals being made by GP's to community services through social prescribing.

Priorities for development identified as:

- Development of a business case and plan for a Recovery College in Northumberland There are external recovery colleges in North Tyneside and Newcastle/Gateshead. The latter with staff seconded from mental health trust. This is service-user led with support from partnership organisations.

- Build on networking and information sharing through existing Locality Co-ordinator posts

In Focus

A carer for someone with long team mental health problems shared their experience of finding help and support and the importance of continuity:

There is such a lack of coordination between the different community teams, and whilst social services have a legal responsibility to my loved one it was a struggle to get the correct help. We have had 5 different social workers in the last year; the most recent one is good and actually returns my phone calls.

My loved one's mental health is helped by having someone to take them out, but it's mostly been down to me to organise, I didn't have local knowledge to find the right support service. The agencies in this area don't have enough staff and they let you down. I have resorted to looking for someone through Facebook, we have found a lovely person to help, this seems promising- Social Services supported me at the interview.
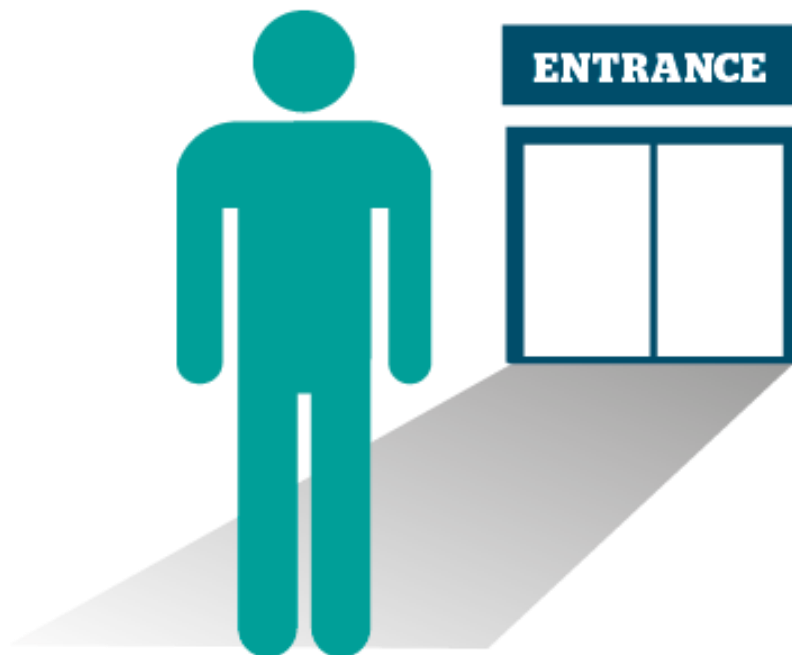
Healthwatch Sunderland:

Implementing technology in primary care services

The NHS and social care providers are embracing technology as part of their drive to offer modern, convenient and responsive services to patients, service users, their families and carers. Healthwatch Sunderland has been watching this progress in Primary Care closely and is involved in Sunderland CCGs New Consultation Types working group.

NHS – Primary Care

In Sunderland the introduction of a range of innovative new services is now available in some GP practices across the city. These include
•   eConsult – an online consultation tool econsult.net
•   Telephone consultations
•   Group consultations
•   Patient online
•   Apps for health conditions myCOPD/myHeart mymhealth.com
•   Appointment reminder text service (mjog.com)
Patients can now consult with their GP online, over the telephone, via video consultation or attend a group consultation for illnesses such as diabetes or COPD. Patients can also download apps that can help monitor and manage specific health conditions.

These services are currently live in 16 of the 40 practices in Sunderland and the CCG aims to introduce the scheme in every practice by 2021.

Dr Raj Bethapudi, Executive GP at NHS Sunderland Clinical Commissioning Group (CCG) said: "These changes will give patients a whole range of convenient ways to consult their GP and make better use of technology. There is no change to the traditional appointment to see a GP in person, but patients will have a range of more flexible options to suit busy lifestyles."

Findings summary

When discussing the use of technology in **Primary Care** people told us both in the workshops we held and those who completed the surveys, that technology can be a very useful tool to enhance the provision of health and care services. However they also stated that it is very important to ensure that the offer to use technology is part of a wider available choice and not the only option. In the main, people talked about technology linked to their GP practice, in particular access to GP appointments via telephone systems, or on line booking apps.

