

NHS Long Term Plan

Engagement Report

County Durham, Darlington, Teesside, Hambleton,
Richmondshire and Whitby

wh  **t**

would you do?

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Table of Contents

Executive summary	3
Integrated Care System Response.....	4
What matters most to people in County Durham, Darlington, Teesside, Hambleton, Richmondshire and Whitby?.....	7
Long term conditions specific survey	16
Focus Groups and Events	18
Engaging people in health service delivery	47
Next steps	52
Acknowledgements	53
Appendix 1 - Methodology.....	54
Appendix 2 - Demographic Information from the surveys.....	57
Appendix 3 - Demographic information from condition specific surveys in Darlington	63
Appendix 4 - Demographic information from focus groups	68
Local Healthwatch contact details.....	69

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 South 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 County Durham, Healthwatch Redcar and Cleveland, Healthwatch Middlesbrough, Healthwatch Hartlepool, Healthwatch Stockton and Healthwatch North Yorkshire

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 Northumberland, Tyne and Wear, 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.

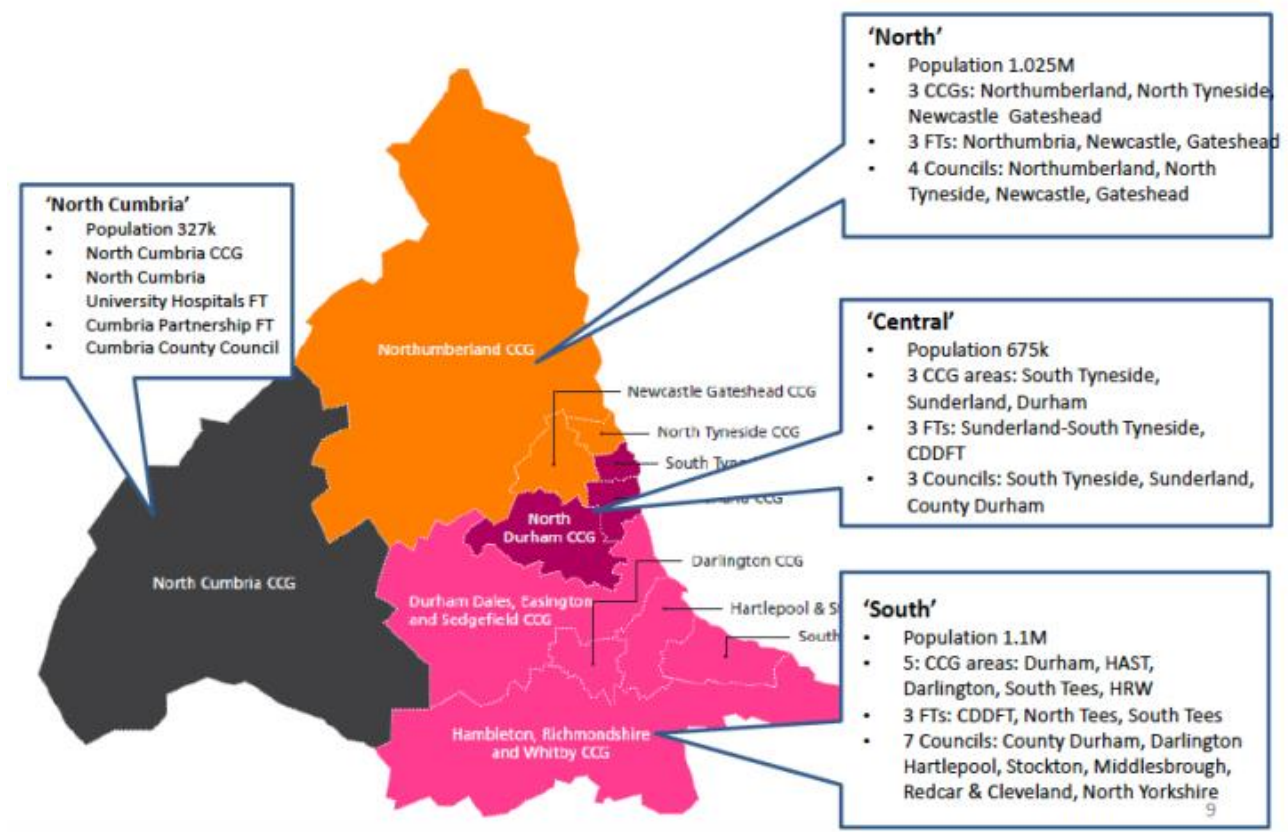
Local Healthwatch worked together to find out what local people think. What people told us will be shared with the NHS and will be used to help develop the plan for our area.

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



Healthwatch Darlington liaised and co-ordinated the engagement activities with Healthwatch colleagues and the ICS Head of Communications and Engagement in the relevant North and South ICP 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 County Durham, Darlington, Teesside, Hambleton, Richmondshire and Whitby?

The findings in this section are based on responses to the surveys designed by Healthwatch England. In total, there were 1143 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.

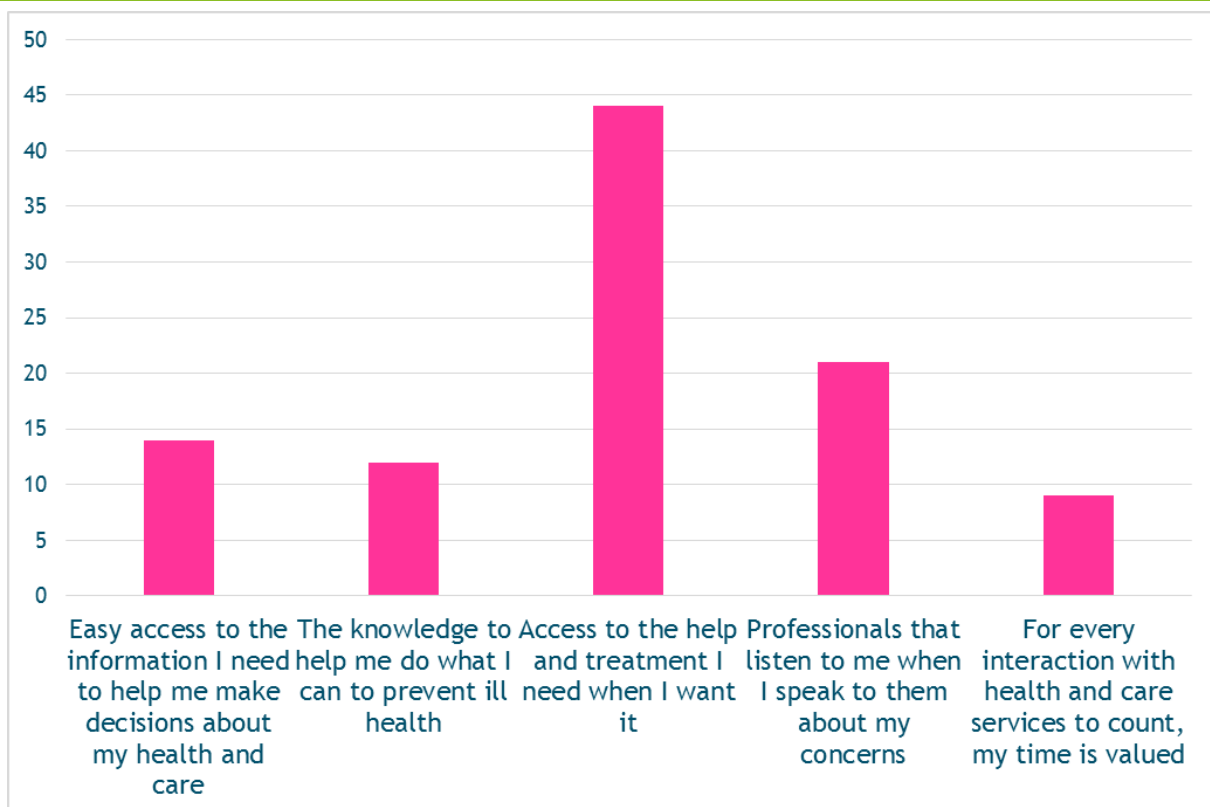
What is most important to you to help you live a healthy life?

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. However, “**professionals that listen to me when I speak about my concerns**” was often noted as close second in the importance ratings.

In addition, we asked people to tell us one more thing that could help them live a healthy life. There were a number of suggestions which can be found in more detail in the individual local Healthwatch reports, but some common themes did emerge from a regional perspective. For example, people wanted more easy access to **services which promote a healthy lifestyle**. Many of the solutions offered seemed to be around having holistic lifestyle choices through diet, exercise, wellbeing support and social activities. This was particularly raised in **County Durham, Middlesbrough, Redcar and Cleveland, Hambleton, Richmond and Whitby** and **Stockton-On-Tees**. It was considered important for these options to be available in their **immediate local areas** and responses suggested that barriers include the costs involved, excessive travel and that the hours when services are available are inaccessible for many local people as it's often during working hours. In **Middlesbrough, Redcar and Cleveland** participants thought support should be offered for weight problems with free, cheap or funded exercise classes and fitness programmes. **County Durham** noted the benefits social activities can have on **reducing social isolation**, particularly in rural areas. The local community of **Stockton-On-Tees** explained how they often don't know who to go to about their health and wellbeing needs and felt it would be beneficial for there to be a **reliable source** or navigator who are easy to access and can help support them or signpost them for the most appropriate support. Some of these ideas may be outside the NHS' remit but could be achievable through joint work with other services and organisations at a local level.

Another frequently occurring solution offered was the idea of **education and prevention** so that people can make informed choices, alongside more accessible and clear communication of information about existing support available. In the majority of responses in **Middlesbrough, Redcar and Cleveland**, there is a focus on early prevention through education (one response focused on educating the parents of young children), information and lifestyle choices with the view that *“Preventing illness [is] better than cure”*. Advice for managing **specific health conditions** was a common theme in **Stockton-On-Tees**. There were suggestions in **Hambleton, Richmond and Whitby** and **Stockton-On-Tees** around having yearly or routine check-up with the GP to help identify health conditions sooner where they will be able to treat the cause rather than the symptoms.

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



The need for **better and quicker access to services** was raised by **Hambleton, Richmond and Whitby**, including GPs, mental health and physiotherapy. This is likely due to the rurality of the area. Many **Hartlepool** respondents were concerned about lack of access and appointments for GPs. Residents of **Stockton-On-Tees** expressed that they prefer to see the same doctor at their GP appointment so they can get to know them and their condition rather than people having to repeat their story over and over again. The use of jargon was frequently mentioned as a barrier, often leaving people unsure and confused about their medical condition and treatment.

“Additionally, be able to see me in a reasonable time when I need it. Have information on websites or around certain areas relating to common health issues and what can” [Darlington resident]

“I would like to see a GP (preferably of my choice) when I need to - right now that’s nigh on impossible for me! Can’t even book appointment weeks in advance, and ‘on the day’ they’re taken!” [Hartlepool resident]

In **County Durham**, being recognised as an **individual** was also important to several respondents to the survey. This could be seen in answers that related to accessibility options (“*I cannot use 111 service as I have a hearing loss*”), timing and practical considerations (“*appointments outside office hours (when people are working)*”), and for communication (“*not to be made to feel as though the lifestyle choices made previously make me a bad person*”). The importance of being listed to by professionals was also raised by a Darlington resident:

“Health professionals that listen to what you are saying i.e. what medications you have, how often and how you immobilise yourself. Living with pain and mobility issues” [Darlington resident]

Nonetheless, it should also be noted that some responses in **Darlington** and **Hambleton, Richmond and Whitby** felt that people have to take responsibly for their own health and lifestyle.

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

We also asked people about how they choose and manage their health support. A significant proportion of people felt that the most essential element was that “*Choosing the right treatment is a joint decision between me and the relevant health and care professional*”. This again was the same across **all individual local Healthwatch areas**, but there was more variance between localities in responses to this area of questioning than the last.

When asked if there was one more thing that would help with managing and choosing how the NHS supports you, many answers echoed the same sentiment about the importance of patient **individuality** and their choices; but ultimately it seems patient ability to make individual choices is based on the **information and knowledge** available to them and their ability to access **more than one option of support** which could all be improved.

Whether it was contact between healthcare professionals and patients or the contact between health services themselves, **improving communication and information** was a reoccurring theme across the region. In **Hartlepool**, it was felt that clear, timely communication can help people to then seek up to date information which should be easily and readily available. **Better communication and feeling listened to** is something that’s important to people living in **Darlington** with service users telling us that often they are not made aware of support in the community offered by the voluntary sector. These groups or services could help improve their wellbeing whilst awaiting treatment or an appointment. In **Stockton-On-Tees** and in **Hambleton, Richmond and Whitby**, there were responses which reflected the need for better communication from professionals to patients but also a need for services to be more clear in their communications to each other for more **joined up working**. For example, better links between social services and NHS were highlighted to ensure “*people aren’t kept in hospital too long*” and can have some choice over care at home or in a nursing/residential home. By working with more services it was suggested that people can have more choice in their care and can therefore be more involved in the decisions made about their care. 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.

More advice and information was thought to be useful for people **Middlesbrough, Redcar and Cleveland**. The preferred format of this advice varied between a 1-2-1 consultation and having online access. There was a shared desire to be able to **quickly access** this information and access feedback of results and diagnosis. This is supported by the people of **Stockton-On-Tees** who felt that it would benefit them if there was a reliable point of contact who can support them to access services and find trusted information about their medical conditions. They also rated early interventions and prevention services to enable people to have more control over their health and identify if they require any additional support.

‘Right information at the right time before it’s too late’ [Stockton-On-Tees resident]

“Communication is vital between NHS and patients” [Hartlepool resident]

“Being able to talk to someone, such as a nurse, at my local medical centre, while waiting (say 3 months) for chemotherapy. If I have questions - waiting 3 months to speak to an oncologist is adding stress. A professional oncologist may have better answers - but something is needed in the interim, to prevent the anxiety of not knowing and feeling like you have no control to help yourself” [Hambleton, Richmond and Whitby resident]

Stockton-On-Tees also found people with a sensory impairments felt the NHS needs to look at the communication support available. There is the need to improve access to BSL interpreters, in particular when needed **at short notice** e.g. emergency GP appointments and in A&E. When services are communicating with an individual with a sensory impairment, it is important that this is in an **accessible format**. Large print or phone calls for people who are visually impaired and text or email communication for people who have a hearing impairment tend to be the most preferred methods. For people who have a hearing impairment it is becoming increasingly difficult to make an appointment at the GP. If each GP practice could offer patients who are deaf the ability to book appointments via text message or online, then this would help these individuals to be able to take responsibility for their own healthcare and feel more independent.

