healthwatch

NHS Long Term Plan: What Would North Tyneside Do?

July 2019

what would you do?

It's your NHS. Have your say.

Highlights

From what people in North Tyneside told us:

- People speak very highly about local health services in general.
- Respondents access to services when needed continues to be a key are of concern for people in North Tyneside, particularly in relation to access to GP appointments.
- Local people stressed the importance of joint decision making processes when receiving health treatment and care. People felt that decisions should be made collaboratively between themselves and the relevant medical professional.
- However, both access to services and the ability to make joint decisions are only possible when local people are informed about what services are available to them. Therefore, more emphasis on what is available locally and where people should go when is essential.
- The majority of respondents felt they would like to stay at home for as long as possible. Therefore, the importance of 'care at home' which provides consistent and reliable support to enable people to stay in their homes and promotes independence is crucial.
- When considering digital approaches in healthcare people felt that it was important that appropriate technology was used for quick communications. However, people also stressed the importance that personal data was kept secure and well-managed.
- People told us about their positive experiences of quality of care when using cancer health and care services. People felt that aspects such as early identification, GP access, communications at key times, patient transport and carer support could be improved.
- People told us about positive experiences of mental health support from the voluntary sector and the support delivered through schools. However, people continued to highlight concerns about waiting times, rationing of support, access to appropriate services and staff approach when using NHS mental health services.
- Information and support for carers was highlighted as an area for development across different health services.
- People told us that ongoing access to advice and support during treatment and when living with a condition is very important.

- There is more work to do about the experiences of people who have Autism or learning disabilities.

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 NHS England and will be used to help develop the plan for our area.

The coordinating Healthwatch for the North East was 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 North Durham
- Durham, Darlington, Teesside, Hambleton, Richmondshire and Whitby

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

Objectives

The ICS priorities across the North East include:

- Prevention - early detection and effective management of the biggest causes of premature mortality: cancer, cardiovascular and respiratory 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 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:

- 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.

Each Healthwatch:

- looked at existing evidence
- received responses from the public using survey's and local events
- provided findings to the coordinating Healthwatch

This report presents findings from North Tyneside residents only. The full report which shows findings from across Northumberland, Tyne and Wear and North Durham can be found at https://healthwatchnorthtyneside.co.uk/nhs-long-term-plan/

What Would North Tyneside Do?

Local Objectives

Healthwatch North Tyneside chose to focus specifically on the key issues below:

- What is important to local people when receiving care and treatment
- Mental Health Services
- Cancer Health and Care Services

These issues were identified from our existing evidence and based on what residents in North Tyneside told us was important to them over 2018/2019.

What did we do?

To address the key issues identified above, HWNT utilised surveys provided by HWE for the general public and people with long-term health conditions. We also carried out two small focus groups with people about their experiences of mental health services and cancer services.

We received **144 survey responses.** 107 responses were from the general public telling us what matters most to them. 37 responses were from people telling us about their experiences of living with a long term condition. 11 people gave their feedback through our two focus groups.

The responses are incorporated into the larger Northumberland, Tyne and Wear and North Durham report. Therefore, this report only provides a brief snapshot into the findings from the Long Term Plan project that specifically relate to feedback received from North Tyneside residents.

What's next?

Healthwatch North Tyneside submitted this report to HWD as the HW coordinator to incorporate into the Northumberland, Tyne and Wear and North Durham ICS report. This will be used to inform work locally and develop our understandings of what matters to local people across the patch. Local HW will work collaboratively to ensure that these findings influence the implementation of the NHS Long Term Plan in our area.

We have included the issues raised in this project into our local intelligence. All the feedback we gather is used to identify future priorities for us to investigate further.