Assessment, diagnosis and treatment

Feedback received from the surveys and engagement work indicated that at this stage of the care journey, the majority of people have issues when trying to access Primary Care and this is becoming increasingly prevalent. This feedback is also backed up with local intelligence we have collated over the past year, which has shown that over 20% of all feedback Healthwatch Sunderland has received was regarding GP's the majority of which was directly linked to peoples lack of access to timely appointments for treatment.

People continually cite to us that they wait on average 2 weeks to gain a GP appointment and booking that appointment is often made difficult due to technology and/or telephone systems available to them;

"The hideous telephone system, where you have to call at 8am and be 31st in the queue is appalling. The list of options that people have to listen to before and after each choice they

make, is appalling. Elderly people and people who have learning difficulties and disabilities struggle with the telephone system for appointments, getting results, ordering repeat prescriptions. Not all appointments can be made using the online Patient Access app either, which is infuriating." (Survey respondent)

51% of those who completed the survey stated that it was very important to them, that they are able to make their appointments on line.

People in the survey and workshops also stated that at this the stage of the care journey that it is important that interactions not involving technology are important and recognised that technology is only suitable for some patients/service users and in certain situations. Examples given included those who don't have access to technology or of those who may have an impairment or are vulnerable. However many people also told us that accessing appointments on line was important;

49% of survey respondents stated that it was very important that they can access services using a phone or computer;

"Modernising the NHS digitally is important to me to be able to access services at a time that suits me and to help reduce waste. There's not enough GPs so we need to do something different." (Survey respondent)

The provision of ongoing care and support

People liked and found it important that they could access their medical records, prescriptions and test results on line. However there appears to be a discrepancy between GP practices in the amount of data that is uploaded to patient records. Some people stated they could see all their records and others stated they could see very little. People were unsure as to why this discrepancy occurs;

"I also cannot access my own personal records via the Patient Access app either, which I thought I would be able to, as this is the impression I have been given, which is completely false as far as I am concerned."

64% survey respondents also stated that any results communicated quickly and making the best use of technology.

Within the workshop with the advocacy group they mentioned that many people who have autism do like to use technology as it does cut down on human interaction which can cause people anxiety. Therefore the option to carry out an e-consult appointment was welcomed and often a preferred option.

Prevention and/or early intervention

People liked and found important some of the technology and apps that are now available to help people with self-care. This includes the COPD apps, the childhood health apps and the e-consult around suitable medications and also other things that can be done to keep them healthy for longer. Tools that are available to people when they have a minor ailment that could be dealt with at home, or people mentioned that they were signposted to their pharmacy.

Also as mentioned earlier survey respondents told us that they would like to see more information available to them on how to keep themselves healthy and happy and the use of technology could be one way of doing this;

"More health and fitness classes at local community centres that are widely publicised and reasonably priced. Having a full listing of services available."

"More information and better signposting of services available would help me."

Engaging people in health service delivery

Gateshead

What people expect during service change and transformation

Many people in Gateshead are not particularly engaged in service change and improvement in the NHS locally or nationally. People have told us that they feel that they are not able to engage as well as they used to, due to changes in the Clinical Commissioning Group engagement processes, although it should be noted that these were always attended by a small group of individuals and therefore this was not particularly representative of the Borough's population.

Our focus groups attendees commented that there had to be a range of ways to communicate and that commissioners and service providers should not just rely on the internet.

Focus group attendees said they believed that people should be engaged with after every experience, whether positive or negative and that when they have shared their experiences and views that it is extremely important, "10/10 importance" that people receive feedback on what has happened, regardless of the outcome.

People in attending one of our focus group said that they wanted to be properly involved, rather than just token communication.

"The public should be more involved genuinely in the commissioning of services."

We have found that engaging through existing groups allows us to hear from people that would not normally attend health related events. When conducting this consultation, we approached a wide range of community groups, places of worship and clubs, and asked them to share the survey. Our young people's focus group was hosted by the young people's charity, Streetwise Newcastle, which encouraged people to attend, supported their participation and established a level of trust as it was a known and trusted organisation.

Newcastle

What people expect during service change and transformation

Many people in Newcastle are not particularly engaged in service change and improvement in the NHS locally or nationally. As our focus group attendees put it:

"It is difficult to be informed. A lot of the meetings some people go to, to stay informed happen during the day. This is hard for workers."

'Normal people' are often underrepresented at meetings and our focus group members felt that this was because most people don't have time to find out about the meetings and then attend them.