“NHS providers must become deaf aware, know who is responsible for booking an interpreter and that the person knows how to do it. Visual aids in waiting rooms. Sensory loss boxes/champion on each ward. NHS must remove the communication barriers for deaf patients” [Hartlepool resident]

The BME community in **Stockton-On-Tees** felt that **better access to interpreters** was also important to them. This community often relies on family members attending appointments with them to translate information therefore easier access to interpreters would enable them to **access services independently** should they wish to do so.

A lack of appointments or the delay in getting appointments were raised in many areas suggesting a need for **better access to primary care**. In **Hambleton, Richmond and Whitby** people hope for **shorter waiting times** to reduce delays in treatment and want to see better access to primary care GP’s. People in **Hartlepool** wanted more GP appointments available to reduce waiting times or complete lack of access. The struggle with the lack of GP appointments in **County Durham** was also highlighted. When they need help and it is not possible to see someone, 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. People in the local community of **Stockton-On-Tees** felt that it is becoming increasingly more difficult to be able to get a GP appointment at short notice and felt that this would be one of the key problems for the NHS to address. In addition to this, people feel that they would benefit from **longer appointment times** to give them time to talk about their health, care and treatment without **‘feeling rushed’** or only being able to speak about one of many ailments.

“Need more GPs. Easy access to GP’s as they are usually the first point of call” [Hartlepool resident]

When it comes to managing and choosing support, **travel and transport issues** were seen as barriers to accessing care in **Hartlepool**. **County Durham** found that 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. **Stockton-On-Tees** locals felt the need for better access to patient transport services and a **review of the eligibility criteria** to enable more people to be able to access the services they need. For similar reasons, the people of **Hambleton, Richmond and Whitby** also had concerns for better local care especially when it comes to **emergency care and hospital services**.

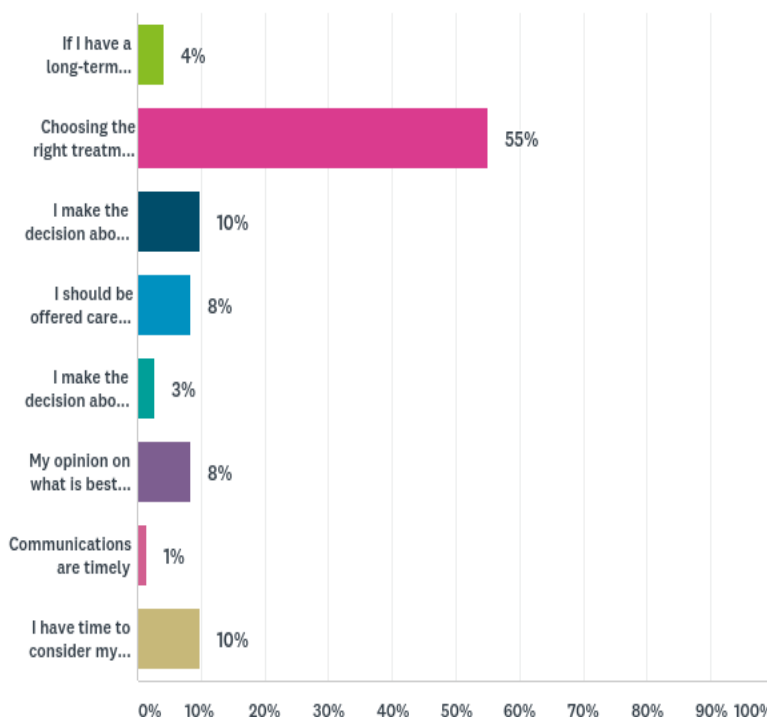
“Access to care close to where I live. A friend is currently having to make 110-mile round trip daily for six weeks” [Hambleton, Richmond and Whitby resident]

“More local services not less. My health authority is centralising many services to the detriment of rural people. This makes access difficult for all but especially the elderly and/or disabled” [County Durham resident]

“I’m scare in case I need to go to A&E because it’s so far out of town. I’m isolated and have no-one to give me a lift” [Hartlepool 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 **Hambleton, Richmond and Whitby** when it comes to managing and choosing support?



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 **Darlington** where that was second to “*I want my family and friends to have the knowledge to help and support me when needed*”. Many of the qualitative answers were reflective of both these aspects of care and support. Generally, people’s answers 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.

County Durham suggested one person’s experience and views overlapped several other individual comments they received:

“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]

Further comments reflected that more involvement and support for family members was a priority for **Darlington**. It was thought that ensuring family members are provided with the information and knowledge to support their loved ones can give them more independence as they get older, enabling them to live in their own home for longer.

“Family / friend carers must be able to take time off. Currently this is a major issue and most carers get no breaks or much needed holidays. There must be an easier way to access intermediate care if the carer is ill or has their own health needs. People can become over dependent on their carer's and intermediate care to get them back to doing basics with support may mean people stay supported by family carers longer” [Darlington resident]

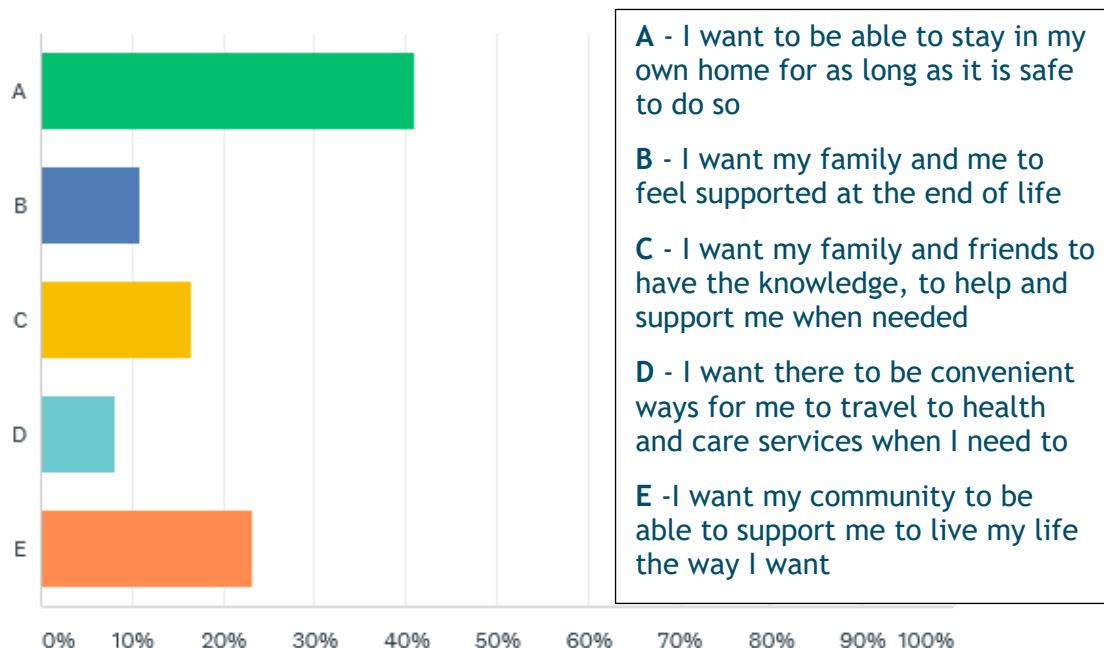
In conjunction with this, responses from people in other areas also reflected the importance of **paid carers and unpaid carers** who may not be family. **Middlesbrough, Redcar and Cleveland** residents highlighted importance within social care as they suggested that there should be “*housing schemes for life with care support on site*” and that there should be funding for paid carers and sitting services. They proposed that, the befriending service could be improved if it were for more than just 1 hour per fortnight. **Stockton-On-Tees** also felt that a buddying scheme would support individuals to be able to get to healthcare appointments as well as support groups. In turn, this would enable people to feel independent and reduce loneliness and isolation. People would like to have confidence in knowing that they will receive reliable and **affordable home care** which is tailored towards their individual needs and can be available 24 hours a day seven days a week. This relates to solutions offered by people of **Stockton-On-Tees** as they highlighted that access to primary care services in peoples’ own home as a requirement for people to enable them to remain independent as they get older. More flexible GP appointments and more frequent health checks was also encouraged. The availability of ‘**hospital at home**’ and support made available in peoples’ own home was raised. Alongside more local support to stay active and reduce isolation, the most important factor for the people of **Hambleton, Richmond and Whitby** was to have good transport links or more services closer to home, due to worries about mobility difficulties as we age and the general need for more healthcare as we age.

“Invest more in community services to ensure local access” [Middlesbrough, Redcar and Cleveland resident]

In line with key themes identified in previous questions around **information**, there’s also a suggestion that there should be specifically more information available to people as they get older to help them find out what they are entitled to receive e.g. adaptations to their home. In **Hartlepool**, there were suggestions that GPs return to doing house calls for the elderly, especially in winter. Furthermore, it is important that services do not rely on putting all the information online as there are a large number of people in the community who would be unable to access this. A suggestion made by a number of individuals in **Stockton-On-Tees** was that it would be helpful to see visits arranged for older people to look around care homes. As *‘a lot of people are frightened as to what they are really like’*, these visits would give them the knowledge of what type of care home they would like to live in should this be required as they get older.

“I would say the older you get the more you need to feel that care is readily available, a lot of older people feel they are lost in the system. I understand there is limited funds throughout the NHS and I feel strongly that with the pension age rising the charities are having to shoulder the burden of age care.” [Hartlepool resident]

What is most important to you to help **Middlesbrough, Redcar and Cleveland** retain independence and live healthily for as long as possible?



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, Hartlepool, Hambleton, Richmond and Whitby** and **Middlesbrough, Redcar and Cleveland**. Whereas Darlington found that *“I have absolute*

confidence that my personal data is managed well and kept secure” was their most prominent response. This was also popular in **Stockton-On-Tees** as well as *“Any results are communicated to me quickly making the best use of technology”*. Although in a different ranking order, the top 3 responses in each locality were similar so perhaps it better to consider all these elements are of importance across the ICS/ICP region.

It was also important for many respondents in **Middlesbrough, Redcar and Cleveland** for the **patient to be treated as an individual** with a set of symptoms rather than a statistic to fit into a condition. People wanted more **face-to-face support** and to have access to **the same professionals so that a relationship can be built**. People wanted to have more/shared responsibility for their health and have positively commented about working with their GP to create a long-term health plan, particularly those with long-term health conditions; to have personal budgets; to be able to discuss different health options.

There was a request for humanity not to be lost within healthcare, looking at emotional wellbeing and for patients to be heard without judgement, which was particularly prominent for those with mental health. Interaction via doctors was a valued access route in **Hambleton Richmond and Whitby** as the **ability to speak to GP** was again of great importance. While face to face support was important, there were also suggestions of using technology to book appointments online to reduce waiting times and being able to get health advice over the phone or via email from professionals. They also wanted the ability to access their health records.

There also needs to **better information and encouragement to access community support groups**. In **Stockton-On-Tees** as they suggested improved access to information e.g. online / via GP surgery was a common theme from the feedback gathered. Easier access to booking appointments and shorter waiting times between referral and appointment date as well as having access to medical records and information was also suggested by the local community there. They pointed out the need for additional training for healthcare staff so that people *‘feel listened to’* during appointments and discussions about their health. Healthcare professionals need to communicate more effectively with patients using *‘less jargon’* and explaining health conditions and treatment options using language that they will understand.

Despite the value in secure personal data management, in both **Hambleton Richmond and Whitby** and **Stockton-On-Tees** respondents also wanted **more linked up working** between services with suggestions that health records to be shared between services. It is of huge importance that the services provide continuity of care with *‘joined up thinking’* and more integrated working. There appear to be *‘so many gaps in communication’* and more work needs to be done to make it a more streamlined system.

When interacting with the NHS some service users in **Darlington** told us that it is not important for them to be able to make online appointments online, this response reflects feedback previously received as not everyone is comfortable using the internet. 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.

“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]

“Taking a blended approach to the provision of information so that all can access, e.g. older people with technology” [Middlesbrough, Redcar and Cleveland resident]

A disabled service user said:

“Having used my phone to access services and speaking with an operator I find this to be very useful” [Darlington resident]

It is a requirement for all healthcare services to comply with the Accessible Information Standard however it is felt that the communication needs for people who have additional needs are still not being met. Suggestions in **Stockton-On-Tees** were made including a ‘**voice activated check in system at the GP practice for people who are visually impaired**’ and better access to BSL and language interpreters at short notice.

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 they 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 Healthwatch County Durham 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.”*



Long term conditions specific survey

In addition to the general survey, Healthwatch **Darlington** 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 from residents in **Darlington**.

Specific Condition Survey

Twelve people took part in the specific long-term health condition survey for Darlington. When we analysed the findings for this survey we noticed a mixed sentiment displayed within the results. Some people reported a positive experience when using local NHS services with a long-term health condition whilst others reported negative.

Survey respondents were a mixture of conditions including heart and lung, diabetes and arthritis.

Healthy Life

When looking at how the NHS can support these individuals with a long-term health condition to live a healthy life. Six respondents told us a lot of support should be provided by the NHS. Four people feel at least some support should be provided by the NHS whilst two were unsure.

Some of the suggestions for the NHS to achieve this are as follows;

“Follow up appointments, more advice in how to manage symptoms / conditions.”

“Regular General health checks could be offered.”

“Help with the mental health conditions that arise from living with long term chronic physical conditions that disrupt every part of your life.”

Managing and Choosing Support

Five of our survey respondents indicated a positive experience when needing further support or ongoing care. They told us that the time waiting for the additional support after diagnosis or referral to a specialist was fast, very fast or ok. One of these respondents had a learning disability and their experience was positive.