The feedback from this project links to work we at Healthwatch North Tyneside will be carrying out over 2019/2020:

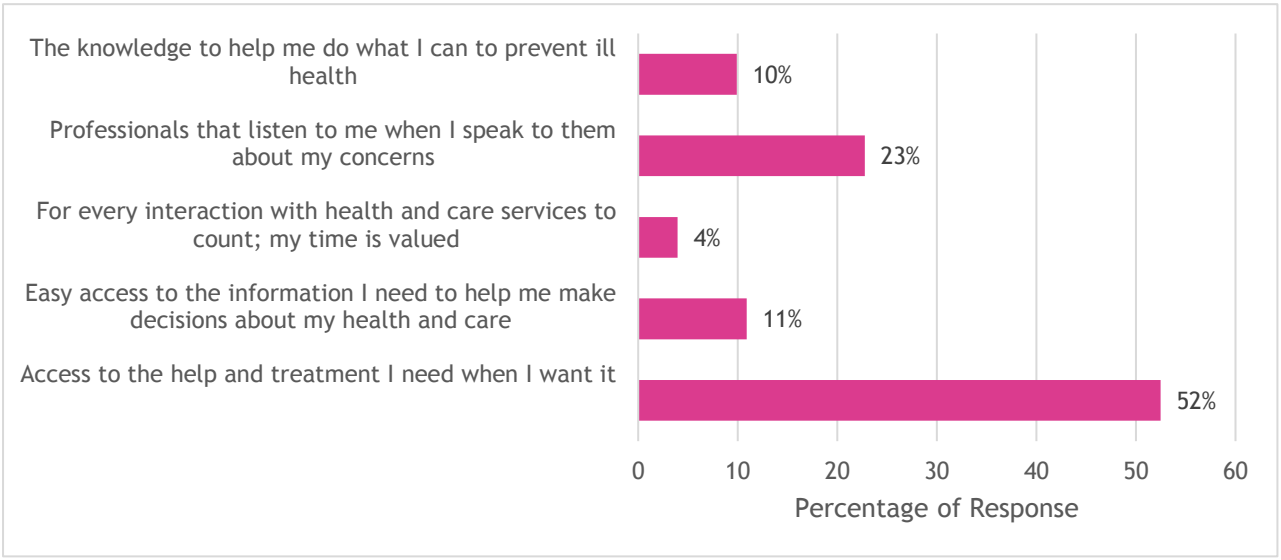
- Talking to more people about their experiences of cancer services;
- Completing our project about access to GP appointments;
- Understanding older people's experiences of accessing mental health support;
- Exploring where local people go when they are ill;
- Continue to support the development of carers information and support services.

Detailed Findings:

What matters most to people in North Tyneside?

1. 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.



The most common aspect people felt was most important to them was around access to treatment when they needed and wanted it. Almost a quarter of people felt that healthcare professionals actively listening to them was most important.

To understand this more clearly, we also asked how important each aspect was to local people when interacting with NHS services. We asked people on a scale of very important to not important each of this statements were:

Rate how important the following statements are to you when it comes to living a healthy life	Very Important	Important	Neutral	Not Important
Easy access to the information I need to help me make decisions about my health and care	63	34	5	3
Having the knowledge to help me do what I can to prevent ill health	52	44	3	3
Access to the help and treatment I need when I want it	87	16	0	0
Professionals that listen to me when I speak to them about my concerns	80	24	0	0
For every interaction with health and care services to count; my time is valued	52	40	10	0

The majority of people felt that each aspect was either important or very important. Similarly to the previous question, the most common aspect which was identified as important was: 'Access to the help and treatment I need when I want it'.

> ***"You should always have access to the same doctors at your own doctors or someone from their team"***

These statements reflect the common issues local people raise with us around difficulties in accessing local services, this is particularly pertinent in relation to accessing GP appointments.

Existing Insights: What Matters to You?

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

- **Both routine and emergency GP appointments** particularly for those with work and childcare commitments and a lack of awareness around extended hour primary care services.
- **Mental health services** such as talking therapies whereby waiting times are significantly high and mental health crisis services.
- **Emergency and Urgent Care** has also been identified as a key issue based on local people's feedback about knowing where to go when they are unwell and mixed experiences of using emergency and urgent care services.