People have also told us that they feel that they are not able to engage as well as they used to, due to changes in the Clinical Commissioning Group engagement processes, although it should be noted that these were always attended by a small group of individuals and therefore this was not particularly representative of the city's population.

Our focus groups agreed that when it comes to keeping people engaged and informed, choice is important. People should be able to choose how they want to engage, and a wide range of methods should be used, e.g. surveys, focus groups, digital tools.

We have found that engaging through existing groups allows us to hear from people that would not normally attend health related events. When conducting this consultation, we approached a wide range of community groups, places of worship and clubs, and asked them to share the survey. Our young people's focus group was hosted by the young people's charity, Streetwise Newcastle, which encouraged people to attend, supported their participation and established a level of trust as it was a known and trusted organisation.

Our focus group attendees highlighted some good practice by Newcastle Upon Tyne Hospitals NHS Foundation Trust who host member event on a regular basis. These take place in the evening and have a speaker. Attendees said that there was a genuine exchange of views.

County Durham

People in County Durham opened up about what was important to them. We heard from those as young as 18-24 right through to those aged 75+ and they were able to share some different perspectives. While there were some comments about the older generation and "ageism (being) alive and well on the NHS", the low response from some age groups (as below) means that some comparisons are difficult to achieve.

Age range of people who completed the survey

18-24: 2%
25-34: 6%
35-44: 10%
45-54: 17%
55-64: 25%
65-74: 22%
75+: 16%
Did not answer: 2%
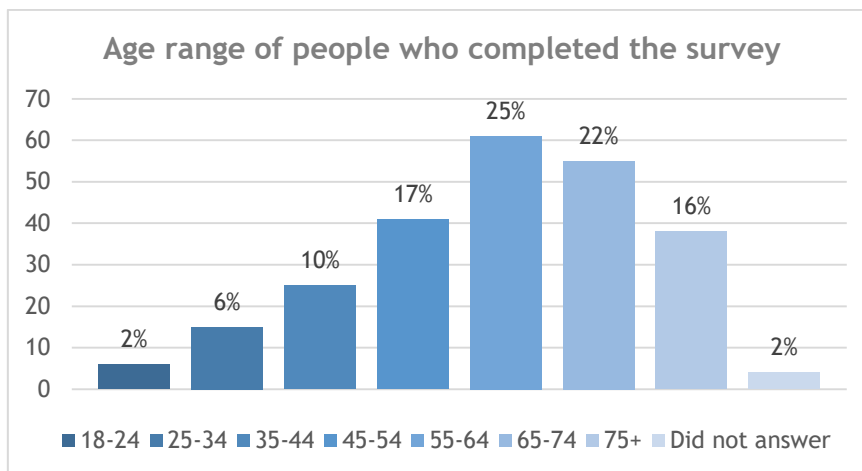
Based on the feedback given in the survey, we would suggest that a range of options need to be provided and maintained to ensure maximum levels of engagement are possible.

People do find comfort in having familiar faces during emotional times, but this might not be a priority when they want a quicker response. For example, when first seeking help, people might agree to see 'any medically appropriate health professional who is free immediately' up to the initial treatment but would rather 'see a health professional they normally see but may have to wait' during long-term support.

North Tyneside

"NHS to have a customer focus"

We wanted to understand people's views on how they should be engaged with service delivery and what ways that people can make a difference to how services are delivered locally. Most people felt that the family and friends test was not an appropriate way of gathering meaningful feedback about services. Some ways in which people should be effectively engaged were outlined:

- Service users should be involved in questions which can be asked to gain meaningful feedback i.e. 'were your needs met?' or 'were you seen promptly?'
- Service users should share experiences with Healthwatch so they can influence services locally
- The CCG and NHS Trusts should talk to people directly through focus groups.
- Patients and service users should be involved in the education of professionals. Service users and carers should be involved in the training.

The importance of being engaged at multiple levels was highlighted.

- Service users and carers being involved in decision making about their own care;
- Service reviews of providers;
- Representation on decision making boards and groups.

Northumberland

What people expect during their treatment journey

From the surveys responses below, people in Northumberland expect good, personalised two way communication during their treatment journey.

