

HUMBER, COAST AND VALE

whot
would you do?

It's your NHS. Have your say.

JULY 2019

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Executive summary

Background

In January 2019 the NHS published a document called the NHS Long Term Plan. This plan identified the priorities and changes that the NHS is going to make over the next ten years. On the back of this report local Health and Care Partnerships (sometimes called ICSs or STPs) are going to be producing localised plans that will focus on what they will do locally to bring about the changes mentioned in the NHS Long Term Plan. One of the priorities of the Long Term Plan and consequently local services is that there is much more involvement from the public, patients and service users. To that effect, Healthwatch across the county have been tasked with engaging the public about what they would like to see change with their NHS services in the future. The piece of work focuses on people's priorities and preferences when receiving care, what people want to live a healthy life, how people want to interact with their NHS. This report focuses on the geographical area of Humber, Coast and Vale. This area has six different local Healthwatch which include Healthwatch East Riding of Yorkshire, Kingston upon Hull, North Yorkshire, York, North East Lincolnshire and North Lincolnshire. All six Healthwatch participated in this research.



Figure 1 - Humber, Coast and Vale Area

Purpose

The purpose of this research is to ascertain what people's preferences and choices would be when shaping future health and social care services across Humber, Coast and Vale. The information gathered from this research will directly feed into the Partnership's Long-term Plan, so that decisions about the future of our services are measured, considered and developed based on public information and service-user feedback.

Objectives

The objective for Healthwatch locally within Humber, Coast and Vale was to gather feedback and information on what people would like to see within their local area. Surveys, public engagement and focus groups were used to develop a robust wealth of information that would provide the HCV Partnership with a large volume of credible data to enhance local plans moving forward. This work was part of a national campaign that was delivered by local Healthwatch across the county on behalf of Healthwatch England. This report will be submitted to the Humber, Coast and Vale Health and Care Partnership to make sure the opinions of the public are formally put forward for consideration.

Summary of Findings:

What matters most to people in Humber, Coast and Vale?

Healthwatch across Humber, Coast and Vale spoke with over 2000 people during the engagement on the Long Term Plan. Methods of engagement included, surveys both general and condition specific and focus groups. The plan was for Healthwatch across the country to gather a wide variety of rich information that will enhance the local plans being made. The volume of information we received from the public have allowed Healthwatch to identify important trends of what is important to the people who live in our area. Some of those key results include:

- Knowledge and Access
- Choice and control
- Independence
- Interacting with your NHS

Knowledge and Access

The public were asked about what is important to live a healthy life and answered questions graded from not important at all to very important. There was an overwhelming consensus in all the answers that followed. The clear theme that presented here was about knowledge and access. 67% of respondents thought easy access to information that will help them make decisions about their future was very important. 66% thought having knowledge to help prevent ill health was also very important. Access to help and treatment received an 85% rating of very important and finally having professionals that listen and making every interaction count also received a majority vote of very important.



We also asked people for comments.... **if there was one more thing that would help you live a healthy life, what would it be?** The following are some of the quotes from this question:

A diet plan tailored for my lifestyle and my body that takes into account all the things you should or shouldn't eat and identify those that are in moderation.

A GPs appointment system that is more flexible.

Ability to make appointments (access doctors) within a reasonable time scale.

Clearer advice for care of the elderly.

Easier access to see consultants for further assessments on concerns and more in-depth advice. GP's are general and more advice is sometimes needed to get at the root cause.

Faster access to GP services. A routine appointment is currently over 3 weeks wait, which puts me off trying to get help for symptoms.

Having more time to exercise and consider my own wellbeing.

Health professionals who really react when there are major issues, not respond with platitudes, but make me feel like they really know me and care for my wellbeing.

Choice & Control

The people who engaged with us also confirmed that there is a real desire to have more choice and control over how, when and where they receive treatment. 71% of respondents felt it either important or very important to be able to have a say in how the NHS spends money if they have a long term condition. 'Choosing the right treatment should be a joint decision between the individual and the health professional' was rated as very important by two thirds of respondents. Making a decision about where to go for treatment was also rated as either important or very important by 85% of all respondents. Over 50% believed that being offered support out of area when treatment isn't available locally is very important and 80% want to be able to say when treatment is delivered. 96% either stated important or very important on communications being timely. Finally 60% would like time to consider their options when making decisions about their care.

We also asked, 'If there was one thing that would help you manage and choose how the NHS supports you, what would it be?

Responses included:

A single point of contact across the health and social care organisations, an integrated approach.

Doctors that listen first time and not have to keep attending.

Full explanation in language I understand.

It is important to me to be involved in the treatment that I receive and that I am listened to about any concerns I may have about my illness or the care / treatment I am to receive.

To appreciate we have busy lifestyles too! Having access to a GP surgery in the hours that suit us! We work, therefore we need flexibility in appointments.

Very important to have my treatment locally and not to be pushed from pillar to post at different centres.

With working full time, I would like to be able to speak with my diabetic nurse/doctor via a video link to save me having to take time off work. Obviously if there was something of concern I would expect to be seen face-to-face.

Options are made available. I have had many appointments where I am left to look at solutions myself.



Independence

Resilience and independence are two key areas that services are currently looking into. With an aging population and more demand on services than ever before, it is increasingly vital to know what is important when it comes to being independent and staying healthy. 80% of respondents believe it is very important to be able to stay in their own home for longer. Half of respondents believe it is very important to have a community who can support you to live a life the way you want. Over 60% of people think it is very important to have family and friends with the confidence and power to help and support individuals. However, this is even higher specifically in North Yorkshire where rurality and isolation are a large factor with over 70% rating it as very important compared to only 58% in York. Following on from rurality and isolation nearly 70% place having convenient ways to travel as very important, with the East Riding and North Yorkshire both scoring much higher as these areas are rurally challenged to deliver local services. 80% of all respondents expect to be supported and that their families will be supported at the end of life.

In addition to this we asked, ‘If there was one more thing that would help you retain your independence what would it be?’

A **person** who could call in at least once a week to do a bit of shopping and maybe sit and talk a while.

Better social services support, increased access to health and well-being support services. Increase the number of social prescribers in our community.

Effective communication with authorised family members.

Good transport system to **enable** me to travel to shops, garden centres, parks etc. The longer that I am able to get around, the longer I will be able to stay healthy. Meeting and communicating with people on a daily basis is very important.

Local health services such as **community** wellbeing clinics.

Look at ways to **combat** loneliness, lots of clubs/meetings but they are/seem to be aimed at certain "class" not very inclusive.

More transport support for medical appointments.

Providing good, **consistent** care at home with adequate time allocated to each patient, information correctly recorded and disseminated. Making this care **affordable** and indeed free in many instances.



Interacting with your NHS

A functioning NHS that works in your best interests will also rely on the way that you interact with the NHS services you use, and your wider local community. We asked a series of questions about how important people in Humber Coast and Vale actually believe this to be. 70% of people who responded believe it is very important to have personal data well managed and kept secure. However there is local discrepancy here as in North Yorkshire this number is only at 50% compared to North Lincolnshire where it was close to 80%. This could be due to a variety of reasons such as demographics and distance that the Humber, Coast and Vale patch covers. Humber, Coast and Vale has a large older population so it was no surprise that accessing services by phone or computer only had 50% placing it as very important. North Yorkshire even less with only 40% thinking this.

Being able to “talk to a doctor or other health professional wherever I am” was rated as very important by around 55%, however interestingly Kingston upon Hull had 15% who stated this wasn’t an issue; the lowest out of all six localities that make up Humber, Coast and Vale. This could be due the fact that it is a small geographical size so travel between points would be deemed easier. Making appointments online again didn’t score as high as previous questions and less so in North Yorkshire where only 39% believe this is very important. The other areas all have at least 50% believing this is very important. 64% think it’s very important to have results communicated quickly by making the best use of technology. This is even higher in Hull with 74% looking to improve communication via technology.