The second most important element that people identified was that 'Professionals that listen to me when I speak to them about my concerns'. The importance of staff manner was illustrated in several comments:

> ***"I want to feel individual - not a number. I want to feel like a patient not a client. The NHS should not feel like a business, but a caring system geared towards helping the individual"***

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

We also asked people what was one more thing that could help them live a healthy life. People described a number of suggestions including access to a safe and personalised interpreting service and access to clear information. The most common aspect people felt would help them live a healthy life was prompt and consistent care when needed. This linked clearly to the issues raised regarding access previously.

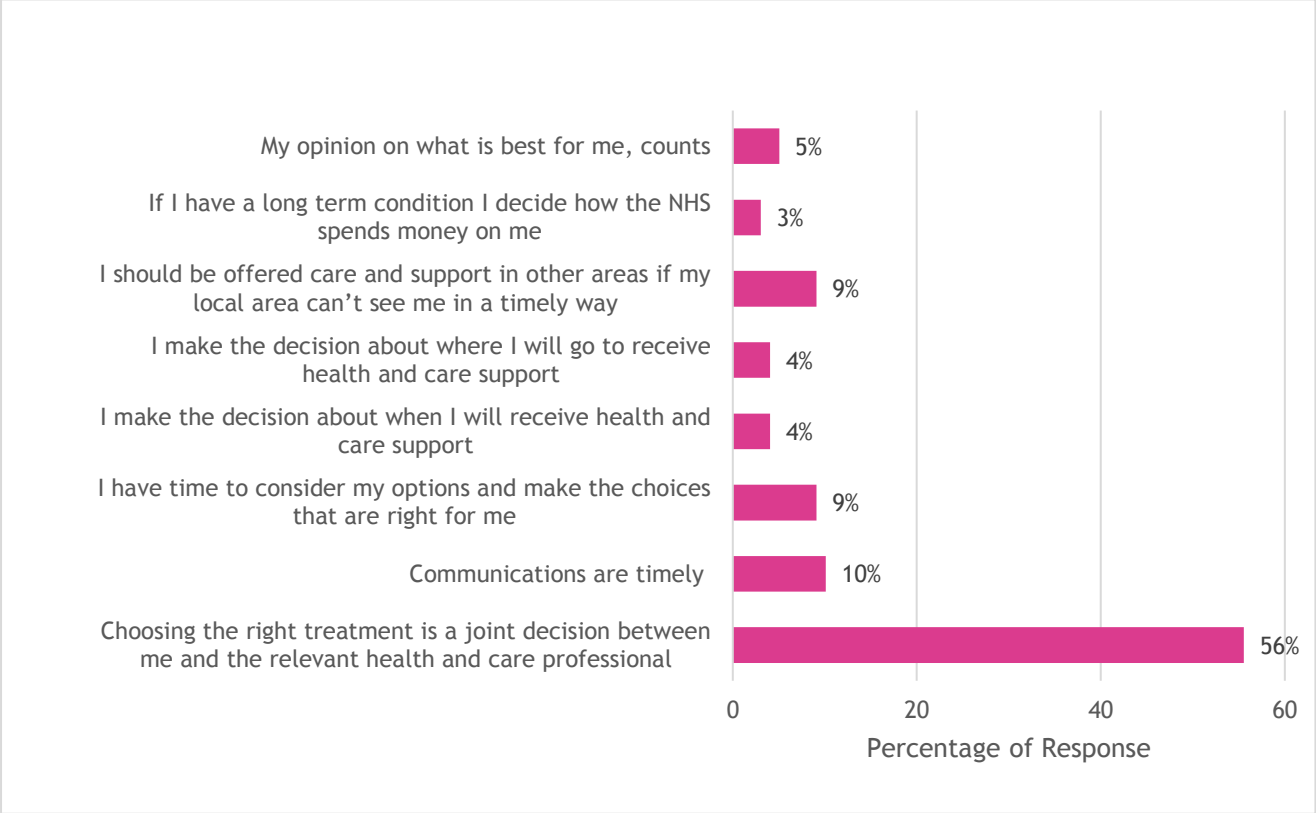
> ***"Prompt attention with on time appointments"***

"The offer of a fairly full health check every year to try to get ahead of emerging problems and offer personalized advice on issues and referral to nutrition or physiotherapy specialists as needed"

Several people also discussed the importance of prevention and lifestyle factors that would help them to live healthily including exercise, nutrition information, stopping smoking and banning high percentage alcohol.