Interacting with the NHS

- Any results are communicated to me quickly making best use of technology
- I can access services using my phone or computer
- I can make appointments online and my options are not limited
- I can talk to my doctor or other health care professional wherever I am
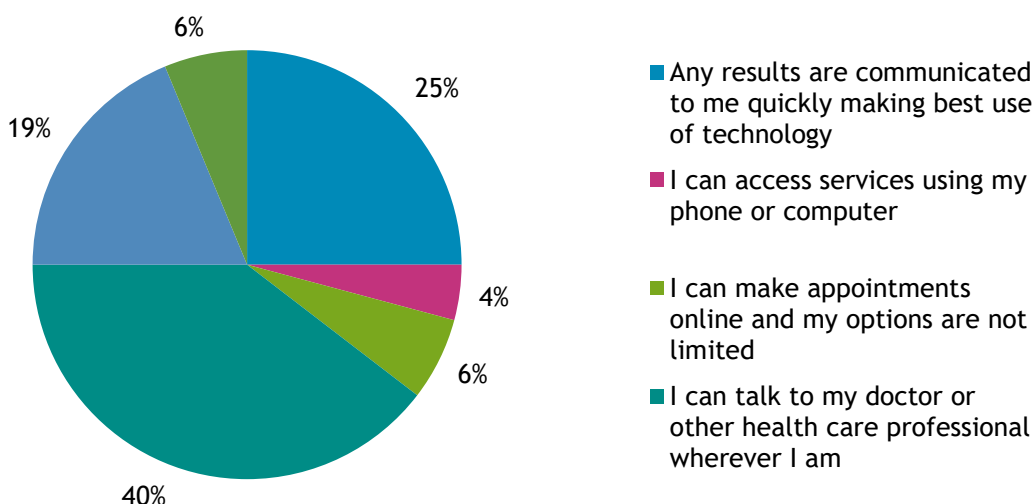
In the focus groups people's experiences of giving feedback was mixed. Many people had been asked and given feedback to different services at different times but were not routinely aware of how the feedback had been used or what difference it had made.

What people expect during service change and transformation

It was noted during the dementia focus group event that no-one present was aware of the NHS Long Term Plan.

Healthwatch Northumberland has engaged with communities across the county where service change is proposed. The services have been at both primary and secondary care levels. In all cases communities have told us their expectations of service commissioners and providers and what could be improved are:

•   They should engagement with communities at the earliest possible stage of the change process before initial proposals are formulated

•   Engagement should be meaningful and the commissioners and providers should be able to demonstrate quickly how feedback received from communities has influenced change proposals

•   Travel and transport are key factors in Northumberland as an issue of fairness and equity. Particular concern for those on fixed incomes or who do not drive and where distances and weather can affect the ability of people to access services or for service providers to maintain a level of service in sparsely populated rural areas and more urban communities.

    Two Healthwatch Northumberland reports in the last year have highlighted the critical importance of robust transport impact analysis on service change proposals.

Sunderland

The survey and workshops looked at how people want to be engaged in changes to service delivery and how often.

What people expect during their treatment journey

• Overall those who engaged in the survey and the workshops all stated that they do like to be involved in health and care service improvements and transformation.
• Some of those who took part in one of the workshops highlighted some good practice that is taking place and in particular a piece of work that they were involved in changes that are happening in the delivery of cancer screening services.
• Another area highlighted was satisfaction surveys via text messages that some people received after their visit to their GP for an appointment. This didn't happen to all participants in the workshops but those who did receive them felt that this was a good way to engage patients on how things could be improved.
• Areas that were highlighted that need improving is the awareness raising to let people know how they can become involved in the work that happens to help improve services and where to go to have their voice heard.

What people expect during service change and transformation

• People were keen to take part in some of the big changes that occur nationally and locally, but only if it was genuine consultation. Some people mentioned about the NHS engagement/consultation work they had taken part in lately especially around changes happening locally with local hospital services. Some people felt that decisions had already been made and therefore consulting with the public wasn't a genuine activity.

• They also felt that if they are consulted on and have the opportunity to contribute their ideas on how services can change for the better that they are then kept in the loop at points in the future.

- They appreciated that Healthwatch should have some involvement in this process and were grateful that we exist to help this process are cited they are often hear about these opportunities via us.