One person told us *“I had a mentor which was excellent”*.

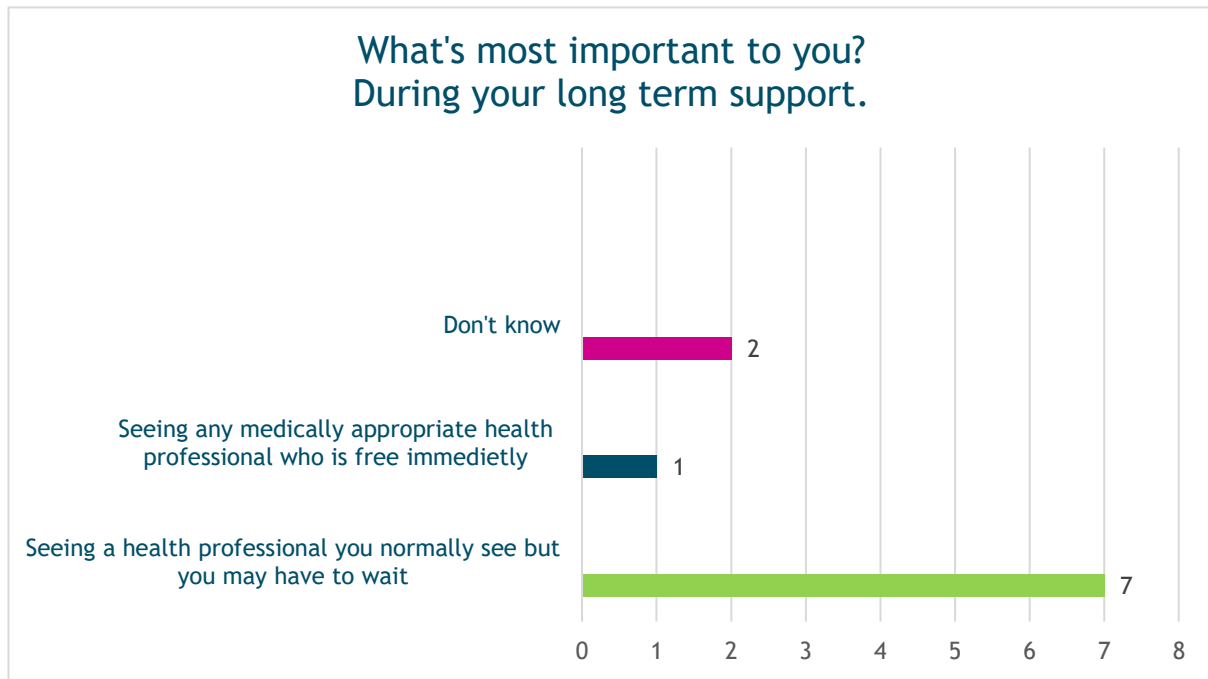
However, three of our survey respondents told us that they were unhappy with the support they received. Some reporting slow waiting times.

One person told us *“I waited a long time for eventual diagnosis, going through many different departments & appointments. After diagnosis Initial support was only for one appointment then more or less left to manage the condition myself. I feel I could at the very least have been offered follow up appointments & more advice on how to cope with distressing symptoms. “I feel very isolated with this issue & struggling to cope with physical symptoms my mental health is now suffering also.”*

Survey respondents indicated they were much more open to seeing another health professional when it comes to initial diagnosis and during treatment/support. However, it was highlighted that this isn't the case when it comes to first seeking help or for long term support.

Figure 1 below highlights the preferred option of seeing a health professional they normally see when it comes to long term support.

Figure 1



Interaction with local NHS

Three survey respondents indicated improvements need to be made to the way the NHS communicates with its patients. Two people said this would help improve the support available and one person indicated a struggle to be included in correspondence despite highlighting their cognitive memory issues.



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 Stockton

Access to health and care services for people with a long term conditions: Sensory Impairment

Assessment, diagnosis and treatment

Visual Impairment

a) Hospital Services

Service users shared their experiences of visiting the Ophthalmology department at The James Cook University Hospital. A number of service users feel that the department carries out unnecessary vision tests before they are seen for their appointment. It was suggested that a simple 'colour coding' system could be used whereby coloured stickers are put on the front of patient notes allowing staff to see at a glance who requires a vision test before an appointment and highlights those who do not require this. This will cut down waiting times and reduce undue stress on patients. It will also help the patients to feel as though they have been listened to instead of having to repeat themselves at every appointment when stipulating that they do not require certain vision tests.

Some attendees also raised concerns that they are regularly being requested to attend diabetic retinopathy screening when this is not required, even though they have tried to tell the service about this. Notes are not being updated as required as appointment requests are still being sent out.

b) GP Surgeries

Concerns were raised about the self-service check-in screens at GP surgeries and how they are not accessible to service users with a visual impairment. It was suggested that an audio option be made available similar to those set up at some ATM machines.

A discussion was raised that the GP waiting rooms are not always on the ground floor, and in some cases there is no reception desk or intercom system, which can cause difficulties in accessing these service should any additional support be required.

A significant number of service users explained how difficult it was to make appointments at GP surgeries. For individuals who are unable to use a phone, and who go to the surgery to make an appointment they are often unable to do so due to the practice policy in place stating that patients must ring at 8am every morning should they wish to make a same day appointment.

On a positive note, a number of service users confirmed that when they are accessing GP services, they are able to request for someone to come and collect them for their appointments from the waiting area and no one had ever had a problem in this regard.

c) Dentists

Healthwatch gathered a lot of positive feedback about access to dentist by people with a sensory impairment. Dental Practices appear to be aware of their patient's additional

communication needs and provide necessary support when needed e.g. offering ground floor appointments and dentists removing their masks when speaking to patients who are hearing impaired. Service users felt that dentists were aware and understanding of their needs and know their patients very well.

d) **Social Care**

In relation to social care for people with a visual impairment, the overall consensus was that Stockton Social Services are very good and very responsive, particularly in relation to providing adaptations to homes. All issues are addressed quickly and there have been no problems when needing to 're-open a case'.

e) **Communication**

Service users with visual impairments explained that they are happy with how they currently receive information about appointments i.e. text messages, letters and phone calls, although all the service users we spoke to said that they have never been asked if they have a preferred method of contact different to the method currently used.

f) **Patient Transport Service**

With regards to the Patient Transport Service, issues raised were around the fact that people get picked up very early to go to their appointment, but could be waiting around for significantly longer than their appointment time before getting home again. Despite this, the feedback about the Patient Transport Service is positive and the staff are very good at getting people to their appointment, checked in and sitting in the waiting room before leaving for their next patient.

Hearing Impairment

A suggestion was made about whether or not GP surgeries / healthcare providers could be given more information to better equip them to signpost people diagnosed with sensory loss along with a 'check-in' service to ensure that patients are managing. Currently, following diagnosis, attendees feel like they are left to 'get on with it'. It was agreed that groups offering support are not well known about and can be difficult to find as they are not advertised by care providers. Systems need to be more integrated.

a) **Communication**

Following engagement with service users with a hearing impairment, it was highlighted that when those for whom English is not their first language receive a letter from a GP or hospital they find information difficult to interpret. Text messages for appointments are ok for some but other people found it a barrier.

When service users with a hearing impairment receive appointment letters and they need to rearrange the appointment, the letters usually state that they must ring to make any changes. Often this will result in service users relying on friends and family to ring up on their behalf, only to be told that they could only speak to the patient even when the situation was explained to them.

The majority of GP Practices now have online appointment booking systems which are available for people with a hearing impairment, however, a large majority of people do not have access to a computer and feedback suggested that the preferred method of communication would be via a text message.

It was suggested that services should look at using new technology such as 'Sign Live' which is a video interpreting service. It is visual communication which allows people with a hearing impairment anywhere in the world to communicate with anyone, at any time, using an app which connects them to a qualified British Sign Language interpreter.

b) GP Surgeries

Many GP's have visual displays which patients can look at to see when their name is being called for their appointment however there are still some surgeries without this facility. One service user shared his experience of missing several GP appointments because they do not have a visual display and instead the GP comes into the waiting room and shouts out the name.

Another service user said that her surgery gives out numbers when you arrive and someone comes into the waiting room and calls out the number which she would often miss. Now she gives her number to the receptionist who comes over and lets her know when her number has been called. Other people in the group who have the same system thought this was a good idea and would like all GP surgeries and receptionists to consider providing this additional communication support.

Concerns were raised by service users with a hearing impairment needing an emergency GP appointment as they can't get an interpreter booked in an emergency. That is where service users felt that Sign Live would be beneficial to both medical staff and the patients.

c) Hospital Appointments

One service user who was profoundly deaf was taking her hearing grandson to a hospital appointment so requested for an interpreter to be booked. When they got to the hospital there was no interpreter. Because they did not want to miss the appointment they ended up face timing a BSL interpreter but could not use a professional interpreter. She had also tried to book patient transport for the appointment but it was too difficult to arrange this due to communication barriers, so just booked and paid for a taxi instead.

Service users explained that on frequent occasions they will arrive at hospital appointments to find that the interpreter has not been booked often leading to the appointment needing to be rearranged.

Although hospitals have a computer system that flags up when a patient is deaf and requires an interpreter, problems still appear to arise. This could be that an interpreter has not been booked or the interpreter booked is not suitably qualified. It is vital that interpreters relay the correct information when it is to do with health and social care but often Communication Support Workers are sent as interpreters for the appointments who are often not suitable or qualified for this role.

Service users requested that alerts are placed on the hospital computer systems for relatives e.g. children / partners where there will be a deaf person accompanying them to ensure they can communicate during the appointment. It should also be taken into account that some people like the continuity of using the same interpreter each time but for others it is not important.

In other areas, service users explained that some service providers use video remote interpreting via the computer which give deaf people full and easy access. It is good for quick enquiries but not so good if it were an hour long appointment.

The provision of ongoing care and support

Service users explained that the support they have received following diagnosis of a sensory impairment has mainly been done through word of mouth and that more signposting and support should be offered to help when they are first diagnosed. In addition to this, more support should be offered to the families who have relatives and children diagnosed with a sensory impairment.

Following consultation, a number of service users felt that health and social care staff should complete sensory impairment awareness training.

Prevention and/or early intervention

For a large proportion of people with a sensory impairment, their long term condition is often not preventable. However, service users felt that it was important for more awareness to be raised around the importance of regular hearing and sight tests to ensure any medical conditions are diagnosed early when they can be more easily managed to prevent deterioration. This could be done in the same way as Public Health Campaigns e.g. Sensory Health Week.

Access to GP services including primary care networks, self-care, community and technologies

Assessment, Diagnosis and Treatment

a) Access to services

Individuals find it difficult getting to the right person or service and often find it always takes more than one appointment to do so. Often, people find that a ten minute appointment is sometimes too short especially if they want to speak about more than one problem. It is becoming increasingly difficult for individuals to access services if they are working full time or they are a carer.

b) How far would you travel to access the right services?

The distance that individuals are willing to travel was found to be dependent on their health and ability to do so. The availability and cost of transport is also a factor which impacts on how far people are willing and able to travel to access the right services.

c) What would make communication better?

A focus needs to be placed on improving communications and ensuring that all services are integrated and working together. Compatible computer systems are essential in ensuring information is communicated effectively. Information needs to be made available in a wider range of languages and formats to ensure it is accessible to everyone.

Focus group attendees felt they would benefit from a key contact or phone number which people can access to be directed to the most appropriate service for them.

d) How should the NHS engage with the community?

Using the correct engagement methods is key to ensuring the NHS feed timely information to the community. Suggestions were made for the voluntary sector to be this key contact between the two stakeholders. A co-production model would help to increase publicity and education for the local community. Individuals felt that it was important to target young people to ensure they are aware what services are available to them. A 'one stop' information hub was also recommended in each Local Authority area to enable people to drop in and access information, advice and signposting.

e) When and how often would you like to give feedback about your care / the services you used?

Individuals felt that they preferred to give feedback about a service they have used in a timely manner either whilst or after accessing the service e.g. using interactive feedback screens or via text message. It is also important that they are told how their feedback is being used to ensure that they feel their feedback is valued.

Members of the public described various ways in which they would like to feedback their views and experiences of local health and social care services, which highlighted that preferences varied depending upon the age group of the individual. Young people tend to prefer giving feedback online and via social media. Emails and links to online surveys are popular along with

up to date mobile technologies with access to free Wi-Fi in venues to complete questionnaires and provide feedback.

Older people tend to prefer to share their views and experiences during public consultations. However, the ideal time to hold these would be during the day as older, vulnerable people are much less likely to attend on an evening. The ability to share feedback in venues such as garden centres, churches, mosques, supermarkets and community centres was also popular with older people. Postal feedback was also considered to be popular, this allows for people to provide feedback as and when they feel necessary and at a time that is convenient to them.

In addition to this, providing feedback through the VCSE sector was also an avenue which should be used to gather feedback. Community groups and regular coffee mornings are ideal opportunities to gather feedback from the public with the attendance of 'influential people' and organisations to facilitate and encourage discussions on certain topics.

An ideal opportunity to gather patient feedback is through the Patient Participation Groups (PPGs) in GP surgeries as these groups meet regularly to discuss information, issues and concerns which could then be shared with the appropriate people via meeting minutes or asking commissioners, services providers etc. to attend a scheduled meeting. It was also felt that there needs to be more opportunities for individuals to feedback information including workshops and public events. With a heightened presence of these in the community, it would encourage more people to attend. In addition to this, it is of great importance to instil confidence in the public that their feedback, good or bad, is welcomed and acted upon appropriately.

The provision of ongoing care and support

- a) Have there been any creative or new approaches used that worked for you e.g. social prescribing?

Feedback gathered from individuals with a long term lung condition explained that the current pulmonary rehab services in the area is working very well. People can be re-referred into the service if they feel this is needed so there are no limitations or restrictions on access to this service as there often are with other services.

There are a number of social prescribing initiatives in place in Stockton-on-Tees, one being the Stockton Service Navigation Project. This service has been found to be very beneficial to members of the local community, whereby navigators provide one to one support to individuals with the aim of helping to increase confidence, control and independence and as a result reducing stress and isolation. Individuals can be referred in by their GP or other organisations and they also have the option of self-referring.