Peer support and being able to speak to others who are experiencing similar challenges had 60% believe it was either important or very important, however in York over 40% believe this to be a non-issue or not important.

Finally we asked, ‘If there was one more thing you think needs to change to help you successfully manage your health and care, what would it be?’

Better co-ordination and communication between health care professionals and more explanation about the purpose of repeated tests, especially when the tests have already been done at a different hospital.

Easier access for advice on managing condition, not just giving out medication.

Ensure that health records are available to all necessary departments - so the left hand knows what the right hand is doing!

Have a copy of my personal data.

There are no online appointments at my own GP. However the practice also has a surgery in a nearby village where there are always an abundance of available appointments, but only if you live in that village. Surely they need to re-evaluate availability across both areas?

While technology has helped with quite a lot of aspects of healthcare which has improved some services noticeably I feel that sometimes it is too impersonal and I would prefer to speak to a real person if I want to.



What would you do?

Priorities

Healthwatch also asked the public to choose a priority from the areas discussed above. Respondents were only able to select one answer. The results to those questions are as follows:

Question 1. What is most important to you to help you live a healthy life?

Access to the help and treatment I need when I want it	46.72%
Professionals that listen to me when I speak to them about my concerns	23.05%
Easy access to the information I need to help me make decisions about my health and care	13.24%
The knowledge to help me do what I can to prevent ill health	13.24%
For every interaction with health and care services to count; my time is valued	3.76%

Question 2. What's most important to you to be able to manage and choose the support you need?

Choosing the right treatment is a joint decision between me and the relevant health and care professional	43.27%
I should be offered care and support in other areas if my local area can't see me in a timely way	14.37%
I have time to consider my options and make the choices that are right for me	9.20%
I make the decision about where I will go to receive health and care support	9.15%
My opinion on what is best for me, counts	7.69%
If I have a long term condition I decide how the NHS spends money on me	7.07%
Communications are timely	5.89%
I make the decision about when I will receive health and care support	3.37%

Question 3. What's most important to you to help you keep your independence and stay healthy as you get older?

I want to be able to stay in my own home for as long as it is safe to do so	56.59%
I want my family and friends to have the knowledge to help and support me when needed	14.19%
I want there to be convenient ways for me to travel to health and care services when I need to	11.04%
I want my family and me to feel supported at the end of life	10.87%
I want my community to be able to support me to live my life the way I want	7.32%

Question 4. What is most important to you when interacting with the NHS?

I can talk to my doctor or other health care professional wherever I am	32.33%
I have absolute confidence that my personal data is managed well and kept secure	20.58%
Any results are communicated to me quickly making best use of technology	16.65%
I can make appointments online and my options are not limited	13.28%
I can access services using my phone or computer	9.46%
I am able to talk to other people who are experiencing similar challenges to me to help me feel better	4.16%
I manage my own personal records so that I can receive continuity in care	3.53%

Question 5. Any further comments?

Adult mental health services should be offered as soon as someone leaves CAMHS.

All data should be protected and not shared with people that the patient doesn't want it to be shared with.

Mental health services should use medication / inpatient treatment as a last resort.

I feel from personal experience that waiting times are getting longer. I was told in December that I would be seen in January for a skin problem. It is now March and I haven't got an appointment.

Most important is timely appointments, I don't consider having to wait days is a good service.

One should not forget that the NHS is a marvellous services and one that should be appreciated by all of us, patients also have a duty to keep it marvellous!!!

They do well under such pressures. They need more money, more people working here.

To get more help and support for my illness, which I cannot currently do. Thank goodness for my friends and family that have been there for me.

More effort needs to be put into prevention and people taking responsibility for their own health. It's no use people following unhealthy lifestyles and expecting the NHS to pick up the pieces when they are resultantly ill.

It feels as though the decisions have been predetermined. All options relate to the health care provision being shifted to family and friends. As support for carers is so minimal and carers are more likely to experience ill health as a result of caring I believe that this method of transferring the responsibility to family and friends will inevitably place more pressure on health long term. Therefore, the plan is not sustainable and in my opinion is trying to 'pass the buck' to others rather than find innovative and creative ways of working that can be flexible in the face of changing demands and an ageing population.

A good clean hospital, well run, would give me confidence.

Themes and Conditions

In addition to the general survey and general focus groups, Local Healthwatch across Humber, Coast and Vale also carried out a condition-specific survey and held targeted focus groups for people who have experienced services in particular clinical areas. The information that follows is information about those patient journeys from the perspective of those who experienced the journey or those closest to the service-user such as family members or carers.

The clinical service areas were all selected because they align with the priorities of the Humber, Coast and Vale Health and Care Partnership and with the priority areas identified within the NHS Long Term Plan. The Partnership agreed with local Healthwatch that having relevant service user engagement and feedback on these service areas would be important in terms of influencing improvement in these services.

Cancer services

Assessment, diagnosis and treatment

Healthwatch across the Humber, Coast and Vale area received a total of 62 survey responses from people who identified Cancer on the conditions survey and also held a series of focus groups (two in each local Healthwatch area) that help provide a rich amount of information to provide a summary of what those who participated in the research think of their Cancer services.

Participants stated that during assessment, diagnosis and treatment, they would like to have access to prompt appointments with their GP, consultant, specialist nurses and radiologists. It is important to patients that they are offered the best treatment and support, in a location that best suit their needs. Patients are aware that in order to receive the best possible treatment, they may have to travel. In such cases, distance has to be considered as travelling long distances are not always practical for people with cancer, who may be suffering from tiredness and sickness. There are also cost implications to having to travel, as well as a likelihood that this would have an impact on relatives, who may not be able to visit and/or offer support from afar. In addition, it was strongly felt by attendees of our Cancer service focus group, that there is a “postcode lottery” when it comes to accessing treatment, with a wider range of treatment options offered in other areas of the UK. Patients would like to see this changed. Suggestions were made of specialist’s centres working across satellite surgeries, enabling consultants to see more patients in areas that are more local to them.

In order to make informed decisions about treatment, patients want information that is clear, concise and in plain English. Information should include details of where, when and how long the treatment will take, success rates and details of any side effects. In order to feel supported during this period, patients want to know that they are being listened to and subsequently supported. Many patients want to have a say on the treatments they receive and be consulted regarding this rather than told.

Participants identified examples of what is working well, with the main theme being NHS staff. Many were keen to praise nurses and hospital staff. Some quotes we obtained during the Cancer Services Focus Group were -

“Staff go over and above to make individual patients feel that they are important to them”

“Staff at Castle Hill exceptional”

However, it was raised that staff levels are low, particularly ward staff and specialist nurses. Many patients reported having long waits for discharge from hospital, with many stating that they have waited a full day before being sent home.

“Took many hours to be discharged from ward. Waiting for meds and letter. (10am told - 8pm home)”

Hospital communication was raised as an issue, whether this be communication internally between departments or communication with patients. Participants told us of appointment letters arriving after the appointment and the frustration of not receiving test results without having to call the hospital/surgery. It was questioned whether this was standard practice, and if so, this advice should be passed to the patient at the time of the tests.

The provision of ongoing care and support

During this stage of the journey it is important that the patient feels supported, not only with the cancer treatment, but holistically, taking into account mental health and the effect that the illness and treatment may have on the person as a whole. Participants want to feel listened to and be cared for by staff that are professional, supportive and empathetic. Ideally patients should feel able to contact relevant staff, who have involvement in their care, when needed, be it for support or further information. What matters most to patients in terms of support is being able to access it when it is needed, without delay and in a location that is convenient. Suggestions were made of additional support being offered in the GP surgery by the doctor or specialist staff.

It is important to patients that they are kept informed throughout the journey, including updates about how the treatment is working, next steps, and choices going forward. This should be done in an appropriate manner, allowing plenty of time so the patient does not feel rushed.

Patients would like to see the same consultant, specialist nurses, and support staff throughout their care, rather than a different professional at every appointment or treatment. It is felt that this would give better continuity in care and puts the patient at ease being treated by a professional with whom they have built a trusting relationship.