South Tyneside

Focus Group - Mental Health in Young People:

The following comments emerged from the Young Healthwatch focus group where six young people attended;

- Recognise the value of having appropriate staff at relevant hospital services
- Better quality of care when sharing information
- Improved communication with public on services available
- Transport issues for those visiting and attending appointments
- Palliative Care to be dedicated to one hospital
- More community services provided to help people manage their conditions at home
- Referral process; long waiting times makes the situation worse
- Longer diagnosis time
- More awareness of other services before going to hospital – eConsult

Focus Group - *Palliative Care*:

A focus group session was organised with eight people attending to share their experience of supporting someone in need of palliative or end of life care. From the group discussion that took place these were the comments and key points that came from the meeting:

Current Palliative and End of Life Services in South Tyneside:

- Ward 20 at South Tyneside District Hospital, not appropriate.
- What is the pathway now? Talking about the future but what is in place now?
- Discharge plan – doesn't work, patients leaving hospital with no information.
- Integrated Care System has to work
- Now attending St Benedict's in Sunderland, transport issue for families visiting.

What should the 'new model include?

- Need to have a dedicated service / building
- Need a "hospice to care not a hospital that mends", a hospital does not offer the quality of care that a hospice does
- 24hr access, not restricted to visiting times
- Replicate 'dementia hub' and provide a hospice with outside area and more beds
- Depending on the model, people would volunteer to help

Summing Up – Key Points:

- Time frame – Urgent people need care and support now
- Dedicated service / building
- What is the pathway now?
- Discharge Plan – get it right
- ICS this needs to work better than it does. Services need to work together, and those that need the support know where to go to get it.

Next steps

Audience:

All local Healthwatch will ensure that all key stakeholders including system leaders, will receive their findings using an appropriate and agreed method. We will also ensure any significant public-facing communications issued throughout the work, not just the final report, are shared with the Integrated Care System and Integrated Care Partnerships. This is for information, not sign-off, but gives them a chance to factor it into their own communications and engagement activity and is an important part of maintaining an open and positive relationship.

The comments and views that have been shared with us will, joined with other information we have received, help to inform the selection of our own research priorities ensuring that we are focussing on the things that matter to patients, service users, relatives and carers and the public across the North East as well in our own localities.

All local Healthwatch in the North of the patch submitted their individual reports to Healthwatch Darlington as the Healthwatch Coordinator for this engagement to incorporate into the Northumberland, Tyne and Wear and North Durham report. This report and our individual reports will be used to inform work locally and develop our understandings of what matters to local people across the patch. Local Healthwatch will work collaboratively to ensure that these findings influence the implementation of the NHS Long Term Plan in our area.

Evaluation:

All local Healthwatch will be reviewing the impact of the research findings by keeping positive and collaborative working relationships with the Integrated Care System and Integrated Care Partnerships. We will be ensuring that any information fed directly to Healthwatch England from NHS England is also monitored so that we know what is happening at a national level as well as at a local and regional level.

This will be reviewed on a regular basis to ensure the local, regional and national voice has been listened to and has influenced decision making. We expect communications to be released on a regular basis from NHS England in order for it to be fed back to the relevant parties involved including participants and the general public.

Acknowledgements

All local Healthwatch would like to thank everyone who completed the surveys and to the participants in all our focus groups and workshops. Your experience of local services, your comments and opinions and your patient journeys are so appreciated and will help us to influence at a strategic level to ensure the planning and delivery of services meets your needs and those of your family and friends.

Thank you to all our volunteers across the local Healthwatch network who supported us to achieve this work by actively sharing the surveys in your local communities and with your own contacts. We also appreciate the time you spent filling out our surveys and attending the focus groups, events and community outreach venues. We could not do what we do without your fantastic support.

We are also pleased that a number of local media and news outlets were able to share our press releases and highlight our engagement plans. This really helps raise awareness for the Healthwatch network to patients, carers and the public. Thank you, it is much appreciated.

Healthwatch Darlington extends its gratitude to the North East Commissioning Support team who have helped us liaise with the Integrated Care System to establish regional priorities for the NHS Long Term Plan. This has proved invaluable especially at a local level when working in such a changeable landscape.

We would also like to thank Healthwatch England for all their support across the network. The guidance and documentation have been easy to follow and have ensured consistency across the patch both in the messages conveyed to the public and the engagement coordination. Our Healthwatch England Research lead has been invaluable! Thank you.

Finally Healthwatch Darlington would like to say a huge thank you to all the local Healthwatch who contributed to this report. Working in collaboration with each other has brought together fantastic insight into what matters most to people in our region. Your timely responses and your willingness to work as one has helped to showcase our work as the independent champion for health and care services, not only to commissioners and providers of services but more importantly to patients, carers and the public.