There are also a number of mental health support groups in Stockton-on-Tees offering various groups and activities to help people take the necessary steps to improve and take control of their health and wellbeing.

Focus group attendees gave positive feedback about services providing a more holistic approach encouraging more focus to be placed on giving people more responsibility for their health and wellbeing.

- b) What would be easy to improve?

Appointment booking process across all services need to be made easier with the aim of sharing good practice to ensure all GP practices meet regularly to discuss best practice.

Healthcare services need to be made aware of what's available to the local community in the voluntary sector and how they can work together to provide more support for the local

community e.g. Support groups held within GP surgeries for patients who would benefit from this.

Prevention and/or early intervention

a) Primary Care

It was raised that there should be more promotion of pharmacy services for prevention of long term health conditions. e.g. smoking cessation / blood pressure monitoring. More signposting is required in GPs for prevention services and social prescribing. It was also recommended that when a patient requests an appointment, the receptionist ensures that they are booked to see the correct Dr or nurse e.g. a GP specialising in skin conditions.

Computer systems need to be integrated between services e.g. GP and hospital and GP practices should have the ability to share patient registers so if the GP Practice has no appointments available then they can be booked to see a partner GP practice.

b) Digital Solutions

The local community feel that further digital developments are required focussing on falls prevention, a key cause of hospital admissions. Prevention methods in the form of alarms, lights and telecare as well as being able to access services via skype or videocall would be beneficial for individuals who are frail, elderly or housebound.

For individuals with long term conditions e.g. high blood pressure, there should be the facility to be able to monitor these individuals remotely e.g. home blood pressure monitor where results are sent straight to GP daily.

Emergency interpreter and translation services also require further work especially for individuals who require an emergency appointment or when attending A&E.

c) Accessible information & signposting

It is essential for information about accessing services to be kept up to date and due to the nature of funding for services, changes happen frequently but the local community feel that they are not always kept up to date often trying to access services which are no longer delivered.

Sometimes people feel that they are given too much information at the point of diagnosis 'hard to digest it all at once' therefore the information which is delivered needs to be relevant and appropriate e.g. can some information be given during a follow up phone call once the individual has been able to understand the diagnosis?

d) Workforce

There appears to be the need for improved staff training. This was found to be a key topic of discussion with individuals explaining that they often find GPs, Consultants, nurses etc. using a lot of jargon making it very difficult for the individual to understand their medical conditions and treatment plans.

Feedback highlighted the need for GP and hospital department receptionists to receive more customer service training in addition to sensory loss and dementia training to ensure all service users' needs are understood.

Healthcare staff also need to be trained in how to identify social isolation and how to refer individuals to appropriate services without the need for them to see the GP.

Healthwatch Middlesbrough

General health issues that require consideration for BAME groups

Healthwatch Middlesbrough carried out their focus group on general experiences of health and care services which comprised of 30 people. The proficiency of spoken English amongst the women varied greatly. Some were very proficient, whilst others had very little understanding. Those who were more proficient assisted us in translating.

Access, Assessment, Diagnosis & Treatment

Access to primary care services was one of the main issues raised. Participants had varied experiences of getting appointments at their GP surgeries but many expressed difficulties and frustration in obtaining these. These difficulties are compounded due to language barriers and a method of making an appointment without having to constantly telephone the surgery would be preferable.

For those living with long-term conditions or *multiple conditions* seeing consistent and dedicated health professionals was important to reduce the need of continually explaining their condition and to also have consistency in the quality of care given.

Listen effectively to older people and not treat their age but the person. Give appropriate attention and treat the person holistically and look at alternative treatments other than prescribing medication.

Improved access to health professionals to reduce the likelihood of conditions worsening. Health professionals to be more aware of cultural differences and provide increased support for the management of long-term conditions such as diabetes.

For people for whom English is not their first language digital and online solutions could improve access to health and care services. As well as using text for appointment reminders, greater use of this method to give support would be useful. Development of apps that could be accessed in different languages would be of great use to this community and save on producing documents/leaflets in other languages.

Provision of ongoing care and support

Timely access to health professionals to manage ongoing conditions.

Provision of services locally, with access to dedicated professionals.

Greater use of technology to obtain feedback from BAME communities. Due to language barriers they are often not given the opportunity to share patient experiences. Increased use of this can only lead in improvement to services for the BAME population.

Prevention and/or early intervention

Many conditions experienced by the group could be prevented or treated more effectively with a greater knowledge on how to stay healthy. More information on how lifestyle and diet can have an impact on certain conditions could lead to better self-regulation from patients.

Greater understanding of cultural lifestyles and signposting patients to groups that will support them, e.g. social groups, exercise classes, healthy living (social prescribing)

Greater use of social prescribing to combat factors that could lead to a decrease in health and wellbeing.

There is stigma attached to mental health and people are reluctant to disclose as they have a fear it will have a detrimental effect on their asylum application or other adverse consequences.

There is stigma attached to mental health and people are reluctant to disclose as they have a fear it will have a detrimental effect on their asylum application or other adverse consequences.

Use digital solutions to raise awareness of certain conditions and how to prevent them.

Case Study

A female member of the group told us about her experiences of caring for her son. Her biggest concern was that she doesn't feel she is listened to. Her son is 9 years old and has a long-term kidney problem and from experience she can recognise symptoms when he is taking a turn for a worse. The problem she has experienced is that her doctor's do not understand the urgency she has to see a doctor. When symptoms appear, she finds it very difficult to make an urgent appointment and has repeatedly been told that none are available and to ring back the following day.

When she does finally get an appointment her son's condition has deteriorated and often needs hospital admission. She feels quicker access to appointments would prevent this from happening and also her son's notes being flagged as having a long-term condition that requires immediate attention. Her consultant at the hospital has told her that he will put something on her son's notes to be passed to her GP, but this has not been done.

She would like to see better communication between the hospital and her GP surgery. She has not been referred to the out of hour's system that operates locally which provides 7-day access to GP services.

General and mental health issues that require consideration for asylum seeking groups

“No-one will speak up about mental health. They fear what will happen to them”

Asylum seekers and refugees have very specific issues due to their status. Due to the complex and unique challenges they face, they are at a higher risk of developing mental health problems. The asylum seeker application process, which was described as ‘hostile’ causes many to suffer mentally, especially as the process can be very long if appeals are made. Financial hardship is a huge factor also in being able to attend or make appointments.

Asylum seekers and refugees are reluctant to access services as they have serious concerns that medical information could be used in immigration enforcement. Therefore, those with serious conditions, infectious diseases and poor mental health and unlikely to seek treatment.

Asylum seekers do not know what they are entitled to and are not given enough information on the function of services and how to access them. There is also a lack of awareness amongst health

professional of what people seeking asylum are entitled to and can lead to people being turned away from services or not receiving medication.

Access, Assessment, diagnosis and treatment

Health and care services for asylum seekers and refugees can only be delivered effectively if asylum seekers feel that they are able to disclose their conditions with the confidence that this will not have a detrimental effect on their application.

A greater understanding from *healthcare professionals* on cultural issues associated with certain conditions which can affect peoples' decisions to seek treatment together with increased compassion and understanding.

Greater provision of services outside of statutory NHS services. Asylum seekers who have been supported by voluntary or charitable organisations, who can overcome language barriers and signpost, are more likely to be engaged in services.

Digital applications could improve awareness and access to services. At present, there are considerable differences in access to information. *Development of an app* to support asylum seekers that could improve access and understanding of services.

Provision of ongoing care and support

On-going support for long-term conditions, especially mental health. Recognition of mental health amongst asylum seekers by health professionals. Appropriate access to mental health services is poor, especially for severe mental health problems.

Prevention and/or early intervention

Asylum seekers should receive a mental health assessment on registering with GP practices as a *gateway into mental health services*.

A greater understanding amongst health professionals on what asylum seekers are entitled to. Lack of understanding on both sides can lead to not seeking treatment or treatment being refused.

Use of technology to increase awareness for both asylum seekers and health and care professionals on rights and entitlements.

Important information

A female asylum-seeking refugee with a mental health issue sought help and her children were taken away from her and not returned. It is believed that this was done so that she can then be treated as a single person with no dependents and be easier to deport.

Other conditions also carry a stigma, for instance Healthwatch were told of a mother with epilepsy who was told not to disclose her condition as her children would be taken from her.

Some people with serious infections, e.g. TB are afraid to disclose their condition for fear of information going to the Home Office.

“The worst thing is to gain asylum when it’s too late - the person has lost it - gone through too much! (mentally)”

People fear accessing healthcare services as they are afraid that information will be passed to the Home Office and used in immigration enforcement.

‘Everyone should have the right to an equal level of confidentiality when accessing health and care services’

Healthwatch Redcar and Cleveland

Health issues - SEND children and young people and their families

Assessment, diagnosis and treatment

The social, emotional and physical needs of children with ASC's and associated conditions such as ADHD are not being adequately met as parents/carers are not taken seriously, the assessment process is too long or delayed until the child is older. When needs aren't properly assessed and long-term conditions haven't been recognised (ASD), then this can be problematic for the child's development, learning and mental and physical wellbeing as appropriate support strategies cannot be put in place, specialist support cannot be accessed and education/schools don't understand the underlying factors of behaviour. *Primary care professionals are gatekeepers into the service* and are in many ways responsible for the journey experienced by each family.

When needs aren't properly assessed and long-term conditions haven't been recognised (ASD), then this can be problematic for the child's development, learning and mental and physical wellbeing as appropriate support strategies cannot be put in place, specialist support cannot be accessed and education/schools don't understand the underlying factors of behaviour.

The presence of multiple conditions affects this process; in the diagnosis of children with autism, there were instances when other conditions, such as ADHD, were diagnosed later and separately and instead lumped to "the Autism". This meant that the appropriate support strategies weren't implemented, and the child's overall needs weren't understood. One parent, talked about wanting to try medication for her child because she felt this might enable him to engage more positively, particularly in school life. However, without a diagnosis, ADHD medication could not be considered.

Recommendations:

- 1) Open Autism Pathways.
- 2) Improve working together with parents - keep them informed of progress during assessment.
- 3) Improve diagnosis for girls.
- 4) Consider colour coded flags for ASD / LD health files, to include needs/diagnosis, long term conditions, carer status etc.
- 5) Early intervention, pre-diagnosis needs-based support, and (full) assessment for ASD and related conditions by fully trained professionals who recognise associated long-term conditions.
- 6) Multiple presentations to trigger specialist assessment and investigation, leading to a long-term treatment and care plan.

Provision of ongoing care and support

Although there were some individual examples of good and excellent health and care provision, focus groups highlighted children, young people, parent's and carers are experiencing significant hardship. This included mental ill health, due to poor and inconsistent provision of ongoing care and support. The consultation has highlighted poor practice in regard to *workforce related matters*, such as *inappropriate systems* to access health care such as GP, consultant and specialist appointments. To improve access to healthcare, *digital online solutions* were discussed however within this, there was the need for flexibility and support, highlighted by the two young people at

Brotton Farm who both stated they would be happy to book an appointment online but they would need step by step instructions and maybe a carer to help them. School behaviour policies were also seen as an issue that could be resolved through social care and education working closely together, ensuring ongoing care and support.

Recommendations:

- 1) Access to appointments, support, treatments, therapies etc needs to be according to specific needs of SEND children and carers (not set programmes i.e. 6 weeks) and consistent in quality
- 2) Waiting times for specialist provision needs to improve
- 3) NHS needs to improve working with schools/education. This is relevant in meeting ongoing day to day overall needs of children and young people as well as EHCP's and annual reviews
- 4) Improve social care by offering a range of options, including direct payments, registered personal assistants and employment support, based on individual interests and needs rather than commissioned short break options.
- 5) Review short break provision to include benefits to parents and carers
- 6) Better awareness of the needs of parents/carers and appropriate action to support them across the range of health and care provision e.g. dispensing prescriptions locally and sending out appointment reminders
- 7) Improve post 16 transitions to adult services
- 8) Improve CAMHS reputation
- 9) Improve understanding of complex behaviour support needs and develop approaches embedded in prevention, support and de-escalation as opposed to punitive approaches

Prevention and/or early intervention

The strongest message from the focus groups is that early intervention and prevention across health and care provision would significantly improve the mental wellbeing of children, young people and families need to be much more vigilant in their *preventative practice*; recognising the signs of ASD and LD and acting upon their findings to prevent crisis intervention.

“Not getting the right health and care support when needed puts pressure on mental health services later down the line”.

Recommendations:

- 1) Early assessment and diagnosis to understand the specific needs of the individual and communication of this as well as any other relevant information, e.g. entitlements to benefits, to parents/carers and also education/schools
- 2) Better prevention measures for parents and carers, recognising often undiagnosed conditions and multiple caring roles. Adapting health and care provision to better meet their needs and working across services and sectors to increase holistic care and support.
- 3) Consistent good quality in the right health and care support across all provision
- 4) Find alternatives to discharging ASD/LD children from specialist provision, especially mental health services
- 5) Better management of ASD related long term health conditions



Case Study

“From very early on I knew my daughter was autistic. She was different, unique, her ways made her special yet unbelievably hard work. Then here’s the thing, what makes one autistic child unique is completely different to another child’s traits and needs. Which is where it gets tricky for diagnosis. How can you tick boxes to get a diagnosis if your child doesn’t fit into the boxes that they’re ticking? You simply can’t. So, they go unnoticed, not helped, undiagnosed and in desperate need. The fighting started when trying to get some advice. When she was around 3, [the GP] just brushed it off as normal toddler behaviour. Her routines were so rigid, and her sensory problems were really taking their toll on us all but sat in the GPs office she just acted like a neurotypical child, all sweetness and light. She learned to mask at a very young age, as a lot of females with autism do and the questionnaires required for completion, ask very male dominated questions regarding autism.