It was acknowledged that there are support groups in the community; however, this information isn't always passed on to the patient and isn't always easily found. Participants would like to see such information handed out by the medical professionals. Signposting patients to support services, gives the patients an opportunity to discuss symptoms, treatments plans and any other questions with someone who has been or is currently in the same situation. In addition, support should be available for relatives of those receiving cancer treatment and to bereaved family members.

Praise was given for the support offered by Lindsay Lodge (in Scunthorpe, North Lincolnshire) and Macmillan. This support ranged from the care received to the information offered to patients and families.

Prevention and/or early intervention

Good experiences were shared regarding early intervention including praise for having timely referrals and investigations.

“Speedy referral to fast track cancer department”

“Diagnosed and had bone scan, MRI and CT scan within 2 weeks”

Although many participants were pleased with the fast diagnosis, it was still reported that the access to primary care is slow, and the service sometimes received during the initial GP

appointment isn't working well. Patients reported having to wait a significant amount of time before being able to access a GP appointment, only to feel like their concerns were brushed off with a "watch and wait" approach by the doctor. One patient shared his story of how his concerns were dismissed by the doctor and he was sent away with "groin strain" when in fact, he had prostate cancer, which was identified shortly after, through a visit to A&E.

Attendees of the focus group acknowledged that information on prevention and early intervention is well publicised, however it was said that screening programmes are down to individual choice and therefore should be widely available through community clinics, GP surgeries, pharmacies and at home in order to get and enable more people to participate.

Survey Results

Results from the conditions survey pertaining to Cancer assessment, diagnosis and treatment:

- 78% of people received support that met their expectations when first accessing treatment.
- Close to 75% found the overall experience of getting help very positive.
- Half of respondents to the cancer survey had another long term condition. Of those, 35% stated that it made accessing treatment harder.
- Nearly 40% answered "very fast" for the time taken to receive treatment, whilst only 15% felt it was slow.
- 38% felt getting their initial assessment was very fast, a further 25% felt it was fast.
- 70% were offered further access to services after their diagnosis.
- 95% were referred to a specialist or consultant.
- 60% thought that the time between referral and seeing the specialist was fast.
- 60% felt that finding ongoing support was either okay or easy.
- 55% stated that they received ongoing timely communication throughout the pathway.

In focus

- Whilst most attendees did not feel that their age played a part in the equality of service received, one attendee stated that they have not been offered certain treatment due to their age, however, they are aware of other similar aged patients being offered the treatment in other parts of the country.
- Half of respondents of the cancer survey had another long term condition. Of those 35% stated that access treatment for more than one condition became harder.

Mental Health services

Healthwatch across the Humber, Coast and Vale area received a total of 90 survey responses from people who identified Mental Health on the conditions survey and also held a series of focus groups that help provide a rich amount of information to provide a summary of what those who participated in the research think of their Mental Health services.

Assessment, diagnosis and treatment

What matters most to patients during this stage of the journey is being seen and being in receipt of appropriate treatment and support in a timely manner. Respondents stated that they felt accessing support wasn't always easy and many told us that they felt their concerns were dismissed or "played down" by the GP. A theme that had arisen from feedback received is that the GP is quick to prescribe medication (anti-depressants) in what is seen as an attempt at a "quick fix". Patients want to feel listened to and know that they are being taken seriously. They want to speak to staff who are empathetic and show an interest. Suggestions were made of having mental health professionals in all GP surgeries as well as better mental health training for GP's.

"Nobody really checked up on me/my progress and the last time I visited the GP, he brushed my feelings and upset under the carpet... He told me I had no reason to be depressed, it was all in my head and I needed to pull myself together."

Patients want to be seen in local areas to limit any additional anxiety that sometimes stems from having to travel. It has been raised that patients are being passed from service to service with no clear diagnosis, making seeking appropriate treatment more difficult. Parents struggle to find help for children with mental health issues as CAMHS waiting lists are too long.

Patients who do get referred for further treatment, including therapy and counselling, report long waiting lists. Many turn to other organisations and charities such as MIND and Open Minds in the meantime. Some patients stated that online therapy wasn't for all and face to face interaction with a psychologist was much more constructive. Respondents reported that they would like medical professionals to recognise that each individual will need support that is catered specifically to them and their condition.

"I accessed 'ieso' but only had so many sessions (approx. 10). I found it difficult to discuss my thoughts and feelings by typing in a ½ hour slot and quite often didn't manage to address all my issues within the sessions."

"I made an application for the online therapy which is run by the NHS, thinking this could offer some support in the meantime, only to be told I couldn't make applications for two therapy methods and must either chose one or the other. I was expected to wait all this time without being entitled to seek extra help because I was already on a waiting list for elsewhere."

There is a general feeling that there are not enough staff within mental health services and that other NHS staff are not always trained to be able to recognise the signs of mental health issues and respond appropriately. Examples given included A&E staff, and other medical consultants who may be treating the patient for another condition. Respondents would like continuity in care and a reassurance that professionals were speaking to each other as well as communicating with the patient.

Some respondents told us of gaps in services, such as services specifically for eating disorders. Many claim to have been referred to a dietician but report that they did not receive support in regards to the mental health aspect of the condition. It was reported that more could be done for the mental health needs of veterans as well as individuals who are seeking employment.

Positive examples of care included having the ability to self-refer for online counselling and the support offered through charities and external organisations.

The provision of ongoing care and support

Mental Health patients we spoke to believe care and support services are no longer able to cope with the high demand and increase of people with mental health issues. They believe that funding has not increased to meet said demand and therefore staff resource is low.

Crisis lines that are put in place are not coping with demand resulting in patients having to wait hours to speak to someone. One respondent stated, “this is far from ideal for individuals who are suffering and possibly suicidal.” Many think that call handlers need further training, with some reporting that they felt that their illness was trivialised with suggestions such as; “Why don’t you have a cup of tea and watch X-factor.”

Patients described the care journey as a vicious circle; starting with seeing the GP, then receiving a bout of counselling before being discharged and then having to go through the process again to get further help. This has also been referred to as “revolving door admissions”. Patients want to be treated as individuals and receive the care and support that is necessary for them and for health professionals to understand that some forms of support are more suitable than others for different individuals.

It is felt that many people become dependent on a mental health service and professionals are wary of discussing discharge for fear of unsettling the patient. This in turn creates a bottleneck scenario, where new patients are struggling to access services until others are moved on. Respondents suggested that the NHS make better use of other organisations and charities at this point and discharge patients to relevant services who will aid in rehabilitation back in to everyday life.

Parents and guardians of children reported that the waiting list for CAMHS was upwards of 12 months with little or no support put in place in the meantime. Many respondents feel that families of those living with mental health issues should also receive support and training on how to live with the condition.

Patients would like to see more support in way of social prescribing; some had tried yoga and meditation classes and found them to be very useful. It was felt that information about social prescribing should be more readily available and possibly passed on through health professionals during treatment. Similarly, many patients would like someone to speak to at any time, someone that they can build a relationship with and trust. Many suggested that this would not need to be a professional but could be a support worker or even a volunteer.

Prevention and/or early intervention

Many respondents felt that a lot of mental health issues could have been less severe, had they received earlier intervention. Many stated that by the time they waited to see the GP, then waited to receive treatment, their mental state had deteriorated further. Patients do not want to reach crisis point before any support is put in place.

Mental health awareness should be taught in schools and colleges and further work done to eradicate the stigma attached to it.

“Teach people about mental wellbeing and self-care and make asking for help easier.”

Survey results

Results from the conditions survey pertaining to Mental Health:

- Less than 10% of respondents received support that fully met their expectations when first accessing treatment.
- 73% found the overall experience of getting help negative or very negative.
- Over 51% of respondents had another long term condition, of those patients, 50% stated that accessing treatment for more than one condition became harder.
- More than 50% answered slow or very slow for the time taken to receive treatment.
- Nearly 50% said that getting their initial assessment was fast, very fast or okay.
- 57% were offered further access to services after diagnosis.
- 66% were referred to a specialist or consultant.
- 43% thought that the time between referral and seeing the specialist was slow or very slow.
- Nearly 60% found it difficult to find ongoing support.
- 40% reported that they do not receive ongoing timely communication throughout the pathway.