Appendix 1 - Methodology

Engagement Method:

Each local Healthwatch undertook the following core activities to gather relevant evidence to answer research questions and meet objectives:

- Two general and specific condition surveys utilised by Healthwatch to encourage local people to complete and to be available in a range of formats with the aim of 250 responses overall per local Healthwatch

- Localised communications for local Healthwatch using a Healthwatch England communications toolkit to encourage people via social media, website, local media and local communities.

- 2 focus groups to be delivered in each local Healthwatch area using Healthwatch England topic discussion guides.

- A monthly feedback report by Healthwatch Darlington to Healthwatch England to be informed by local Healthwatch feedback from across the patch.

- Local Healthwatch were encouraged to test their research methods such as asking volunteers to test an online survey or hard copy to ensure the right questions were being asked.

- Qualitative data makes it difficult for the person doing the analysis to separate themselves from the data so in order to maintain objectivity and avoid bias local Healthwatch where possible were encouraged to:
  - Use multiple people if available to interpret the data. If there is some consistency then it is more likely that there is some truth by agreement in interpretations.
  - Have participants review results to ensure interpretations are representative of their views.
  - Verify with more data sources such as local plans, statistics or reports already gathered to support interpretations.
  - Ask others to review conclusions such as peer review because a second set of eyes might see things that have been missed or can identify gaps.
  - Review data throughout the process rather than doing all analysis at the end of the project. This can help identify gaps in data collection and address them early.

- A research plan, quality assurance checklist and final report for Healthwatch Darlington to complete with the support of the Healthwatch England Research Lead to help with engagement, research, analysis and reporting.

- Demographics collected were used by local Healthwatch as a sampling method of selecting a representative part of the population for the purpose of determining parameters or characteristics of the whole population.

Data Management:

All local Healthwatch were expected to ensure all evidence collected and recorded was kept secure in line with their individual Data Protection and GDPR 2018 policies and procedures. Therefore collection and recording methods were consistent with all Healthwatch in order to support the analytical processes and techniques used by Healthwatch Darlington in the final report. For instance:

- All hard copies of surveys to be inputted online via a platform such as Surveymonkey and results forwarded to Healthwatch Darlington.

- Small report template used to compile all evidence collected by each Healthwatch via focus groups/events and results forwarded to Healthwatch Darlington.

Risk Assessment:

A clear assessment of risk as per own policies and procedures was undertaken by each Healthwatch before undertaking any engagement to ensure the physical, emotional and mental wellbeing of participants, staff and volunteers was considered and mitigated including safeguarding.

It was important that Healthwatch followed their safeguarding policy and procedures if they heard any feedback that related to abuse or neglect of a vulnerable person, or if someone disclosed a safeguarding concern.

The risk assessment also informed the processes that needed to be undertaken to ensure that consent was given and to consider how the information was to be used so that the correct permissions were in place. This ensured that all information security considerations were appropriately discharged.

Conflicts of Interest:

Healthwatch leads who had a potential conflict of interest listed below made it known to HWD as the coordinating Healthwatch, should a direct conflict of interest occur with any connections they have with organisations or agencies during the course of this project.

Healthwatch	Conflict of Interest
HW Newcastle	CEO – Steph Edusei Tell Us North & North East Commissioning Support Project
HW Gateshead	CEO – Steph Edusei Tell Us North & North East Commissioning Support Project

Ethical Considerations:

All Healthwatch proactively championed ethical behaviour and reflected and applied their organisational values in all activity they undertook, in addition to meeting their legal and regulatory requirements.

This included a good practice ethical statement which included statements about how the following was assured in any engagement, e.g.:

- Respect every individual's dignity and rights to privacy and confidentiality
- Health and safety when participating
- Support for participants including signposting where appropriate.
- Commit to challenging any instances of sexism, gender inequality and other power imbalances that leave some people at risk of harm.

Consent:

Healthwatch needed to ensure they received the right consent from all attendees in order to use the feedback they provided effectively. All local Healthwatch needed to use a consent form to assure attendees that their data was managed well in line with their Data Protection and GDPR 2018 policies and procedures as well as being informed that anonymised data would be sent to Healthwatch Darlington as the ICS coordinating Healthwatch, and to Healthwatch England to inform the national project.

Who was engaged?

All Healthwatch used their local knowledge to focus on particular groups to ensure they included ages, gender and other variables that could have affected the engagement methods.