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

We also asked people about how they chose and manage their health support.



A significant proportion of people felt that the most essential element was the joint decision making between themselves and the relevant health and care professional. This was reinforced when people highlighted the level of importance each aspect had for them.

"Choosing the right treatment is a joint decision between me and the relevant health and care professional"

Rate how important the following statements are to you when it comes to managing and choosing support	Very Important	Important	Neutral	Not Important
If I have a long term condition, I decide how the NHS spends money on me	15	41	37	6
Choosing the right treatment is a joint decision between me and the relevant health and care professional	58	34	11	1
I make the decision about where I will go to receive health and care support	32	46	20	3
I should be offered care and support in other areas if my local area can't see me in a timely way	37	49	13	1
I make the decision about when I will receive health and care support	32	43	24	3
My opinion on what is best for me, counts	36	49	14	3
Communications are timely	56	41	5	0
I have time to consider my options and make the choices that are right for me	44	48	9	1

People told us that clear communication was significant when managing and choosing their support and that this is an area where improvements needed to be made.

> ***"Clear guide to what is available sent to all residents. Email or post! 111, GP surgeries, pharmacies, A&E and walk in centres"***
>
> ***"Clarity on what services GPs offer"***
>
> ***"honest, informative conversations and information that allow you to partake in decision making"***

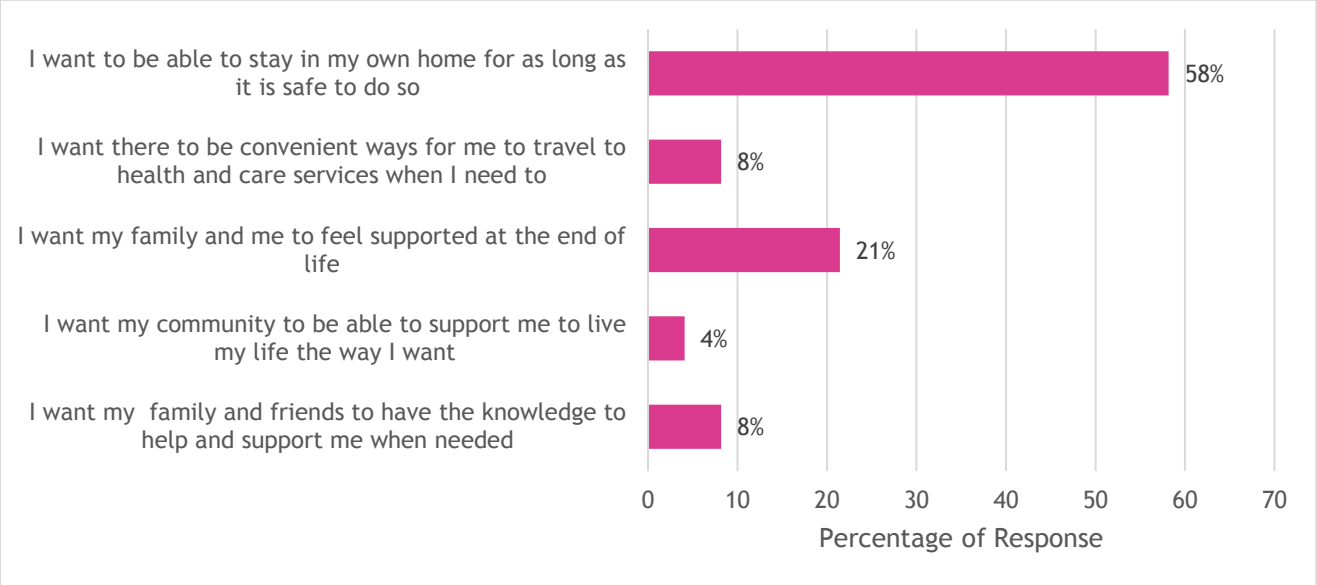
People told us about two key elements of managing and choosing their support:

- Knowing what services were available locally
- Being informed to make decisions about their own treatment.