In focus

- Half of those who answered the survey said receiving treatment was either slow or very slow. In addition to this 43% thought that time between referral and seeing a specialist was slow.

Autism and Learning Disabilities services

Healthwatch across the Humber, Coast and Vale area received a total of 34 survey responses from people who identified Autism and Learning disabilities on the conditions survey and also held a series of focus groups that help provide a rich amount of information to provide a summary of what those who participated in the research think of their autism and learning disabilities services.

Assessment, diagnosis and treatment

What matters most is that patients receive a fast diagnosis and a timely referral on for treatment. Respondents stated that it has sometimes taken years to be formally diagnosed and they believe this is due to a shortage of staff who are experienced enough in this field. Suggestions were made of employing learning disability nurses to work within a primary care setting alongside other staff.

“It took 4 years to get a diagnosis of Autism shortly before his 7th birthday. The route to diagnosis is too long for children and families who need support.”

“It took over 3 years to be referred to CAMHS and even they didn’t know how to help.”

Only a small proportion of respondents claim that the support and treatment they receive meets their needs. Services such as CAMHS and SALT (speech and language therapy) are struggling to keep up with demand and therefore, patients are having long delays between diagnosis and receiving the treatment that they need.

Patients want to be consulted and allowed to have a say on any treatment they receive, without feeling that their wishes are being disregarded.

“I’d ask that my wishes are taken seriously.”

The provision of ongoing care and support

Many respondents told Healthwatch that after they were diagnosed, they received no support from the NHS. Those that had been offered support reported having to wait a long time to receive it. Issues were also raised with regards to information leaflets not being appropriate i.e. dyslexia friendly.

Carers and family members of people with learning disabilities and autism would also like to receive support and advice.

“I feel that counselling should be offered to us as a family as it is life changing living with someone who has a disability”

Although examples of good support were shared with Healthwatch, in many cases this support ceased when the patient became an adult.

“Lime Trees (York) support was great but stopped aged 18.”

Further support to help people with Autism move on into adulthood was suggested as an area for improvement. It is also apparent from Healthwatch findings, that having a learning disability and/or Autism made it harder to seek support for other conditions.

Prevention and/or early intervention

Suggestions were made to allow people to self-refer for assessment.

Survey results

- For Autism, only 12% of people who received support, stated that it met their expectations when first accessing treatment, compared to 44% for those with a Learning Disability
- 53% of those with a learning disability have additional conditions or disabilities, almost half of which say that this has made seeking support harder. Although a smaller proportion of people with autism reported having additional conditions, 75% stated that it had made it harder to seek support.
- 47% of autism respondents answered slow or very slow for the time taken to receive initial assessment, whilst only 6% felt it was fast. Nearly 30% of learning disability answers were slow or very slow, whilst less than 4% selected fast.
- 41% of people diagnosed with autism were referred to a specialist, whilst nearly 70% of those with learning disabilities were not.
- Nearly 30% of people felt that finding ongoing support for autism was okay or easy. This figure was almost 45% for those with a learning disability.

In focus

- For Autism, only 12% of people who received support, stated that it met their expectations when first accessing treatment, compared to 44% for those with a Learning Disability

Dementia

Healthwatch across the Humber, Coast and Vale area received a total of 22 survey responses from people who identified dementia on the conditions survey and also held a series of focus groups that help provide a rich amount of information to provide a summary of what those who participated in the research think of their autism and learning disabilities services.

Assessment, diagnosis and treatment

Patients want fast diagnosis and easy access to surgeries in a close proximity to where they live. They would like to see an increase in the number of doctors specialising in dementia. Respondents stated that they wanted GPs to be more open and honest about what happens next and would like this information written down as sometimes they struggle to remember once they have left the surgery.

It was stated that some patients felt that when they attended the GP surgery, the doctor would speak to the carer/family member as if the patient was not in the room.

“When sitting in the surgery conversations end up being between my wife and the GP excluding me. This is very frustrating and you feel like you are immediately less human, just an object with a problem.”

Suggestions were made of all dementia inpatients at hospital having one to one care as they may struggle to complete tasks such as eating and drinking without assistance. They may also be confused with unfamiliar surroundings and people. Information specific to the patient would also need to be readily available close to the patient. Issues were raised in regards to discharge times, with some reporting being discharged late at night.

It is felt that there is a variation in standards of care between services generally, and between different conditions, for example it is felt that cancer patients receive “wrap around support” whilst dementia patient are faced with a poor attitude toward the condition.

The provision of ongoing care and support

The provision of ongoing care and support is highly important to the respondents with many stating that they use VCS groups, however, they report that it isn't clear which groups they should access and when. Clear and simple guidance to support good navigation of local support networks is needed.

Respondents would also like to see better support in place for family members who care for those with dementia. It is recognised that there are support groups available; however, it is said that accessing these with no alternative care for the patient is difficult.

Patients want to have a say in the care that they receive and be a part of the decision making when it comes to choosing the best treatment. Participants state that there needs to be an improvement to research and the understanding of dementia, giving members of the public information about research and drug trials happening in the area, which they could take part in.

Praise was given to dementia friendly venues, such as local cafes etc. Patients and carers would like to see more of this good work happening in the community, raising awareness of the condition and furthering the understanding of the general public.

Prevention and/or early intervention

What matters most during early intervention, is easy, timely access to primary care and a fast diagnosis.

Respondents would like to see more information publically about how to prevent dementia and stay healthy for as long as possible.

Survey results

Results from the conditions survey pertaining to Dementia assessment, diagnosis and treatment;

- Nearly a third of respondents reported that the support they received when first accessing treatment, met their expectations.
- Almost 48% described the overall experience of getting help as average. 24% said it was negative.
- Half of respondents to the dementia survey had another long term condition. Of those, 55% stated that accessing treatment for more than one condition made it harder.
- 45% of respondents felt that the time taken to get initial assessment and diagnosis was slow or very slow.
- 41% answered okay for the time taken to receive treatment, whilst less than 10% said it was fast.
- 59% were offered further access to services after their diagnosis.
- 77% were referred to a specialist or consultant.
- 67% felt that finding ongoing support was either easy or okay.
- Less than half stated that they received ongoing timely communication throughout the pathway.

Heart and Lung Disease services

Healthwatch across the Humber, Coast and Vale area received a total of 39 survey responses from people who identified heart and lung diseases on the conditions survey and also held a series of focus groups that help provide a rich amount of information to provide a summary of what those who participated in the research think of their heart and lung disease services.

Assessment, diagnosis and treatment

Respondents stated that during assessment, diagnosis and treatment, what matters most is being seen by a medical professional in a timely manner. It is felt that delays in diagnosis result in deterioration in health and new conditions emerging. Once diagnosis has been made, treatment is usually good and the majority of patients are seen promptly. Praise is given to NHS staff, especially specialist heart nurses at hospitals and in the community. Many respondents had received treatment at Castle Hill Hospital and spoke highly of the care they received there.

“The heart nurse coming every day was brilliant during the scary times.”

“The team at Castle Hill, Cottingham are amazing.”

However, it has been stated by some patients that communication during hospital stays isn't always clear and concise. Patients said that conflicting information was given from nurses and doctors, causing confusion and unease. Patients feel that treatment isn't always explained and that they have to “badger doctors and nurses to explain more”

“I was sent for lots of tests, and received lots of attention. However, the reasons for the tests were not always fully explained.”

Patients would like to see the same consultant each time to receive better continuity of care. It is also important to the patient that consultants and specialists speak to each other about treatment being given for other conditions, which may have an impact on their health.