Skills and Expertise:

Healthwatch Darlington established the skills requirements from each local Healthwatch to identify gaps and outline what is being done to manage them. This included looking at the capacity across the network and sharing skills and obtaining support where needed. Healthwatch North Yorkshire worked closely with Healthwatch Darlington for analysis and reporting purposes in the North and South of the region.

Technical:

Coding frameworks included key themes and priorities and Healthwatch Darlington worked closely with the Healthwatch England Research Lead to ensure consistency across the region and to aid with data collecting requirements.

As well as those that were provided by Healthwatch England, other quality assurance mechanisms employed were:

➢ Sharing early findings along the way to help test out initial reactions and to start embedding the work in the minds of those drafting the local implementation plans.

➢ Before drafting the final report, we presented our findings to the ICS and set out any potential recommendations. This helped to adjust the way we drafted the final report without having to change the message.

➢ Created an opportunity for the ICS to outline where they are using the insight provided and how this is influencing decisions.

➢ The ICS helped show how it is reacting to the feedback people have shared.

➢ We used the Healthwatch network as a peer review group before finalising the report.

➢ We used the North East Lay Member and Non-Executive Director Network as a sounding board so questions could be asked and points clarified in the final report.

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Appendix 2 - Demographic information from the surveys

Area	Number of surveys collected in total
County Durham	392
Gateshead	49
Newcastle	157
North Tyneside	144
Northumberland	54
South Tyneside	229
Sunderland	312
Total	**1337**

Your Gender	County Durham	Gateshead	Newcastle	North Tyneside	Northumberland	South Tyneside	Sunderland	Total
Male	115	17	63	36	6	66	94	**397**
Female	262	31	85	97	38	152	198	**863**
Other	1	0	2	0	0	0	0	**3**
Prefer not to say	6	0	1	2	2	2	2	**15**
Not answered/Not collected	8	1	6	9	8	9	18	**59**
Total	**392**	**49**	**157**	**144**	**54**	**229**	**312**	**1337**

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Your Age	County Durham	Gateshead	Newcastle	North Tyneside	Northumberland	South Tyneside	Sunderland	Total
Under 18	1	0	5	1	0	0	0	7
18-24	8	2	10	2	0	2	14	38
25-34	19	1	13	9	1	4	31	78
35-44	43	11	16	16	5	20	46	157
45-54	67	17	26	17	10	20	58	215
55-64	91	15	40	32	15	115	69	377
65-74	94	2	25	38	12	43	52	266
75+	57	1	22	27	8	14	36	165
Not answered/Not collected	12	0	0	2	3	11	6	34
Total	392	49	157	144	54	229	312	1337

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Your Ethnicity	County Durham	Gateshead	Newcastle	North Tyneside	Northumberland	South Tyneside	Sunderland	Total
African	0	0	3	0	0	0	1	4
Arab	0	0	1	0	0	1	0	2
Asian British	1	0	3	0	0	3	1	8
Bangladeshi	0	0	0	0	0	0	0	0
Black British	0	0	5	0	1	1	1	8
Caribbean	0	0	0	0	0	0	0	0
Gypsy or Irish Traveller	0	0	0	0	0	0	0	0
Indian	1	0	1	0	0	0	0	2
White British	361	45	117	129	47	211	284	1194
Pakistani	0	1	1	0	0	0	0	2
Any other white background	6	1	10	0	2	3	6	28
Any other mixed background	2	1	1	1	1	0	2	8
Other	9	1	10	6	0	1	2	29
Not answered/Not collected	12	0	5	8	3	9	15	52
Total	392	49	157	144	54	229	312	1337

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Do you consider yourself to have a disability	County Durham	Gateshead	Newcastle	North Tyneside	Northumberland	South Tyneside	Sunderland	Total
Yes	141	14	48	57	9	40	100	409
No	224	33	102	77	41	167	187	831
I'd prefer not to say	19	2	7	8	4	9	7	56
Not answered/Not collected	8	0	0	2	0	13	18	41
Total	392	49	157	144	54	229	312	1337

Are you a carer?	County Durham	Gateshead	Newcastle	North Tyneside	Northumberland	South Tyneside	Sunderland	Total
Yes	80	11	27	21	10	23	57	229
No	299	38	128	121	40	194	234	1054
Not answered/Not collected	13	0	2	2	4	12	21	54
Total	392	49	157	144	54	229	312	1337