I spoke to the health visitor, then school and still no one listened. The thing you seem to find in this fight for help is that anyone in authority thinks they know best and ignores what a mother is telling them. The people of CAMHs need training to understand the variables for each autistic trait as they could help so many more children. I understand they need to follow rules and assessment guidelines, but a female autistic child doesn’t follow these so neither should they. My daughter tried CBT, each week but came out angry with herself for not being able speak up about her feelings. I rang the crisis team several times as she tried to head butt a mirror or was running away from school daily, but this wasn’t enough for any extra help from CAMHs and I was told by her keyworker this was ‘just anxiety’. At this point I sought out a private psychologist for advice and diagnosis.

These people really got to know my daughter over a period of around 6 months and did full autism testing with the Autism Diagnostic Observation Schedule (ADOS) and diagnosed her with autism 5 months later. There was no question about it, she scored above and beyond the diagnostic criteria for a diagnosis. This is something we should have got via CAMHs on the NHS. It has been a really long road to diagnosis and help and she has suffered terribly because of the lack of help and understanding. Once she was diagnosed it helped her understand why she was how she was and why she felt a certain way inside herself. I understand people don’t like labels but sometimes a name to why is so helpful for the person themselves.”



Case Study

Evidencing the impact of early diagnosis v's late diagnosis

During conversations with 2 young people at Brotton Farm focus group, it was evident that their personal experiences of having a disability were opposites. K was very happy and confident. She had great relationships she could draw on, she felt cared for and safe and had achieved an awful lot in life. A, on the other hand, had been very unhappy in his life, especially before diagnosis in his teens. He suffered from anxiety and poor mental health. He had poor relationships with his parents and his peers, being frightened and experiencing bullying at school. He felt judged for his behaviour and continued to find it extremely difficult to communicate in some circumstances.

The significant difference for A was that he had a hidden disability. He was not diagnosed with ASD until later in his teens and as a result his behaviour was misinterpreted, and his needs were not understood or met by all support services including his family. The consultations with parents and carers of children with ASD very much supported the lived experiences A was telling us about and highlight the recommendations required to improve services across health and care and for NHS to work more closely with education.

Supporting reports for Healthwatch Middlesbrough and Healthwatch Redcar and Cleveland

Dementia Summary

https://www.healthwatchredcarandcleveland.co.uk/sites/default/files/dementia_summary.pdf

The Prime Minister set two key objectives for the Challenge on Dementia 2020:

- the best country in the world for dementia care and support and for people with dementia, their carers and families to live; and
- the best place in the world to undertake research into dementia and other neurodegenerative diseases.

Redcar & Cleveland accepted this challenge and carried out engagement activities with people living with dementia and their carers to gather their views and experiences. We had the opportunity to speak to individuals and their carers about:

- Memory Clinic service.
- Information, support and training.
- Social activities.
- Dementia friendly communities.

A summary of the intelligence we collected are as follows:

- Patients are experiencing difficulties in accessing the Memory Clinic due to poor signage and we have been informed that this will be rectified in the near future.
- Patients are unsure of the role of the Memory Clinic and would benefit from a clear communication of the services provided and what can be offered in their ongoing care. For example, explanation of changes in behaviour and crisis contact details.
- Information provided to those living with dementia and their carers appears to be a key issue, whether that being about their condition, other services that can support them or

what is on offer within the community. Having the right information at the right time seems to be important as well as ensuring that there is consistency on how this is distributed.

- Redcar & Cleveland is not currently a dementia friendly community and those living with dementia and their carers feel that they would be able to have more fulfilling lives if steps were made to rectify this. A dementia friendly community would open up more opportunities without relying on bespoke activities for those with dementia.

U3A Community Intelligence

http://www.healthwatchmiddlesbrough.co.uk/sites/default/files/u3a_older_people_november_2018.pdf)

U3A provides an opportunity for those who are retired and semi-retired to share and gain new interests and knowledge. We spoke to 84 members who completed the 'Share Your Experiences - Shape Our Priorities' survey. The surveys targeted several key issues associated with the older population, based on research; this included accessible appointments, appropriate care, the 'digital move', independence, isolation within the community and future care. The survey aimed to explore these key themes by the gathering both qualitative and quantitative information. A summary of the intelligence we collected are as follows:

- Respondents felt they can struggle in the process of making appointments, with issues such as waiting times, making phone-calls and getting access to their preferred GP.
- Digital resources split opinion in terms of whether respondents would use the alternative methods, and if they would feel confident using them to access services. Telephone and online services were the most likely to be used, while Skype and video calls were much less likely to be an option. Highlighting that some more guidance could be useful to support people to be more confident.
- Some respondents noted how digital moves such as the online service and the sending of reminders helps to ease the process of booking appointments. However, there are some people who may not be interested in the digital move at all; further work could be done to highlight the benefits of using online services.
- Community support needs to be more prevalent within society so that everyone has knowledge of what services are available and how to access them, this could be visibly linked to and showcased in NHS services so that people are aware, prior to there being a need.
- The respondents recognise the benefits of keeping fit and healthy and keeping the brain active, this reflected in their desire to maintain an active lifestyle to prevent problems in future care.

#Haveyoursay Stakeholder event

http://www.healthwatchmiddlesbrough.co.uk/sites/default/files/haveyoursay_event_report_feb_2019_1.pdf)

The Healthwatch South Tees team hosted a stakeholder event, inviting stakeholders and community leaders of groups that represent older people, the BAME population and those diagnosed with long-term health conditions. The aim of the day was to gain an insight into the barriers and issues that these groups experience when accessing and using health and social care services. 37 people attended the event and were able to share valuable intelligence.

After discussing the barriers different themes were identified, the groups were then asked to prioritise the top five areas they thought to be of most importance. The Healthwatch South Tees team then compared these priority lists across the six groups to discover common trends. The following were identified:

- Finance and support (impact of funding)
- Communication (individual, between services language)

- Knowledge and awareness
- Isolation
- Systems (Process, capacity, navigation)
- Barriers/stigma

The majority of the issues and barriers that were discussed by the groups on the day align themselves to those recognised as national problems, for example funding for care and transport. There were very few issues that couldn't be shared across the three different demographic areas of older people, the BAME population and those diagnosed with a long-term health condition. This was prominent in the discussions surrounding isolation and communication. It is interesting to note that a lot of the group discussions centred around those with long-term health conditions, in regard to eligibility for care, accessing services, knowledge about conditions and preventative self-care.

In focus

Engagement through surveys and focus groups has identified health inequalities that need to be clearly raised.

- Due to the complex and unique challenges asylum seekers face they are a higher risk of developing mental health problems.
- The asylum seeker application process, which was described as 'hostile' causes many to suffer mentally
- Financial hardship is a huge factor for asylum seekers being able to attend or make appointments.
- Asylum seekers and refugees are reluctant to access services as they have serious concerns that medical information could be used in immigration enforcement. Therefore, those with serious conditions, infectious diseases and poor mental health and unlikely to seek treatment.
- Asylum seekers do not know what they are entitled to and are not given enough information on the function of services and how to access them.
- There is a lack of awareness amongst health professional of what people seeking asylum are entitled to and can lead to people being turned away from services or not receiving medication.
- In the diagnosis of children with autism, there were instances when other conditions such as ADHD were diagnosed later and separately. This meant that strategies to support ADHD symptoms were not considered and the child's overall needs were not fully understood.
- A diagnosis for single or multiple conditions should not be required to acknowledge and provide for the identified and individual needs of the child.
- When a child with ASD presents multiple times with the same issue, the GP should action further investigation leading to a health and care plan for long term treatment.
- Appointment systems and waiting times need adjusting in GP surgeries to better meet the needs of children with ASD and LD.
- Access to mental health support should depend on whether you have the confidence and knowledge to push for the right treatment

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:

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

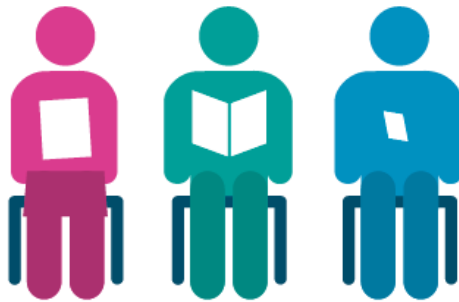
We are frequently seeing the inclusion of the voluntary sector as being able to address the gap or limitations in service provision for long-term support. A number of other comments also reflected on the invaluable help and support that nurses from Macmillan Cancer Support have provided for the patient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

RECEPTION



Hambleton, Richmondshire and Whitby

Mental Health Services

Healthwatch North Yorkshire held a focus group with mental health service users who were very positive about the benefits of mutual aid and support in the community and this serves as the most important part of care for them. They told us how living with a mental health problem can be very lonely and isolating.

There was a lot of value placed in being able to talk to someone and having trusted, consistent support workers and GP's so they can spot a difference in you, not just judge you on how you present on the day or based on previous notes. This importance of having someone to talk to was also a reason why digitalisation was not favoured, alongside a lack of phone memory; fear of potential costs to download; the complications in using technology. It was largely thought to be impersonal to use technology for patients.

Another topic of discussion was around the distance of hospitals. It was suggested that more support on discharge from hospital is needed. “You can be admitted or taken in an ambulance, to a hospital far away, and then discharged when there’s no public transport running. You’re

expected to get back home from wherever the ambulance has taken you - not everyone can afford taxis”

It was important for some that they see the same GP on a regular basis. Some had good experiences of this happening and some had negative experience where this didn't happen. There was a suggestion that some GP's are “not clued up” about mental health. One respondent shared their experience of physical health and mental health being treated as 2 separate entities, “if you go in with leg pain, they say it's because of your mental health problems. Doctor's just fob you off for your physical health problems because you have a mental health diagnosis”

There were some positive experiences of people being supported to stay in their own home, with more in home care support. Age and other conditions sometime made it harder to access services. One female shared struggles with stairs, meaning she can't access some community activities in some buildings.

Primary Care Access

Healthwatch North Yorkshire held a focus group with the Gurkha community and it was said that having an interpreter was highly important for their accessing of services. However as this is only available two mornings a week, the lack of interpreter also means there is a limited availability for the appointments.

The idea of digitalisation was not favoured, as interpretation would be needed and many would not be able to access computers or technology without the help of a younger family member, and not all members of the community do have that support available to them.

A major top of discussion was the distances to travel for hospital services. One man shared his experience of having a cut on his finger which was bleeding and needed stitches, so he went to his doctors to get it bandaged up, but they signposted to Darlington hospital. So he tried the pharmacy but was also told the same again [minor injuries unit approx. 20-mile trip, 30minutes if able to drive by car, lacking public transport links]. He was expected to travel on a bus with a heavily bleeding finger. There was a shared disappointment in group in relation this and many expected that a doctor could have done ‘something’ to help like providing a bandage.

Having to travel far for appointments was seen as a major problem in this rural area, especially since participants felt aging often leads to more health appointments and more difficulties with mobility. Phoenix house was praised, and the old military hospital before it was closed. There were suggestions of having appointments closer to home like the outpatient clinics at Richmond. But it was thought they could be closer still. When asked what would be most important to have close to home, eye clinics were suggested as eye problems make travel even more difficult and cataracts seems to be a common problem in an aging community.

A common theme across the surveys and focus groups were issues around having access to a GP quicker. There were many that wanted to see the same GP throughout, particularly for those with complex issues. The length of time you have to wait for an appointment with a GP was thought to be too long and the length of time you then have in an appointment was thought to be too short. Though, there were some exception to this where regular doctors were thought to spend quality time with their patients.

One member of the focus group shared an example of going to the GP about the side effects of his medication making him feel dizzy. After raising his concern, he was told by the GP to stay on the same medication, so perhaps more options and information around medication is needed and clear explanations for decision given to patients. This is also supported by some survey

respondents. A similar experience was shared about needing a repeat prescription due to running out of medicine, but the GP surgery advised to wait 48 hours for appointment to get a repeat - “we sometimes forget”. It seems there could be more done to remind patients when appointments and medication is needed, or perhaps better communication to reassure patients when they’re off prescription medication with clear explanation and empathy listening to their concerns.

Healthwatch Hartlepool

Healthwatch Hartlepool held a general event for people to find out about the attendees’ experiences of local health and care services with reference to the Long Term Plan priority areas. This include their experience of local services at the present time or services they have accessed elsewhere in the past. The discussion focussed on what attendees think works in practice based on their personal experience, or that of someone they know or care for, and what could have made a poor experience better. The attendee’s focussed on growing older healthily, including dementia and children and young people’s health.

Healthy Ageing

What Works Well

a) Improved Care in Nursing/Care Homes

Over the last three years there has been a noticeable improvement in the nursing and residential care within the town. This is reflected in both patient/carer experience and through a significant improvement in the grades awarded to homes as result of CQC visits. Two new homes have opened in the town providing additional nursing and residential capacity. This has played an important part in reducing the numbers of delayed hospital discharges and the numbers of Hartlepool residents having to move out of the town to access residential nursing care provision. This is hugely important to both residents and family members and takes away the need to travel to visit loved ones.

b) Dementia Services

Healthwatch Hartlepool has had a strong focus on dementia services in recent years and has noted a consistent improvement year on year in services available to people who are living with dementia and their families and carers. Much of this improvement has been driven through the Dementia Friendly Hartlepool Partnership which includes partners from health, social care, the community and voluntary sector, local commercial and business sector as well as people with real life experience or living with dementia or caring for a person with a dementia. Recent enter and view visits have also found a generally improving picture in the residential care sector in relation to supporting residents who are living with dementia although standards do vary from home to home, and there is still much room for ongoing improvement.

Finally, Healthwatch Hartlepool has worked closely with Hartlepool Carers in examining carer experience of supporting a loved one who lives with dementia. One of our key findings was that continence products provided in hospital and community setting were often inappropriate for individual needs. This has led to an examination of commissioning arrangements within the Hospital Trust and an improved and more appropriate service for patients.