The provision of ongoing care and support

The majority of patients who took part in the survey are happy with the provision of care and support, with many receiving rehabilitation and physiotherapy after treatment. Again, cardiac nurses were praised for work in the community. Examples of good support given included exercise programmes being provided by outpatients and community nurses helping patients with using inhalers and other health aids correctly.

Patients would prefer to have regular check-ups with a specialist nurse or doctor in order to ensure their condition was under control. Respondents also expressed an interest in being able to speak to other people with the same condition, as a form of support.

Prevention and/or early intervention

To prevent relapses, respondents would like to see a consultant annually and receive regular check-ups with the GP or specialist nurse to ensure the condition is under control.

Many reported that access to the GP is slow and waiting times can sometimes be upwards of two weeks. Faster access for individuals with chronic conditions, as a preventative measure was suggested.

Survey Results

- 69% of people received support that met their expectations when first accessing treatment.
- Close to 42% found the overall experience of getting help positive or very positive.
- 59% of respondents of the heart and lung survey had another long term condition, of which almost half stated it made no difference when accessing other treatment. 22% say it made it harder.
- Nearly 80% of people said that the time it took to receive initial assessment or diagnosis was okay or fast.
- Around 73% of respondents felt that the time they had to wait between initial assessment and receiving treatment was okay or fast.
- 71% were offered further access to services after their diagnosis.
- 71% were referred to a specialist or consultant.
- 88% thought that the time between referral and seeing the specialist was okay or fast.
- Nearly 70% felt that finding ongoing support was either okay or easy.
- 54% stated that they received ongoing timely communication throughout the pathway. 20% stated that they did not.

Engaging people in health service delivery

What people expect during their treatment journey

From access to discharge, patients will have expectations of what a patient journey should look like. Healthwatch spoke to members of the public to gather views on what works well, what doesn't, and how would the public like to be more involved. Below is the summary of those conversations.

What's working well?

Community Support - Community services and support from the third sector received a lot of positive remarks. Being able to access services locally or even services that come to you are helping a lot of people receive the support they need. Having services in the third sector that perhaps are funded by the NHS but as a result of being in the community provide a more personalised and focused service is extremely beneficial. This is no more appropriate than in isolated communities across Humber, Coast and Vale.

Personal interaction & feeling listened to - Overwhelmingly the need to have face to face interaction with consultants, primary care physicians and clinical staff is something that was recognised as having a positive impact. There is a concern that with more digital technology, online systems and large primary care facilities with rotating staff the patients desire for continuity of care could be compromised and have a detrimental impact on relationships with clinical staff and individual's wellbeing.

"Being able to talk to my GP who I have seen for years, who knows me, knows my background provides me with feeling of getting the right service and the correct diagnosis."

Staff attitudes and work ethic - "NHS staff work their tails off". This is a sentiment echoed by everybody that Healthwatch spoke too. The consensus was that throughout difficult times in the NHS with stretched services, tight budgets and a depleted and strained workforce, the staff who continue to work in the NHS work hard, go above and beyond and most importantly care. Whenever Healthwatch heard any negative comments as part of this research it was always proceeded with the comment, "But first, let me say the staff do an amazing job considering their workload." Staff were being repeatedly praised for being resilient, professional with good conduct, and welcoming and supportive manner.

Cancer Services - Humber, Coast and Vale cancer services were repeatedly praised. The specialist centre at Castle Hill Hospital received overwhelmingly good feedback and a lot of people we spoke to who had personal experience of using the centre had achieved a positive outcome. Obviously this is not every circumstance, however people were quick to say that communication, support, diagnosis, referral to specialists and speed of treatment were all excellent.

Some triage and nurse practitioners in primary care - Services in primary and secondary care, and community services are constantly under strain of high demand and limited resource. Recently in parts of Humber, Coast and Vale there have been attempts at putting in place forms of "triage" within primary care to make sure that people who attend primary care and perhaps do not need to see a GP are receiving the most appropriate form of support and a signpost to a relevant service where appropriate. An example of this triage in effect locally is Social Prescribing, which tries to find social, community based opportunities that may have a more positive effect on an individual than repeated GP appointments or other more traditional forms of medical treatment. Take depression for example. If somebody had seen a GP they may have been diagnosed and prescribed anti-depressants, instead if social prescribing note that somebody has depression they may suggest attending a social club once a week which in turn lifts the individual's self-esteem, helps them to make friends and lifts the mood of somebody who may have been struggling. A lot of people we spoke to told Healthwatch that forms of "Soft

Triage” such as this free up staff resource and provide positive outcomes. The only slight draw is that it is a “culture shock” as this is new to a lot of people that have had a local GP for 30 years and been used to a more traditional approach to care.

Digital systems (When they work) - Digital systems sits on both sides of positive and negative, because there was a split on how effective methods such as online bookings and receiving results online actually are. Humber, Coast and Vale is very diverse, with certain parts of the area having an older more isolated demographic who in some instances don't have access to the internet or won't be well-versed on using these systems. The other half of the patch which includes Hull and York have large city populations with potentially a younger demographic who rely on online systems and in many circumstances would prefer them. It is this demographic (not everybody and equally some people from those isolated communities mentioned above) who do rely on digital solutions. Being able to book appointments via your phone as you're on the go, and being able to access results quickly and efficiently are things that patients told us improve their service experience and in turn foster positive outcomes.

Where are the areas for development?

Waiting times - whether it be visiting A&E or getting an appointment to see their local doctor, waiting times seem to be a constant cause for concern for local people. Across Humber, Coast and Vale which includes numerous services from a range of different providers, being able to see a professional without waiting is something that continues to plague the public. One sentiment that was mentioned repeatedly was that in some GP surgeries you would have to wait up to two weeks to get an appointment, which by then things can progress a lot further and faster. The issue of waiting times hammers home the underlying trend about resource and workforce across the region. A growing population vs an under pressure NHS will mean that waiting times and triage to services become a lot more important.

Access to primary care/appointments systems - This is one example of many who echoed this statement. This is not true of all primary care services however a lot of people told us they have to call straight away as their centre will not book appointments for the days coming. As stated previously in the report, certain areas of Humber, Coast and Vale do not have people who use the internet, have the internet or want to use the internet so booking appointments online is out of the question. The challenge services face here is how do they ensure equality of access to make sure those without internet have the same opportunities to book important appointments than those who do.

“If I don't get an appointment when I call at 8am, I will be on the phone for half an hour to tell me that I have missed all of the available slots for today. This system doesn't work.”

Poor Communication - The public often mention to Healthwatch how sometimes they are concerned by failings in communication. This includes internal communication from professionals to prevent the public having to repeat themselves; communication from services to patients regarding appointments, cancellations etc.; and communication from the commissioners about how services work, times of services, and changes to services. One of the bigger issues we heard about was the communication the public felt that was missing when a service is closing or changing.

Transport - With Humber, Coast and Vale being rural, isolated and at times difficult to navigate it is no surprise that transportation concerns were highlighted as an area to develop. Services are spread across a large geographical area and people who live in pockets of Humber, Coast and Vale feel that providing their own transport, accessing hospital transport or anything in between is costly and timely. Decisions are made across health and social care services that invariably will have an impact on an individual's ability to access services. In some instances the local doctors are becoming a little less local; the service that has been down the road for years is now that little further away. It may be that the decisions for those moves are rational and sensible but people still want services that are easy to access. Should somebody have to travel two - three hours on community transport without the opportunity to use the bathroom to attend a

routine appointment? These are the basic things that patients want to see addressed when services make changes.

Digital systems (when they don't work) - For the demographic who may not be able to use these digital systems, How do they book an appointment? If they can access these digital solutions can somebody explain how they work? With every digital system there will be a failsafe such as still being able to make an appointment via the phone, however as the NHS moves closer to paperless working, digital will only become a larger issue. Rural, isolated communities across the region will need to be supported frequently during a progressive transition to digital solutions. The onus should not be on the public to adapt. It should be on services to make sure their offer is as inclusive as possible to provide equal opportunities for the vulnerable people in our community, who more times than not require services more frequently than those for whom digital technology comes most naturally.