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Do you have	County Durham	Gateshead	Newcastle	North Tyneside	Northumberland	South Tyneside	Sunderland	Total
A long term condition	115	16	47	70	18	70	100	**436**
Multiple conditions	68	14	21	28	3	31	63	**228**
Neither	105	19	83	45	30	113	127	**522**
Not answered/Not collected	104	0	6	1	3	15	22	**151**
Total	**392**	**49**	**157**	**144**	**54**	**229**	**312**	**1337**

Which of the following best describes you?	County Durham	Gateshead	Newcastle	North Tyneside	Northumberland	South Tyneside	Sunderland	Total
Heterosexual	323	42	79	46	30	139	257	**916**
Gay or lesbian	5	1	1	2	0	1	4	**14**
Bisexual	3	1	2	0	0	2	4	**12**
Asexual	0	0	1	2	1	0	0	**4**
Pansexual	2	0	1	0	0	0	0	**3**
Other	12	5	9	2	0	3	5	**36**
Prefer not to say	0	0	0	7	0	5	0	**12**
Not answered/Not collected	47	0	64	85	23	79	42	**340**
Total	**392**	**49**	**157**	**144**	**54**	**229**	**312**	**1337**

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Your Religion	County Durham	Gateshead	Newcastle	North Tyneside	Northumberland	South Tyneside	Sunderland	Total
Buddhist	1	0	0	0	0	0	2	3
Christian	239	26	45	30	17	115	176	648
Hindu	1	0	0	0	0	0	0	1
Jewish	2	1	1	0	0	0	0	4
Muslim	1	1	1	0	0	2	0	5
Sikh	0	0	0	0	0	0	0	0
Other	5	1	6	3	0	4	2	21
No Religion	108	18	33	23	19	31	19	251
I'd prefer not to say	25	2	4	3	2	6	6	48
Not answered/Not collected	10	0	67	85	16	71	107	356
Total	392	49	157	144	54	229	312	1337

Appendix 3 - Demographic information from condition specific surveys in Northumberland

Number of surveys collected in total
26

Please select the condition you would like to tell us about	Number of respondents
Cancer	2
Heart and lung diseases	3
Mental health	13
Dementia	3
Learning disability	0
Autism	1
Long-term condition e.g. diabetes, arthritis	1
Not answered/Not collected	3
Total	26

Your Age	Number of respondents
Under 18	1
18-24	1

25-34	0
35-44	0
45-54	6
55-64	14
65-74	2
75+	1
Not answered/Not collected	1
Total	**26**

Your Ethnicity	Number of respondents
African	0
Arab	0
Asian British	0
Bangladeshi	0
Black British	0
Caribbean	0
Gypsy or Irish Traveller	0
Indian	0
White British	21
Pakistani	0
Any other white background	1

Any other mixed background	0
Other	3
Not answered/Not collected	1
Total	**26**

Do you consider yourself to have a disability	
Yes	6
No	17
I'd prefer not to say	1
Not answered/Not collected	2
Total	26

Are you a carer?	Number of respondents
Yes	3
No	21
Not answered/Not collected	2
Total	26

Do you have	Number of respondents
A long term condition	11
Multiple conditions	14

Neither	0
Not answered/Not collected	1
Total	**26**

Which of the following best describes you?	Number of respondents
Heterosexual	21
Gay or lesbian	0
Bisexual	0
Asexual	0
Pansexual	0
Other	0
Not answered/Not collected	5
Total	**826**

Your Gender	Number of respondents
Male	9
Female	15
Other	0
Prefer not to say	0
Not answered/Not collected	2
Total	**26**

Your Religion	Number of respondents
Buddhist	0
Christian	8
Hindu	0
Jewish	2
Muslim	0
Sikh	0
Other	1
No Religion	12
I'd prefer not to say	0
Not answered/Not collected	3
Total	26

Appendix 4 - Demographic information from focus groups

For further demographic break downs please see local reports which will be available on their respective websites

	Focus Group topic	Number of participants	Total
County Durham	Durham Deafened Support	24	34
	Open Group	10	
Gateshead	Young people's mental health (shared by both Newcastle and Gateshead)	5	5
Newcastle			6
	Primary care	6	
North Tyneside	Mental Health	6	11
	Cancer	5	
Northumberland	Dementia	8	17
	Mental health	9	
South Tyneside	Palliative care	8	14
	Young people's mental health	6	
Sunderland	Long term conditions	12	22
	Learning disabilities and autism	10	
Total		109	109

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Local Healthwatch contact details

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