This was particularly in relation to accessing primary care and having open discussions about the range of treatment options available locally.

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

People told us about the importance of support to live independent, with the majority highlighting that they wanted to be able to stay at their own home for as long as possible.



Rate how important the following statements are to help you keep your independence and stay healthy as you get older	Very Important	Important	Neutral	Not Important
I want to be able to stay in my own home for as long as it is safe to do so	87	16	3	0
I want my community to be able to support me to live my life the way I want	48	37	20	0
I want my family and friends to have the knowledge, to help and support me when needed	62	35	5	3
I want there to be convenient ways for me to travel to health and care services when I need to	65	34	5	0
I want my family and me to feel supported at the end of life	74	21	10	0

A number of people also commented on the importance of 'care at home' and the importance of consistent and reliable support to enable people to stay in their homes and promote independence.

> ***"More money should be invested into domiciliary care to help me stay in my home"***

> ***"Reliable home help services. Not ones that are time-limited and feed, clean and go. The service needs to be personable"***

Existing Insights: Care at Home

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

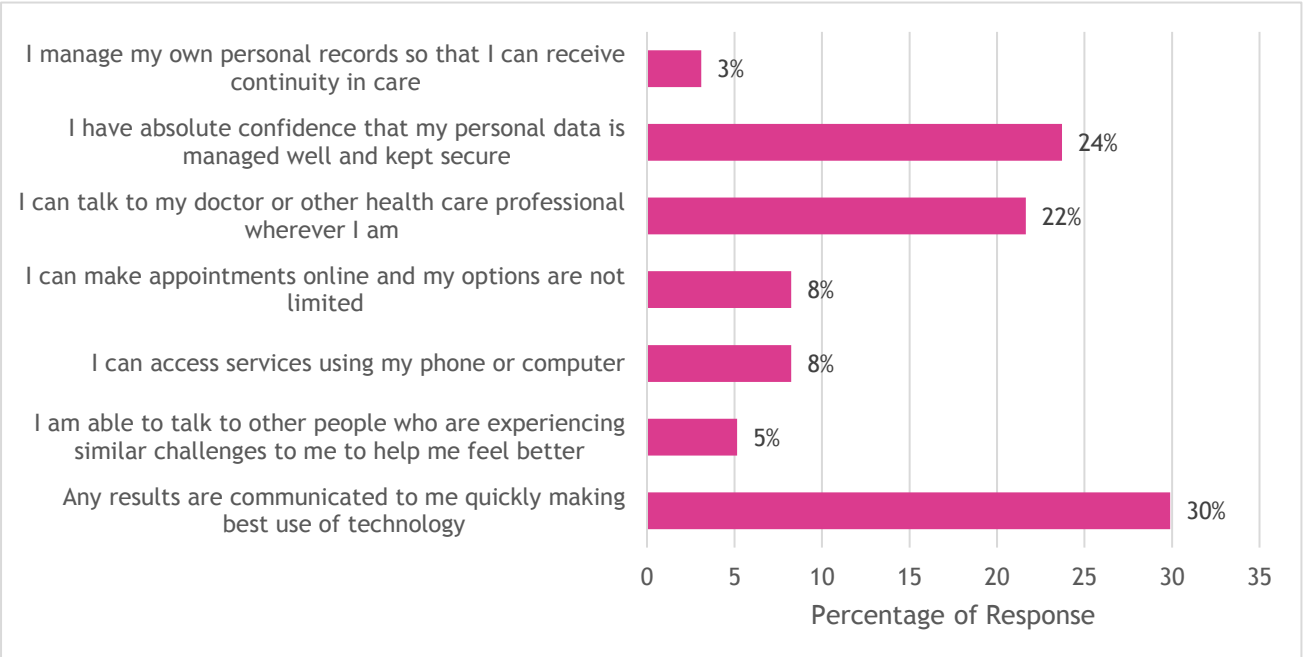
> ***"Overall care within the community with the provider is second to none"***