Lack of staff/workforce - There is a clear understanding about some of the issues faced by the NHS in 2019. One of those issues that clearly can be identified is about the amount of staff available. Whenever there is a service change the first thing that is normally said to Healthwatch is "It will either be about saving money or they do not have the staff". There is not a clear and simple answer to this situation but this is certainly a concern to the public have that a reduced workforce will lead to a reduced service. Locally system leaders need to look at the workforce issues and put in place long term plans that will help address this issue. Local progression, training and recruitment are crucial. Being creative with what roles will help reduce workforce pressures whilst potentially not requiring the same level of training. Examples of this are Nurse Practitioners taking on a lot of primary care appointments to help ease the pressures on the doctors in the services.

Transitions between services - There is a consensus from the public that transitions between certain services can be a very difficult time in a patient journey. Being able to access a service as a child up until a certain age, and then being too old to use that service but too young to access adult services can mean that patients can go a long time without treatment.

What matters the most to the public?

Continuity of care - Seeing the same doctor or professional is something that is very important to people. This is for a couple of reasons. Firstly to make sure that there is a level of familiarity with the individual and the doctor. Symptoms and previous visits are well known and medical history is taken into account when making future diagnoses. This isn't to say that previous medical history is not taken into account when doctors who are unfamiliar to the patient are making a diagnosis. However there is something to be said for having knowledge and history with a patient. So how do services make sure there is a level on continuity? The challenge that services face is that due to resource and growing patient lists being able to hold onto patients that would PREFER to see the same doctor becomes less about being a priority and more about being a preferable option if available. However the public feel strongly about this and believe that seeing the same doctor or consultant is crucial to receiving better treatment. This is also true of people who are accessing care in secondary care facilities. Being treated by three different doctors, or being moved from pillar to post is bound to create concerns for the public, is invariably creating road blocks in being able to truly provide continuity of care.

Person Centred - Care should be person centred: "I am not just a number". Care should be about the person receiving it. The public understand that time with consultants is limited however at times a ten minute window isn't enough. An important issue for the public is that they as a person is at the heart of their care, they are consulted with and part of the communication and process.

Customer Service - Although to some people these may seem like low level priorities, this was overwhelmingly something Healthwatch heard numerous times and it is something that won't cost the earth for the NHS to continue to improve. ¹In the 2018 report, "Fair Access" by Healthwatch East Riding, Healthwatch carried out an audit of the politeness of local practices, of which, close to 80% received a high score. Having this level of professionalism in NHS services is a priority for the public and hopefully will encourage local services to look at their own processes to see if they meet these standards.

"Having a polite voice at the end of the telephone, and a receptionist who is welcoming and warm when I visit the doctors."

Parity for Mental Health - The profile of Mental Health is on the rise and is something that is becoming a much high priority for the public. Having mental health on an equal footing as physical health was recognised as a priority with members of the public. This will be an ongoing challenge for services as a broken leg can be much easier to diagnose than depression. However with the public wanting more parity and parallels between the two this needs to be a priority of focus for Humber, Coast and Vale Health and Care Partnership moving forward.

Independence - Remaining at home for as long as possible was identified as something that matters the most to the public. The public are becoming an older population and there is a going to be an ongoing strain and pressure of social services to provide care home places for people across the region. Providing the public with resilience, and the tools to remain independent and healthy at home will go a long way to easing that pressure not only now but for years to come.

What people expect during service change and transformation?

Service transformation and change are going to be a constant within the NHS moving forward. Services change, fluctuate, develop and end. The public again are generally accepting of this. However where there is a slight area of unrest with the public across Humber, Coast and Vale is with how they are consulted, informed and enabled to be part of that process.

The question was asked to the public about what role do the public and professionals play in service improvement and delivery. A couple of the key takeaways included:

- Public involvement prior to decisions being made
- Using vehicles like Healthwatch for change
- Community involvement (consultation and design)
- Easy Consultation
- Transparency & Communication

Public Involvement prior to decisions being made - This plea was made to Healthwatch numerous times throughout the engagement. There is a perception from the public that often decisions are made about the future of a service, and that it is after the decision is made that consultation and engagement is then conducted as an afterthought or tick box. This may not be the case however it is a perception the public stated to us repeatedly. "What's the point, the decision has already been made, and we won't change their minds". This is a sentiment that in many ways prevents engagement in the first case. If patients don't feel confident in how to engage with services and commissioners then there will not be enough credible information to justify a decision that many public members would want. One of the other themes is transparency in terms of how do services use the information after engagement and feedback.

¹ <http://www.healthwatcheastridingofyorkshire.co.uk/resources/fair-system-access-primary-care>

Providing this feedback would go a long way to making the public feel better about offering their opinions.

Using vehicles like Healthwatch for change - Healthwatch throughout this investigation stated to the public the role of Healthwatch during and after this engagement programme. Many people who participated in the research had never heard of Healthwatch before. However one constant was that the public want to see more opportunities for Healthwatch or services akin to Healthwatch to be an active participant in community engagement on service change. There is an undercurrent of doubt with local service engagement about the level of independence that actually exists when the services who are creating the change are the same ones who are carrying out the consultation and engagement. Many members of the public feel that watchdog services would act as a natural independent facilitator for transparent and fair engagement.

Community Involvement - Local services should involve those who use them in deciding their future, and determine what will they look like, how they will work and importantly what the community needs. Making use of local parties like patient participation groups of community councils and parishes would go a long way at making sure people have a say and are heard.

Easy Consultation - Although engagement has been identified as important and crucial for local people to participate it is also important that consultation and engagement activities aim to be inclusive, and in a lot of cases it needs to be easy to participate. This starts with how it is advertised. Local people have the right to be told that engagement is happening. Even though everybody may not find out there has to be more than just a poster on the wall about future change to a community. Members of the public told Healthwatch of simple methods they would like to see:

- Email engagement
- Text messages
- Cards through the door
- Parish newsletters

There was also a motion that the engagement via these means was easy to do and meaningful. “I don’t want to complete a survey that will take an hour and doesn’t make sense”. The public want quick decisive engagement that offers a transparent view of the community’s feelings towards a change.

Transparency & Communication - A service is carrying out some engagement... Why? What does it mean? What will be the outcome? How do I get involved? When does it end? The public should know the answers to these questions and more importantly how will the services that are planning the change feedback the results in a way that has considered the public’s voice and made a decision that is logical and transparent. It is not enough for the public to be offered a chance to do a survey. Like any participation. Are you going to listen? This is an expectation of local people that their voices are heard and acknowledged when making a decision. If a decision has been made, why has it been made? What will happen next? How will this affect me? Again these are questions with ramifications that are vital to a public who wish to be involved with local services.

Next steps

Humber, Coast and Vale Health and Care Partnership Long-term Plan

The Humber, Coast and Vale Health and Care Partnership has received an early copy of this report and has had an opportunity to review the findings contained within it. The following response has been received:

“It is important that people who are living and working in Humber, Coast and Vale are given the opportunity to have their say on what our plans for the future should look like.

This report and the work that Healthwatch has undertaken, is helping to ensure the voices of local people are at the heart of plans for the future of health and care in Humber, Coast and Vale”

The Partnership welcomes the report and the excellent work undertaken by local Healthwatch to provide such rich insights into the priorities and preferences of our local populations.

Our local health and care services are designed and delivered for the benefit of the people who live within our region. As a Partnership we are committed to involving local people in the work that we do and strive to be as open and transparent as possible in all our work.

The report from Healthwatch is a fantastic starting point for developing our Partnership Long-term Plan and ensures the voices of local people who use our services are taken into account before the plan is written. Many of the themes that were raised - such as increasing choice

and control for people over their own health and improving knowledge and access - fit well with the aims and priorities the Partnership has already set out in its vision statement (you can read this [here](#)). The detailed responses and suggestions for areas to improve provide us with lots of material to help shape our emerging plans.