What's Not Working Well

a) Life Expectancy and Mortality Rates

In recent years Hartlepool has seen reduced life expectancy levels for men and (particularly) women. This is deeply worrying and reflects to some degree increased poverty which has gone hand in hand with the national austerity agenda. It also reflects higher than average levels of heart disease, COPD, cancers and other life limiting illnesses. Lifestyle factors, such as smoking, obesity and drug and alcohol consumption are also playing a part although up until recently smoking levels had been in steady decline (although still well above national averages). Health partners and Hartlepool Borough Council have worked hard to reverse these trends, but current trends are worrying and undoubtedly will place additional strains on primary, secondary, mental health and social care services within the town going forward. Also, treatment and support outcomes for patients with drug and alcohol dependencies are worryingly poor and Healthwatch Hartlepool has heard from several service users whose pathway through treatment and support systems has been complex, problematic and ultimately unsuccessful.

b) GP Services

Generally, patients find the service, treatment and support that they receive from GP's to be of a consistently high standard. However, getting to see a GP in a timely and consistent manner can be quite another story. Patients at many practices within the town report increasing difficulties getting an appointment with a GP in less than a week. They also report that it is almost impossible to see the same GP on a consistent basis. Appointment systems also come in for much criticism with patients frequently reporting being held in an automated telephone queuing system for more than 30 minutes only to be told all appointments have gone and to phone again the following day.

Carers have reported particular problems accessing appointments as the key times for accessing telephone based appointment systems clash with their busiest caring times (e.g. between 8am and 9am). Also access to and awareness of online booking systems is often limited and appointments available in this way can also go quickly. Consequently, this can lead to patients not accessing treatment in a timely manner or using urgent care or accident and emergency services as first ports of call. Evidence has also been received from patients with mental health conditions that problems accessing GP appointments has led to their condition deteriorating and consequently accessing service in a much worse mental state or via crisis.

Other issues that were raised around Ageing Well

- Safe handling of medication
- Safe discharge/late discharge
- Dialogue/Continuity of care
- Information sharing/GP's
- Symbol on records to identify deaf/dual sensory loss patients
- Listening to Carers i.e. dementia, understanding individual
- Person Centred Care Plan
- Communication
- Mortality Rates high and life expectancy has decreased for both men and women in recent years
- Transport, both local services and health related
- Carer/Companion to help support with appointment etc
- Dual Sensory loss - bus shelter
- Education investment - immunisation, screening etc
- Treatment and support pathways for people with drug and alcohol issues

Issues raised around Children & Young People's Health

What works well

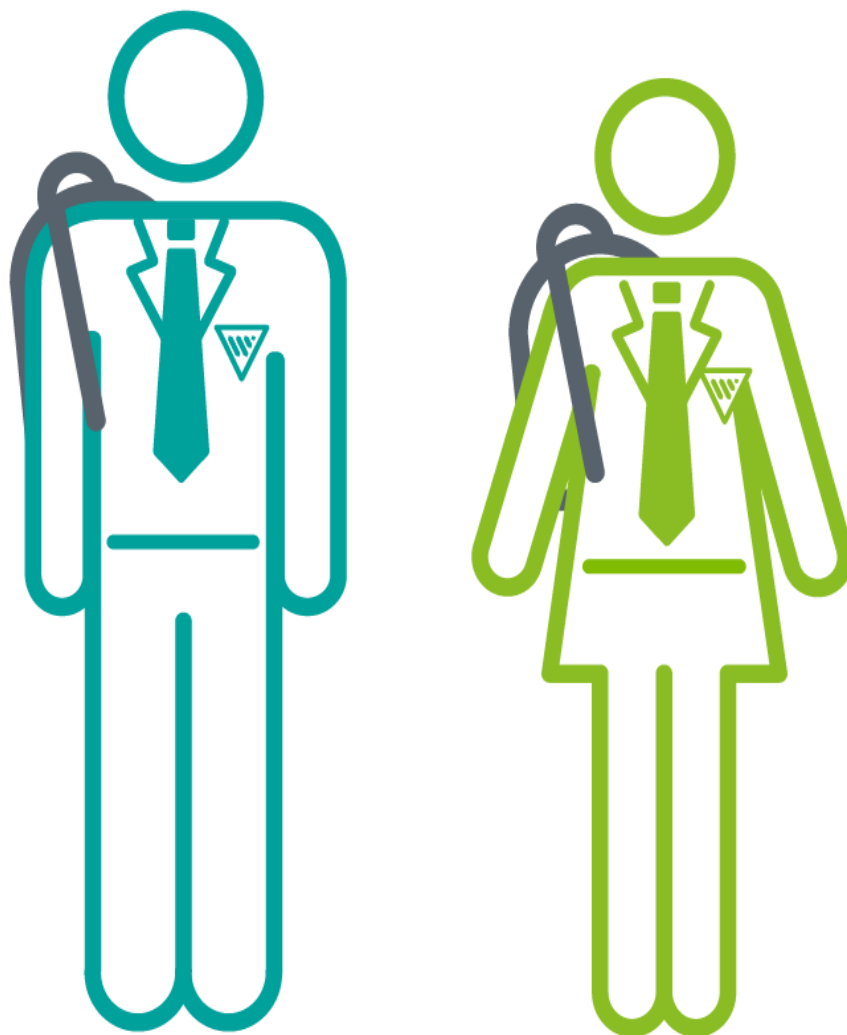
- EHC - Education Health Care
- Transition 0-25
- CAMHS - 15minute appointment within 48hours

What could be improved

- 1 Child has a medical intervention - back on waiting list, how long before next intervention
- Prevention - Oral health not so good
- Utilising Social Prescribing for Children & Young People

How would you like to see it delivered locally?

- Recognition and support for Children & Young People
- Reduced waiting time to see a GP
- Promote District Nurses
- Implement schools to support/recognise young carers
- Personal Health Budgets - Continuing Health Care choice



Healthwatch Darlington

Improving community support and breaking down the barriers to care

Healthwatch Darlington thought it was important to visit this priority as it has been indicated as a priority area for our ICS, it has been identified in our annual 'What's Important to You?' survey for 2019/20 and within our Black, Minority and Ethnic (BME) GP Accessibility and Registration Report for 2018.

The Borough of Darlington has a resident population of around 106,000 people. The ethnic population according to a 2011 census from the Office for National Statistics (ONS) states that 3.8% of Darlington's population is made up of BME communities. There has been no recent update on figures, but it is expected that this population figure will have increased due to immigration and refugees.

Several members of the BME community raised concerns back in 2018 that they felt registering with a GP surgery or arranging interpretation/translation support within their GP surgeries was a negative experience. Furthermore, we were told that in some situations the wrong interpreter was being sent to appointments which was causing a communication breakdown. This was shared with NHS England North who are in the process of trying to recruit localised translators to meet the needs of different dialects. Further detail from this report can be found via:

http://www.healthwatchdarlington.co.uk/sites/default/files/gp_bme_report_-_updated_october_2018.pdf

222 people took part in this year 'What's Important to You Survey'. 25% of these people also indicated that primary care and community support was an area they wished for us to priorities in this year's work plan. Some examples of comments are as follows:

"Better communication from GP's and more care with diagnosis results."

"Have to wait so long to get appointment."

Focus Group - BAME Community

Healthwatch Darlington conducted a focus group with fourteen local primary care service users from the West Asian community in Darlington. The group was made up of seven males and seven female participants. A further nine individuals shared feedback later which has been included within our findings.

We spoke to the group about the NHS Long Term Plan and we explored in further detail the priorities to develop primary care.

Assessment, diagnosis and treatment

The group started by highlighting how grateful they were for their NHS in Darlington.

The group went on to raise concerns that women from different cultures find it difficult to engage with primary care services. They believe this is because of cultural barriers which mean women are less likely to engage effectively with a doctor. They believe women will often suffer in silence because they don't want to be nuisance to the doctors.

The group told Healthwatch Darlington that GP's don't probe for further information and because of the difficulty to share concerns, a normal GP appointment is not enough time for some people.

“We can only speak about one ailment at a time and we are told to make another appointment if we want more time. This doesn’t help an elderly patient as getting to just one appointment alone may have created a lot of planning and effort.”

The provision of ongoing care and support

The group told us they would like to see their own GP. Their own GP will know their medical history and medication needs. They believe seeing lots of GP’s could lead to new medication that might not be needed. 10 minutes is not long enough for an appointment, they would like longer appointments.

When discussing patient stories and their experiences in accessing other services through primary care, one male said it took him one year before he was referred by his GP for a steroid injection to relief pain within his knee. He suffered with pain for a long time and he feels this referral should have been made sooner. He believes more attention and listening to patients is needed.

Cancelled appointments within Hospitals made by the NHS was mentioned by our group, as for some individuals they need family members to attend who may have travelled from a far, one example was Birmingham. This may cause problems because the family member won’t be able to keep travelling to Darlington for rebooked appointments.

The group told us travelling to different locations for lots of different appointments can be hard to keep up with when you’re not as energetic as you once were. Sometimes they can struggle to remember appointments. They believe this needs to be taken into consideration when your older.

One female told us that she believed that once you’re over the age of 80 years old a different approach to their care is given. The female said she got the impression they are not as eager to treat everything. I’ve been told *“there’s nothing they can do, it’s my age.”*

Communication with family members was highlighted as an area that needs to be considered within primary care services. The group all stressed how important it is for their family members to be able to communicate with health professionals on their behalf if this is needed.

When discussing technology it was raised that not everyone knows how to use emails and computers. This could be especially true for some members of the West Asian community who have language barriers. Learning how to do this may be difficult so in turn access to GP services will be limited for these individuals.

Prevention and/or early intervention

The group discussed how primary care services could prevent miscommunication or confusion within GP surgeries. They suggested an easy to read leaflet outlining patients’ rights within a GP surgery would be helpful for everyone.

The group said more assessments are needed to check on your health needs as you get older. They suggested that perhaps a support worker, community champion or community nurse could pop into people’s homes once a week.

The group believes that primary care services need to work closely with social care services. In turn this would prevent health conditions from possibly deteriorating.

They believe primary care services should be making an effort to make patients more aware of services on offer. They said their GP would be the main health service that they would use.

They also told Healthwatch Darlington that they would like to find out about other services via a letter which would be addressed to them and it would indicate all of the support services available within the community.

When talking to the group about living in their own homes for longer they told us everyone should be given assistive technology in their own homes once they become older. One member of the group suggested that properties should be adapted now to cater for everyone's needs and not when the need arise later on. They think bigger stairs would be useful in case you need a stair lift.

Safety of home checks need to be more frequent. One individual raised a concern about elderly people smoking in bed. This doesn't just put the individual's life a risk but also effects the neighbours and the person who might own the property.

Social interaction with someone is needed for isolated individuals. A community service aside from the NHS needs to be developed so that everyone can be checked on, if they need it.

When speaking to the group about workforce they told us, more work is needed in Darlington to attract GP's to the local area. A lot of concerns were raised that they feel GP's move onto the bigger and better Hospitals for teaching. One member suggested our local authority could help with this. Another suggestion was incentives should be available for junior doctors.

Cardiovascular and respiratory disease - prevention, diagnosis and treatment

Healthwatch Darlington conducted a focus group event with fourteen individuals. Twelve of these individuals live with a lung and/or heart condition and two knew someone who did. Some of the conditions were a triple heart bypass, heart failure, heart attack or long-term respiratory problems. Two of the participants have lost a son at a young age to an undiagnosed heart condition.

Some members of the group who live with a lung condition felt that respiratory conditions/ services were given less attention than heart conditions. One point was raised that they feel disappointed that heart conditions features within the long-term plan in more detail. The group members went onto highlight this could be due to a lack of awareness about lung conditions.

Assessment, diagnosis and treatment

People living with a heart condition believe that the physiotherapists and GP services are the most important services to them although, they did mention that waiting times to get an appointment are too long within their surgeries. Some individuals feel that COPD is 'looked down on'. 'You must have smoked'. It is seen as self-inflicted. They would like more training for professionals. Asthma is different to COPD but they believe professionals do not appear to know this.

One individual admitted that when he was diagnosed no-one within the NHS initiated discussions about his mental health. It's been 4 years and this subject has never been discussed with him by health care professionals. A patient said he was given support to think about his drinking and the GP was very helpful. He remembers this being a positive experience.

Another person told us that before his surgery, it got to the point where he felt he had to demand treatment as he felt that he could not continue with medication alone. He said he felt that this was what helped him to get the surgery and had they not been so proactive this may not have happened.

A female told Healthwatch Darlington about her young son who died suddenly from an undiagnosed heart condition. He lived an active life and was a keen cyclist and there was no indication that he had any health issues. She believes that if he was screened earlier he could have survived.

Some members of the group with lung conditions felt that medical personnel are not trained enough about respiratory problems and information is not given to patients. They went onto say that pharmacists were good at giving information as patients tend to use the same ones, so pharmacists are aware when medication may not be suitable or appropriate. Patients feel there is no continuity with GP's as they cannot see the same doctors regularly. They feel that there is too long between first presentation to GP's and then a diagnosis. People can be prescribed antibiotics and getting repeat prescriptions (one female reports 20 GP visits before diagnosis), but they feel left to self-medicate as they cannot always see a doctor when they need. One female says a respiratory nurse in her practice left a list of her patients with receptionists so they could have an appointment immediately. The receptionist has now left and the system is no longer used.

Service delivery/suggestions for improvement

It was suggested that pharmacists need more training, so they can support GP surgeries. If pharmacists can ease pressures on GP services, this would reduce the waiting times. Depending on the illness they would not mind being diagnosed by a pharmacist or nurse practitioner as long as they were made aware of who they would be seeing before attending their appointment. On the other hand others felt more continuity was needed and to see the same doctor if possible when attending appointments.

The use of technology was discussed and some felt that older people in particular may be worried about the safety of accessing things online. However others felt that booking appointments online is ok and it is felt that telephone consultations were also positive although it was felt that some patients need to be seen personally for the health care staff to get an accurate picture as "You can't feel empathy online."

"Digital/online is not for everyone - can't always say exactly what you want to say or express yourself and be clear this is much easier if speaking face to face or over the telephone."

"Email and text is not for everyone, however, it will suit others as it could be quicker and more convenient."

"Technology is wonderful but many people cannot access it due to ability, cost, location etc."