The Humber, Coast and Vale Health and Care Partnership Long-term Plan will describe our vision, priorities, values and ways of working and include examples of how these are working out in practice. It will focus on outcomes rather than actions, describing what will be different for local people as a result of the work the Partnership is undertaking.

Our local health and care services are designed and delivered for the benefit of the people who live within our region. We are committed to involving local people as far as possible in the work that we are doing. We will strive to be as open and transparent as possible in all that we do.

In line with this commitment, the Partnership will undertake an inclusive and transparent approach to the development of our Partnership Long-Term Plan with a clear plan for engaging and involving relevant stakeholders at each stage of the process.

The work that Healthwatch has undertaken to support the development of our Partnership Long-term Plan provides vital insight into the views and perspectives of local people across our region. The insights in this report will inform the work of our collaborative programmes and enable them to adapt their plans to better meet the identified needs and desires of local people.

The Partnership will build upon this work with further engagement and involvement opportunities for a range of stakeholders to review and refine our plans as these are finalised over the summer months.

Methodology

In accordance with the Healthwatch research quality framework, the coordinating Healthwatch (East Riding of Yorkshire) produced a research plan that details the methodology used to complete this investigation.

Healthwatch East Riding of Yorkshire Research Planning and Design	
Purpose:	Long Term Plan Programme Objectives: Healthwatch across the Humber, Coast and Vale are engaging with the public to inform the Humber, Coast and Vale Health and Care Partnership (HCV Partnership) of what people want to see in their local health and social care services. This information will contribute to the local plans being created by the HCV Partnership. Local Objectives: In consultation with the Partnership Communications and Engagement Lead we decided to use the national surveys as a guide for the research being carried out in our area. However our Partnership Communications and Engagement lead also asked for information on the following clinical priority areas: Maternity services, Elective care (including diabetes, CVD and respiratory), Cancer, Mental Health, Urgent and Emergency Care and Primary Care. Unfortunately although maternity was identified as a priority Healthwatch could not gather enough information to draw reasonable and detailed conclusions from to provide to Humber, Coast and Vale Health and Care Partnership. Key Research Questions: This will be done using the surveys and discussion guides provided via Healthwatch England. No further questions will be added. Limitations or what the proposal will not do: Within the Humber, Coast and Vale STP footprint this engagement will not address concerns or decisions that have already been made or are in the process of being made that the public wish to see changed. This engagement is for developing local plans and will not be used for lobbying purposes.
Timeframes for Delivery:	The following is the timeframe for the delivery of this plan: February - Planning with STP Lead and local Healthwatch March & April - Engagement and focus groups May - Analysis of data and production of report June/July - Publication of report.
Method:	Engagement Method: Each Healthwatch within the STP are all are responsible for delivering on the following: 250 Surveys & 2 Focus Groups Local Healthwatch will be engaging with the public face to face, via social media and through external channels such as the local media and

	partners/stakeholders. This engagement will filter down to completion of the surveys where data will be collected centrally and shared with the lead Healthwatch. The Lead Healthwatch used local volunteers to test the survey to make sure it was fit for purpose. Where issues were found (specifically around the North Yorkshire boundary), conversations and discussion were held with Healthwatch England to overcome this. The entire project will be done as scientifically fair as possible. This includes: • Appropriate staffing levels • Time spent in each locality • Targeted groups engaged with • Making the entire process anonymous. Data Management: The surveys will be the primary use of data collection. Information collected by the surveys will be sent centrally and then shared monthly with the lead Healthwatch. It is the role of each Healthwatch to provide HWERY (Lead Healthwatch) with any additional data they collect including focus group information, anecdotal information and any other information fit for research. The lead Healthwatch will be responsible for providing resources if needed and analysing the final data when collected. No Healthwatch should keep any data with personal information post publication.
Research Participants:	Risk Assessment: The entire process of data collection will be anonymous. Where data will be needed, for example people who sign up for focus groups or wish to be contacted about the surveys or project, their data will only be held with their permission until it has been used and at that point will be destroyed. No names will be published in the final report and the report will protect any identifiable characteristics. Ethical Considerations: For this process to be fair we are making sure that we spread ourselves across the footprint fairly and appropriately to give everybody the same access and opportunity to contribute. Consent: As per above no data will be kept without permission and held after use. Who will be engaged: Everybody has the opportunity to participate in this piece of work. Different approaches and methods will be used dependent on who at that time we are engaging with, however there will be no bias or exclusion with the engagement. In addition to this across the STP we will be engaging with different focus groups in the hope to provide a varied amount of representation with minority groups.
Resources:	Skills & Expertise: Across the region the six Healthwatch that make up the STP have different levels of staff, resource and job roles. This means that where possible the opportunity to work cohesively and collectively is crucial. Healthwatch are being encouraged to share, loan out or provide extra resource to support those with little resource (however this is not to be at the detriment of their own work and will be at the discretion of the local Healthwatch manager). Technical: Hopefully there will not be too much technical difficulty with this project as Healthwatch England will be sharing updates with the coordinating Healthwatch at the end of each month to provide data on

	work done so far. This information will be shared across the region and with our STP leads. North Yorkshire Healthwatch are using a Survey Monkey in addition to the other survey to collect geographical data to divide their data appropriately for the three STP areas their boundary sits across. This information will be shared with the Coordinating Healthwatch as requested.
Collaboration:	Roles and Relationships: List of key contacts for this project include: Matthew Fawcett - Manager, Healthwatch East Riding of Yorkshire (Project Coordinator) Nigel Ayre - Manager, Healthwatch North Yorkshire Carrie Butler - Manager, Healthwatch North Lincolnshire Catherine Scott - Manager, Healthwatch York Tracy Slattery - Manager, Healthwatch North East Lincolnshire Gail Baines - Manager, Healthwatch Kingston Upon Hull Linsay Cunningham - Head of Communications and Engagement - Humber, Coast and Vale Health and Care Partnership
Quality Assurance:	Quality assurance to be carried out by Healthwatch England prior to publication of final report.
Conflicts of Interest:	N/A
Intellectual Property Rights and Publishing:	N/A
Evaluation	The coordinating Healthwatch will be receiving survey data monthly from HWE and sharing this information with all the named contacts above. At the end of April the lead Healthwatch will be producing a report that analyses the information collected from both the surveys and the focus groups. Focus group data will be provided with the coordinating Healthwatch one week after completion of the group. This information will then be shared with key contacts so all are aware of the results being gathered.

Results Appendices

The following are the results of the **General** Healthwatch Survey:

Who are you responding on behalf of?	
Yourself	1758
Someone else	32
Grand Total	1790

What I need to live a healthy life?

Easy access to the information I need to help me make decisions about my health and care?	
Very important	1244
Important	501
Neutral	74
Not important	10
Not important at all	5
Grand Total	1834

Having the knowledge to help me do what I can to prevent ill health	
Very important	1204
Important	534
Neutral	75
Not important	10
Not important at all	4
Grand Total	1827

Access to the help and treatment I need when I want it	
Very important	1563
Important	237
Neutral	27
Not important	1
Not important at all	2
Grand Total	1830

Professionals that listen to me when I speak to them about my concerns	
Very important	1541
Important	254
Neutral	29
Not important	3
Not important at all	1
Grand Total	1828

For every interaction with health and care services to count; my time is valued	
Very important	1229
Important	478
Neutral	101
Not important	4
Not important at all	3
Grand Total	1815

Being able to manage and choose the support I need?

If I have a long term condition I decide how the NHS spends money on me	
Very important	673
Important	619
Neutral	412
Not important	65
Not important at all	17
Grand Total	1786

Choosing the right treatment is a joint decision between me and the relevant health and care professional	
Very important	1219
Important	520
Neutral	81
Not important	10
Not important at all	1
Grand Total	1831

I make the decision about where I will go to receive health and care support	
Very important	1008
Important	578
Neutral	216
Not important	17
Not important at all	3
Grand Total	1822

I should be offered care and support in other areas if my local area can't see me in a timely way	
Very important	982
Important	620
Neutral	196
Not important	18
Not important at all	5
Grand Total	1821

I make the decision about when I will receive health and care support	
Very important	836
Important	662
Neutral	278
Not important	27
Not important at all	7
Grand Total	1810

My opinion on what is best for me, counts	
Very important	1025
Important	578
Neutral	195
Not important	19
Not important at all	4
Grand Total	1821

Communications are timely	
Very important	1237
Important	497
Neutral	74
Not important	2
Not important at all	4
Grand Total	1814

I have time to consider my options and make the choices that are right for me	
Very important	1090
Important	597
Neutral	108
Not important	5
Not important at all	2
Grand Total	1802

The help I need to keep my independence and stay healthy as I get older

I want to be able to stay in my own home for as long as it is safe to do so	
Very important	1475
Important	284
Neutral	62
Not important	8
Grand Total	1829

I want my community to be able to support me to live my life the way I want	
Very important	972
Important	570
Neutral	233
Not important	29
Not important at all	7
Grand Total	1811

I want my family and friends to have the knowledge, to help and support me when needed	
Very important	1155
Important	499
Neutral	142
Not important	11
Not important at all	7
Grand Total	1814

I want there to be convenient ways for me to travel to health and care services when I need to	
Very important	1229
Important	454
Neutral	116
Not important	11
Not important at all	3
Grand Total	1813

I want my family and me to feel supported at the end of life	
Very important	1425
Important	299
Neutral	73
Not important	3
Not important at all	3
Grand Total	1803

How you interact with your NHS

I have absolute confidence that my personal data is managed well and kept secure	
Very important	1239
Important	412
Neutral	152
Not important	11
Not important at all	3
Grand Total	1817

I can access services using my phone or computer	
Very important	967
Important	593
Neutral	183
Not important	40
Not important at all	25
Grand Total	1808

I can talk to my doctor or other health care professional wherever I am	
Very important	1074
Important	517
Neutral	197
Not important	22
Not important at all	8
Grand Total	1818

I can make appointments online and my options are not limited	
Very important	929
Important	499
Neutral	263
Not important	70
Not important at all	42
Grand Total	1803

Any results are communicated to me quickly making best use of technology	
Very important	1152
Important	475
Neutral	142
Not important	18
Not important at all	24
Grand Total	1811

I manage my own personal records so that I can receive continuity in care	
Very important	749
Important	586
Neutral	369
Not important	71
Not important at all	28
Grand Total	1803

I am able to talk to other people who are experiencing similar challenges to me to help me feel better	
Very important	693
Important	541
Neutral	420
Not important	95
Not important at all	50
Grand Total	1799

Your age	
18-24	149
25-34	163
35-44	200
45-54	239
55-64	342
65-74	349
75+	237
Under 18	137
Grand Total	1816

Your ethnicity	
African	5
Any other mixed background	4
Any other white background	34
Arab	5
Asian British	8
Bangladeshi	8
Black British	5
Caribbean	2
Gypsy or Irish Traveller	3
Indian	1
Other	17
Pakistani	1
White British	1684
Grand Total	1777

Do you consider yourself to have a disability?	
I'd prefer not to say	67
No	1368
Yes	363
Grand Total	1798

Are you a carer?	
No	1547
Yes	248
Grand Total	1795

Do you have a long term health condition:	
No	967
Yes I have a long term health condition	567
Yes I have more than one long term health condition	221
Grand Total	1755

Which of the following best describes you?	
Asexual	5
Bisexual	34
Gay or lesbian	33
Heterosexual	1474
I'd prefer not to say	149
Other	41
Pansexual	11
Grand Total	1747

What gender do you identify as?	
Female	1277
I'd prefer not to say	31
Male	479
Other	9
Grand Total	1796

Your religion	
Buddhist	10
Christian	950
Hindu	3
I'd prefer not to say	84
Jewish	6
Muslim	22
No religion	669
Other	48
Sikh	2
Grand Total	1794

The following are the results of the **Specific Conditions** Healthwatch Survey:

Please select the condition you would like to tell us about	
Autism	17
Cancer	62
Dementia	22
Heart and lung diseases	39
Learning disability	27
Long-term condition e.g. diabetes, arthritis	151
Mental health	90
Grand Total	408

Who are you responding on behalf of?	
Myself	319
Someone else	92
Grand Total	411

Has the condition you are telling us about started within the last three years?	
No	249
Yes	157
Grand Total	406

Your experience of getting help and support

When you first tried to access help, did the support you received meet your needs?	
Yes	171
No	124
Somewhat	99
Not applicable	15
Grand Total	409

How would you describe your overall experience of getting help?	
Very positive	84
Positive	95
Average	110
Negative	54
Very negative	53
Don't know	12
Grand Total	408

Do you have any other/additional conditions including long term conditions or disabilities?	
No	188
Yes	215
Grand Total	403

If so, how would you describe the experience of seeking support for more than one condition at a time?	
It made it easier	25
No difference	76
It made it harder	89
Don't know	11
Not applicable	11
Grand Total	212

The health and care support you received after initially seeking help

How would you describe the time you had to wait to receive your initial assessment or diagnosis?	
Very fast	49
Fast	52
Ok	126
Slow	79
Very slow	80
Don't know	21
Grand Total	407

How would you describe the time you had to wait between your initial assessment /diagnosis and receiving treatment?

Very fast	54
Fast	52
Ok	124
Slow	74
Very slow	70
Don't know	31
Grand Total	405

After being diagnosed or assessed, were you offered access to further health and care support?

No	169
Yes	220
Grand Total	389

Were you referred to a specialist? For example, a hospital consultant, psychiatrist or physiotherapist

No	95
Yes	293
Grand Total	388

How would you describe the time you had to wait between initial appointment and seeing the specialist?

Very fast	40
Fast	46
OK	98
Slow	54
Very slow	37
Don't know	13
Grand Total	288

If you needed it, how easy did you find it to access ongoing support after you were diagnosed or assessed?

Very easy	46
Easy	49
OK	113
Difficult	75
Very difficult	64
Don't know	25
Not applicable	19
Grand Total	391

Did the support options you were offered meet your expectations?

No	132
Somewhat	104
Yes	145
Grand Total	381

During your whole experience of getting support did you receive timely and consistent communication from all of the services that you came into contact with?

No	138
Somewhat	98
Yes	138
Grand Total	374

Time spent travelling to access support and care

What is your main means of transport?	
Another person's car	68
Bicycle	6
Bus	54
Other	16
Own car	239
Taxi	13
Train	1
Grand Total	397

How much time would you be willing to travel for to receive a quick and accurate diagnosis?	
1 - 2 hours	62
30 minutes to 1 hour	176
Less than 30 minutes	101
Over 2 hours	54
Grand Total	393

How much time would you be willing to travel to receive specialist treatment or support?	
1-2 hours	92
30 minutes to 1 hour	165
Less than 30 minutes	54
More than 2 hours	81
Grand Total	392

What is most important to you?

When first seeking help	
Don't mind	68
Seeing a health professional you normally see but you may have to wait	109
Seeing any medically appropriate health professional who is free immediately	172
Grand Total	349

When you received a diagnosis and explanation of treatment or support options	
Don't mind	52
Seeing a health professional you normally see but you may have to wait	131
Seeing any medically appropriate health professional who is free immediately	150
Grand Total	333

During your initial treatment or support	
Don't mind	54
Seeing a health professional you normally see but you may have to wait	123
Seeing any medically appropriate health professional who is free immediately	155
Grand Total	332

During your long term support	
Don't mind	57
Seeing a health professional you normally see but you may have to wait	170
Seeing any medically appropriate health professional who is free immediately	109
Grand Total	336

What level of support do you want the NHS to provide to help you stay healthy?	
A lot of support	89
Don't know	18
I don't need support	28
Some support	243
Grand Total	378

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- *Strategic Lead for Communications and Engagement, Humber, Coast and Vale Health and Care Partnership*

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