Discussions took place regarding medication and how it appears that GP's and doctors are now prescribing medications that are cost effective rather than based on patient care. Some individuals believe that treatment for anyone living with a lung condition seems to be part of a 'disease lottery-quality' and it will depend on the disease to what type of treatment you receive. The group would also like to see a priority system for certain conditions. It can take a long time to see a consultant (one person had to travel to Manchester). As people generally always feel ill, they would like access to a service close to home.

"How will I survive an emergency ambulance journey of 25 minutes or more??"

All attendees said they believe that health care professionals know best and they would trust them to make the best choices about their care and treatment, although the trust needs to be there initially for this to work.

The provision of ongoing care and support

When exploring the provision of ongoing care and support, emphasis was made about peer support groups and the value of these in the community providing individuals with a listening ear. Patients feel the NHS should provide easier and better access to support groups or peer support, so more service users and patients have someone to speak to about their health & wellbeing. The value of these groups should be recognised.

Long Term Health Conditions and Mental Health

The group explored mental health support and how there is a link for individuals living with a long term health condition such as heart and/or lung disease. They highlighted the need for this to be recognised and how it would make a difference to their ongoing care and this should be done as early as possible - particularly for young people. One female was asked if she was depressed by a health care professional and although she said yes, it was not followed up and she feels it was a 'ticky box' exercise. It was also felt that the 111 service exacerbates mental health by asking long winded questions which they find stressful. Bearing in mind their respiratory problems they would like their partners to be able to answer for them. Often 111 passes them on to a nurse and the questions are repeated, they would like this to be addressed. A patient with a lung condition pointed out that her world has become very small and she is isolated. She has friends that she can go out with but not as regularly. The result is she now lives with depression. This hasn't been recognised by GP's but it would make a difference to know that someone cares, will listen and support. Another individual raised a concern that there is no bereavement service available in Darlington as Cruse has now closed.

Car Parking and Transport

The group raised a number of concerns about the car parking facilities on offer for patient using health services in Darlington. They discussed this making a massive difference to their ongoing care. Individuals living with heart/and or a lung condition may be using health services more frequently so in turn they will need to use more parking facilities.

“Car parking is a major problem at hospitals; expensive and often unaffordable, location of disabled bays unacceptable. (May be appropriate for patients in wheelchairs but those with mobility problems, breathing and heart conditions they are too far away.)”

An individual was in tears at Bishop Auckland Hospital because they didn't have the money for the car park. Others often feel there is no option for which hospital to attend. This worries some service users who may not have their own car. Some individuals feel the voluntary driver service that is on offer in Darlington is not well known and hospital transport takes far too long. Blue badge for parking-has to be obtained/renewed at the Town Hall and there is limited disabled parking nearby. The multi storey car park is too far away and up a hill.

Rehabilitation

Some individuals told us rehabilitation needs to be closer to home. Three individuals told us they feel better support is needed for the cardiac rehabilitation staff. They all agreed the staff are outstanding but should be provided with more support from the NHS.

Prevention and/or early intervention

There was a number of points raised about the need to improve information sharing about the services/support available for patients living in Darlington. They feel this could help prevent ill health from deteriorating and enable earlier interventions from services.

It was thought that health care professionals need to be doing more to provide information about mental health support that's available. NHS staff need to be thinking about mental health when addressing physical health, it needs to become a natural part of the NHS service delivery process.

The individuals said that the NHS should be utilising organisations like Healthwatch so that they can help provide information and signposting within local areas as it's already there and it's independent.

Individuals raised concerns that at present they will not screen young people for heart conditions unless they present with problems. More awareness is needed so they this may be able to change in the future.

Some individuals who live with a lung condition said they only see a respiratory nurse once a year whereas previously they regularly saw a nurse. They feel more nurses are needed and restoring bursaries would encourage more people to become nurses. They pointed out that there are Macmillan nurses available for cancer but nothing for respiratory patients.

All agreed that online medical record sharing needs to be secure and the NHS needs to provide the right access to services for people who don't want to use digitalised methods. They feel investment into assistive technology is more important than digitalisation to improve access to services. A suggestion was that everyone who has worked should be entitled to free assistive technology if they need it as they get older, so they can live in their own homes for longer.

The group feel that the lack of funding is down to a North/South divide. Heart problems are prevalent in the south. You are 30% more likely to have respiratory problems in the north but the funding is a lot less. They would like to see face masks being considered to protect them environmentally. They pointed out that they believe cancer, percentage wise, has a smaller group of people yet they get more funding for support and publicity. The British Lung Foundation get less money than other national organisations.

In focus

In Darlington individuals living with a lung condition feel that their experiences of using local services has been somewhat negative compared to the experiences of individuals living with a heart condition. It was regularly raised that this condition felt 'left out' 'forgotten about' and generally less prioritised than other conditions.

Supporting reports for Healthwatch Darlington

Substance Misuse and Mental Health Report 2018

The voices of service users in recovery from drug and alcohol addiction was brought to our attention throughout our recent 'What's Important to you survey?' We listened and spoke to local service users from the Recovery and Wellbeing service which sits under a regional charity called NECA. Sometimes an addiction can be seen in the wrong way when in fact it is an illness. More education, training and awareness is needed to change people's perception. This was highlighted in Healthwatch Darlington's recent 'Substance Misuse' report which highlights a number of discrepancies in the treatment and access to mental health services for a patient living with an addiction. The report can be visited here:

http://www.healthwatchdarlington.co.uk/sites/default/files/substance_misuse_report_2018_0.pdf

Children and Young People Mental Health Report 2018

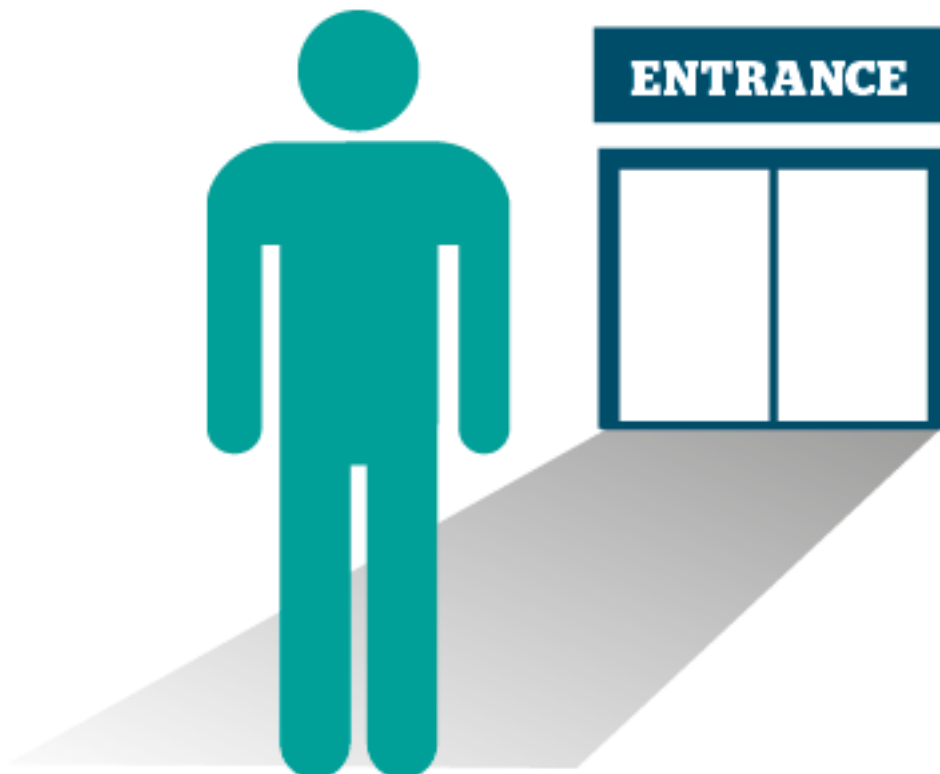
The voices of young people, parents and carers was brought to our attention throughout our recent 'What's Important to You survey?' The large number of responses to our survey highlighting mental health services for children & young people as a priority and the frequency in which we signpost children, young people and parents & carers in the community for mental health support reflects

a wider trend of mental illness amongst children and young people in the rest of the UK. The report can be visited here:

http://www.healthwatchdarlington.co.uk/sites/default/files/cyp_mh_report_2018_final_01.pdf

In Focus

In Darlington the need for carers to be supported, involved and listened too is a priority. Carers have been identified regularly throughout Healthwatch Darlington's engagement work in the past 18 months. A prevalence has been highlighted across research into mental health services, hospital services, NHS Continuing Health Care, Healthwatch Darlington's last two consecutive annual 'What's important to you' surveys and in the general NHS Long Term Plan survey.



Engaging people in health service delivery

Healthwatch Stockton

What people expect during their treatment journey

People expect to be engaged with in a way which is accessible to them paying particular focus to the requirements of the Accessible Information Standard.

People who had additional communication needs e.g. sensory impairments or if English is not their first language they often find that there are barriers as to how health services communicate with them. People feel that there should be improved access to services which meet people's individual needs. This involves making information available in a range of languages and formats and for services to be better equipped to communicate effectively.

The elderly population prefer to be contacted by telephone and like to see healthcare professionals face to face when discussing their care and treatment, whereas the younger population like to be able to access online or via text message.

People in Stockton-on-Tees would like to be able to access a range of services or healthcare professionals via a single point of access e.g. one phone number, and directed to the most appropriate service rather than having to research online or wait for a referral to access a particular service.

What people expect during service change and transformation

The public would like to see increased publicity at pivotal times to enable everyone to feel involved in the transformation to health services and be given the option to be able to have their say. People feel that more education is needed to ensure people understand how their care is delivered and why changes may be taking place e.g. look at targeting schools.

Feedback also suggested that the local community would benefit from a 'one stop shop' for people to access to find out more about how to improve their health and wellbeing as well as to be able to speak to someone if they need support or advice.

The most reoccurring theme discussed was the importance of tailoring communication strategies to the target audience e.g. older people or individuals who use a specific service. This may involve identifying different ways to inform individuals of changes and developments to local health and social care services. For example; a large proportion of the older population do not have access to or know how to use computers and mobile phones therefore emails and information on websites etc. is not easily accessible. For these individuals, preferred methods of communication include; simplified literature including leaflets in the post, adverts and posters in Doctors waiting rooms as well as individual phone calls.

It was also highlighted that the use of slogans which are recognisable to the public and captures attention would be a good method to use. It is important that information provided to individuals is simplified and reader friendly without medical jargon and overwhelming amounts of information as this would make individuals less likely to read / listen to. The importance of using current resources in the community to target individuals is also vital to inform individuals of changes to services. The use of the Voluntary, Community and Social Enterprise (VCSE) sector would be of huge benefit to circulate information and messages so the development of relationships and links with this sector is imperative. By linking in with the VCSE sector, information can easily be passed on by trusted groups and individuals to service users and the public through their services, community groups, newsletters and events.

It is also important to consider advertising and promoting information in areas which members of the public frequently visit which may not directly involve health and social care services including; shopping centres, large chain supermarkets, cafes, libraries, schools, youth clubs, churches, community centres and bus stations. In addition to this, the use of adverts and publications in free newspapers and magazines would also be of benefit when trying to reach the public.

Better use of GP surgeries and pharmacies was also discussed, highlighting that the use of TV's often found in the waiting areas, is needed to advertise and provide information to patients. In addition to this, better utilisation of frontline staff was also recommended e.g. when a patient visits the GP surgery to pick up a prescription or book an appointment, the receptionist could use this as an opportunity to discuss any relevant changes and provide information and leaflets to patients.

When using emails, texts and social media to send and promote information, a method which is highly preferred by young people, it is important that the content is direct and specific to the changes. The information provided should be concise and appropriate to the target audience without the need to follow links to other webpages. Individuals do not like receiving junk or multiple emails about the same topic as this will likely result in individuals unsubscribing from updates preventing them from finding out about important information in the future.

Members of the public like to hear of success and good practice at their local health and social care services. By sharing positive feedback, individuals are more likely to engage and listen to any proposed changes or updated information. It is hugely important for members of the public to hear information from individuals they trust. This may be their social worker, community group lead or family member so targeting these individuals would be of huge benefit when sharing information.

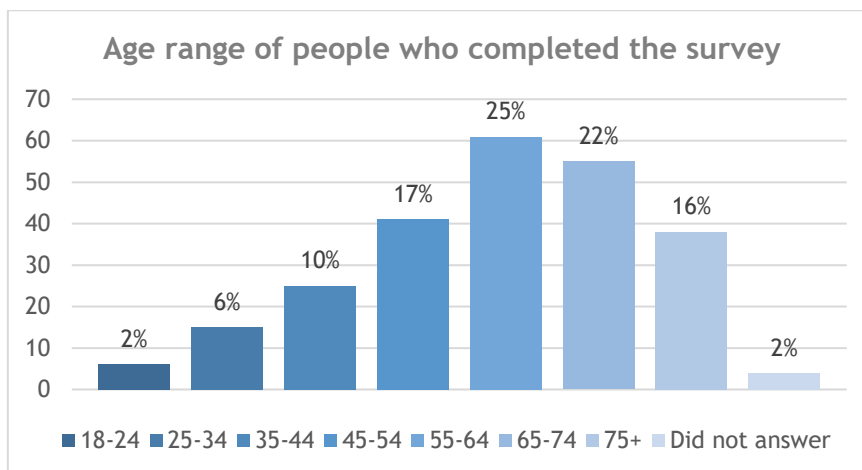
Another option to consider when looking to engage with the public would be to use their place of work to promote information or hold an event. Sending emails via organisation networks and links are more likely to be read as they are felt to be more important and trusted. In addition to this, holding an event in an individual's place of work is likely to have a higher attendance due to the ease of access and convenience. Engagement with the public must ensure that the needs of the audience are met.

Individuals who are visually impaired require information in large print or brail and individuals who are hearing impaired would benefit from a British Sign Language (BSL) speaker visiting community groups to share information and changes.

Effective communication and engagement with the public is vital in informing, influencing, and proposing changes to local health and social care services. Engaging with the public must involve varying methods of two-way communication and ensuring relationships are built and maintained resulting in a positive impact on public knowledge, involvement and confidence as well as strengthening the reputation of an organisation.

Healthwatch 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.



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.

Hambleton, Richmondshire and Whitby

The Northallerton centred focus group didn’t feel listened to and didn’t feel much would change as a result of their input based on past experience. While we were able to gain their views and provide some reassurances, they felt they often weren’t involved in decisions and there was some reference to the Friarage being closed despite their wishes. “Nothing’s going to change”. It was thought that money issues and cost savings were more important than the public’s opinions and views. It was also acknowledged by members of the Catterick Garrison group that “you can’t fix everything”. The surveys also brought forward a few concerns about the lack of money and a failing system, “just pouring money into a malfunctioning and incorrectly managed system is crass”. The public seem aware and concerned about the money struggles within the NHS, which impede their expectations during treatment and service changes.

Despite poor expectations, however, the focus groups seemed to agree that public involvement is important and thought that engagement and outreach in community hubs were a good way forward. It was considered that public reports were important to see how changes are made as a result of public engagement.

The focus group participants were happy to discuss in a group or give individual feedback, though interpreters or text translation would be needed. Our report will be feedback to interpreters but would be useful to have in a language they can understand.

The Catterick Garrison group felt it would be important to get feedback on all changes, not just that which affects them.



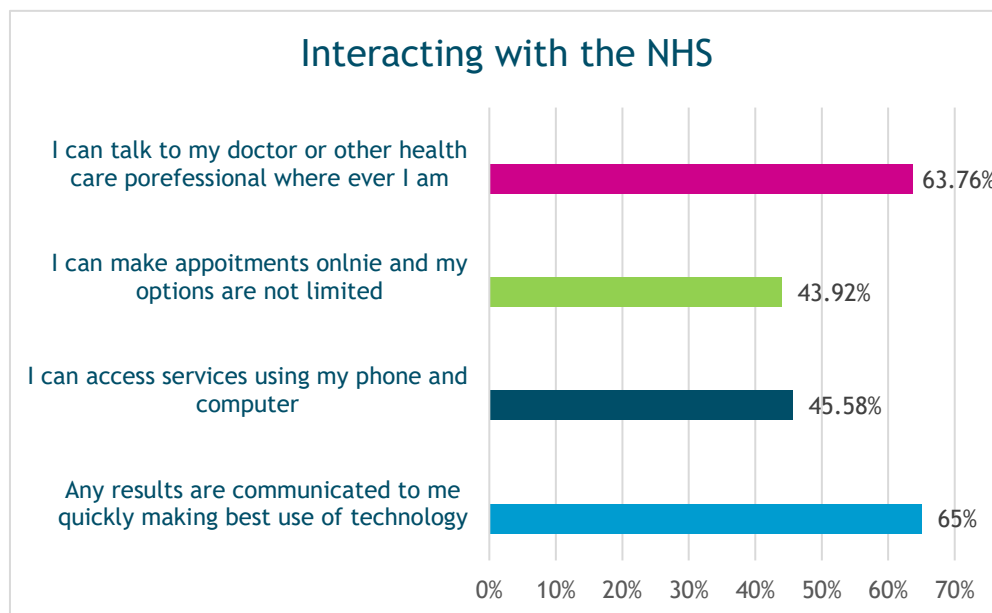
Healthwatch Darlington

What people expect during their treatment journey

Communication has been highlighted as an area of importance for a large proportion of our survey respondents. As mentioned by some of our focus group participant's communication is key in building trust and if this is missing sharing patient feedback is a lot less likely to take place.

What people expect during service change and transformation

Individuals told us during the Heart and Lung Condition focus group that they think the NHS need to do more in-depth patient journey analysis which would help them improve local services in the future. It was suggested that the NHS could work with local Healthwatch who could contribute further to service improvement by conducting enter & view or mystery shopping visits. Another suggestion was to utilise patient participation groups. They could be used as a way of being more involved and increasing awareness. They would also like to feel listened too and that their feedback is acted upon.



Healthwatch Middlesbrough and Healthwatch Redcar and Cleveland

What people expect during their treatment journey

- Long-term health conditions; given a budget and options and information so that they can decide how to manage own health
- Mental health: pro-active, regular appointments for monitoring so don't end up in A&E with self-harm issues
- Mental health: less emphasis on patient to make contact and more help to access this support, more text contact
- SEND: more joint-up working between health services, e.g. GP and specialist, and with the family
- More face-to-face support - don't want over reliance on tech (demographic of survey responses)

- More simplistic language in communications
- Use digital solutions to raise awareness of certain conditions and how to prevent them.

What people expect during service change and transformation

- Parental / carer updates on child's care, e.g. autism pathway closed but not everyone informed?
- Regular updates, communication and patient involvement during this period.



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 South of the patch submitted their individual reports to Healthwatch Darlington as the Healthwatch Coordinator for this engagement to incorporate into the County Durham, Darlington, Hambleton Richmondshire and Whitby 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, as well as Kirsty Elliot Healthwatch North Yorkshire's Research and Intelligence Officer have been invaluable with their help and support with the final North and South reports! 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 Darlington	CEO - Michelle Thompson Darlington CCG Patient and Public Involvement Lay Member
HW Hartlepool	Manager - Christopher Akers-Belcher Leader of Hartlepool Borough Council Development Officer - Stephen Thomas Elected Member of H'pool Borough Council, TEWV Appointed Governor
HW North Yorkshire	CEO - Michelle Thompson Darlington CCG Patient and Public Involvement Lay Member

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.



Appendix 2 - Demographic Information from the surveys

Area	Number of surveys collected in total
County Durham	392
Darlington	156
Hartlepool	141
Middlesbrough, Redcar and Cleveland	209
Hambleton, Richmond and Whitby	79
Stockton	166
Total	1143

Your Gender	County Durham	Darlington	Hartlepool	Middlesbrough, Redcar and Cleveland	Hambleton, Richmond and Whitby	Stockton	Total
Male	115	37	37	42	21	47	299
Female	262	109	90	102	48	109	720
Other	1	0	0	0	0	0	1
Prefer not to say	6	1	3	5	1	1	17
Not answered/Not collected	8	9	11	60	9	9	106
Total	392	156	141	209	79	166	1143

Your Age	County Durham	Darlington	Hartlepool	Middlesbrough, Redcar and Cleveland	Hambleton, Richmond and Whitby	Stockton	Total
Under 18	1	25	0	1	2	2	31
18-24	8	23	0	6	0	1	38
25-34	19	8	6	17	5	9	64
35-44	43	9	5	25	2	11	95
45-54	67	9	15	33	6	24	154
55-64	91	19	27	66	23	40	266
65-74	94	23	38	0	17	39	211
75+	57	35	48	0	16	33	189
Not answered/Not collected	12	5	2	61	8	7	95
Total	392	156	141	209	79	166	1143

Your Ethnicity	County Durham	Darlington	Hartlepool	Middlesbrough, Redcar and Cleveland	Hambleton, Richmond and Whitby	Stockton	Total
African	0	2	0	1	0	1	4
Arab	0	2	0	1	0	1	4
Asian British	1	0	0	4	0	5	10
Bangladeshi	0	0	0	0	0	1	1
Black British	0	1	0	0	0	1	2
Caribbean	0	0	0	0	0	0	0
Gypsy or Irish Traveller	0	0	0	1	0	0	1
Indian	1	1	0	1	0	1	4
White British	361	141	137	131	68	131	969
Pakistani	0	0	0	0	0	11	11
Any other white background	6	4	1	3	0	2	16
Any other mixed background	2	0	0	0	0	0	2
Other	9	2	0	4	1	1	17
Not answered/Not collected	12	3	3	63	10	11	102
Total	392	156	141	209	79	166	1143

Do you consider yourself to have a disability	County Durham	Darlington	Hartlepool	Middlesbrough, Redcar and Cleveland	Hambleton, Richmond and Whitby	Stockton	Total
Yes	141	25	44	51	10	58	329
No	224	115	81	93	58	93	664
I'd prefer not to say	19	3	11	5	4	6	48
Not answered/Not collected	8	13	5	60	7	9	102
Total	392	156	141	209	79	166	1143

Are you a carer?	County Durham	Darlington	Hartlepool	Middlesbrough, Redcar and Cleveland	Hambleton, Richmond and Whitby	Stockton	Total
Yes	80	14	13	32	6	26	171
No	299	128	123	117	64	130	861
Not answered/Not collected	13	14	4	60	9	10	110
Prefer not to say	0	0	1	0	0	0	1
Total	392	156	141	209	79	166	1143

Do you have	County Durham	Darlington	Hartlepool	Middlesbrough, Redcar and Cleveland	Hambleton, Richmond and Whitby	Stockton	Total
A long term condition	115	29	56	36	24	81	341
Multiple conditions	68	19	32	55	8	23	205
Neither	105	95	50	0	40	52	342
Not answered/Not collected	104	13	3	118	7	10	255
Total	392	156	141	209	79	166	1143

Which of the following best describes you?	County Durham	Darlington	Hartlepool	Middlesbrough, Redcar and Cleveland	Hambleton, Richmond and Whitby	Stockton	Total
Heterosexual	323	0	15	126	64	140	668
Gay or lesbian	5	0	2	4	1	2	14
Bisexual	3	0	0	4	0	1	8
Asexual	0	0	0	0	0	0	0
Pansexual	2	0	0	6	0	0	8
Other	12	0	0	7	1	2	22
Prefer not to say	0	0	3	0	0	0	3
Not answered/Not collected	47	156	121	62	13	21	420

Total	392	156	141	209	79	166	1143
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Your Religion	County Durham	Darlington	Hartlepool	Middlesbrough, Redcar and Cleveland	Hambleton, Richmond and Whitby	Stockton	Total
Buddhist	1	0	0	0	0	1	2
Christian	239	0	13	68	40	97	457
Hindu	1	0	0	0	0	0	1
Jewish	2	0	0	0	0	0	2
Muslim	1	0	0	6	0	16	23
Sikh	0	0	0	0	0	1	1
Other	5	0	0	3	0	0	8
No Religion	108	0	5	57	26	33	229
I'd prefer not to say	25	0	2	12	3	4	46
Not answered/Not collected	10	156	121	63	10	14	374
Total	392	156	141	209	79	166	1143

Appendix 3 - Demographic information from condition specific surveys in

Darlington

Number of surveys collected in total

8

Please select the condition you would like to tell us about	Number of respondents
Cancer	0
Heart and lung diseases	5
Mental health	0
Dementia	0
Learning disability	1
Autism	0
Long-term condition e.g. diabetes, arthritis	2
Not answered/Not collected	0
Total	8

Your Age	Number of respondents
Under 18	0
18-24	0

25-34	0
35-44	1
45-54	1
55-64	5
65-74	0
75+	0
Not answered/Not collected	1
Total	8

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	7
Pakistani	0

Any other white background	0
Any other mixed background	0
Other	0
Not answered/Not collected	1
Total	8

Do you consider yourself to have a disability	
Yes	5
No	2
I'd prefer not to say	0
Not answered/Not collected	1
Total	8

Are you a carer?	Number of respondents
Yes	1
No	6
Not answered/Not collected	1
Total	8

Do you have	Number of respondents
A long term condition	8
Multiple conditions	0
Neither	0
Not answered/Not collected	0
Total	8

Which of the following best describes you?	Number of respondents
Heterosexual	5
Gay or lesbian	0
Bisexual	0
Asexual	0
Pansexual	0
Other	1
Not answered/Not collected	2
Total	8

Your Gender	Number of respondents
Male	6
Female	2
Other	0
Prefer not to say	0
Not answered/Not collected	0
Total	8

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

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	
Darlington	Improving support and breaking down the barriers to care (BME)	14	28
	Heart and Lung Conditions	14	
Hartlepool	Healthy Ageing	Unknown	
	Children and Young people's health	Unknown	
Middlesbrough, Redcar and Cleveland	Mental Health within BAME	30	58
	Asylum-Seeking communities	7	
	SEND young	3	
	Parent and Carers of children with disabilities	10	
	Parents and Carers of SEND children and young people	8	
Hambleton, Richmond and Whitby	Mental health support	9	30
	Gurkha community	21	
Stockton	Butterwick Hospice Connections Group	10	20
	Visual impairment	10	
Total		170	170

Local Healthwatch contact details

 <p>healthwatch County Durham</p>	<p>Phone:</p> <p>0191 3781037 (Office Landline)</p> <p>0191 3787696 (Volunteer Support)</p> <p>0800 3047039 (Freephone Signposting No.)</p> <p>07756 654218 (Text)</p> <p>E-mail:</p> <p>healthwatchcountydurham@pcp.uk.net</p> <p>Website:</p> <p>www.healthwatchcountydurham.co.uk</p>
 <p>healthwatch Darlington</p>	<p>Phone:</p> <p>01325 380145 (Landline)</p> <p>07525 237723 (Text)</p> <p>E-mail:</p> <p>info@healthwatchdarlington.co.uk</p> <p>Website:</p> <p>www.healthwatchdarlington.co.uk</p>
 <p>healthwatch Hartlepool</p>	<p>Phone:</p> <p>01429 288 146</p> <p>Website:</p> <p>www.healthwatchhartlepool.co.uk</p>
 <p>healthwatch Middlesbrough</p>	<p>Phone:</p> <p>01642 955 605</p> <p>E-mail:</p> <p>general@healthwatchesouthtees.org.uk</p> <p>Website:</p> <p>www.healthwatchmiddlesbrough.co.uk</p>

 <p>healthwatch Redcar and Cleveland</p>	<p>Phone: 01642 955 605</p> <p>E-mail: general@healthwatchsouthtees.org.uk</p> <p>Website: www.healthwatchredcarandcleveland.co.uk</p>
 <p>healthwatch Stockton-on-Tees</p>	<p>Phone: 01642 688312 08081 729559</p> <p>Email: healthwatchstockton@pcp.uk.net</p> <p>Website: www.healthwatchstocktonontees.co.uk</p>
 <p>healthwatch North Yorkshire</p>	<p>Phone: 01904 552 687</p> <p>Email: admin@healthwatchnorthyorkshire.co.uk</p> <p>Website: www.healthwatchnorthyorkshire.co.uk</p>