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

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

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

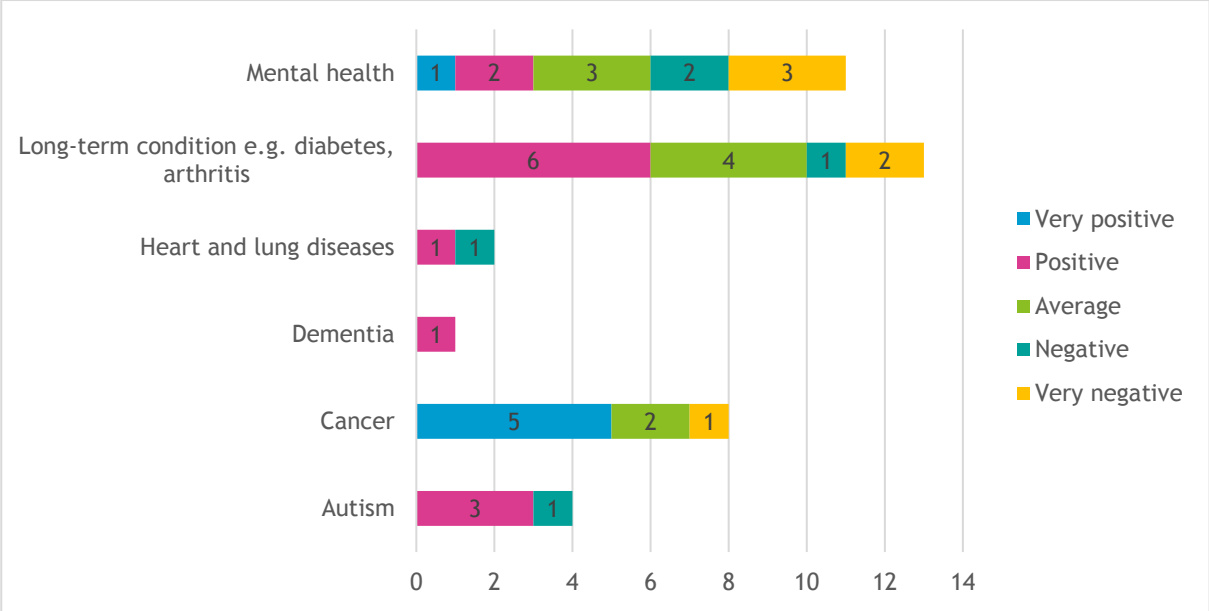
The most important aspects people identified about interacting with the NHS was around appropriate use of technology for quick communications and ensuring that personal data was kept secure and well-managed.



Experiences of Long-term Conditions:

We also wanted to understand how people with long-term conditions can best be supported to live healthily and manage their condition. We heard from 37 people about their experiences through a specific survey.

Experience of getting support



We asked people about how they found their overall experience of getting help for their long-term condition. The chart above illustrates how many people told us about what their long-term condition and how they found their overall experience.

Although sample numbers for this survey were much smaller than that of the general public focused survey, it is important to note that experiences of people using cancer services rated highly with over half those who responded feeling their overall experience was 'very positive'. This reflects feedback received through the focus group outlined on pages 12-14.

Key Issues

Most of these themes were from experiences of people with a range of long-term conditions, however, some elements identified were in relation to specific support and services for one of the conditions outlined above.

- **Cancer services** were rated highly in relation to quality of care and waiting times. Specifically, people praised the support they had received from The Maggie's Centre and Freeman Hospital.

  "I was told I could contact my oncology nurse at any time if I had any concerns and if I needed to see her, she would make an appointment for me"

- However, people also raised concerns about administration processes and the decreasing number of local services in North Tyneside for cancer care.

"We've been left with satellite clinics (if we're lucky) or travelling to Newcastle or Wansbeck, Hexham etc."

- Feedback about **mental health services** was mixed. Most of those who responded stated that the support they received "did not meet their needs". Concerns people raised were often in relation to consistent communication, waiting times and mental health being dealt with in isolation to physical health needs.

  "There seems to be the view that mental and physical health are separate. This needs to change and complete health model adopted"

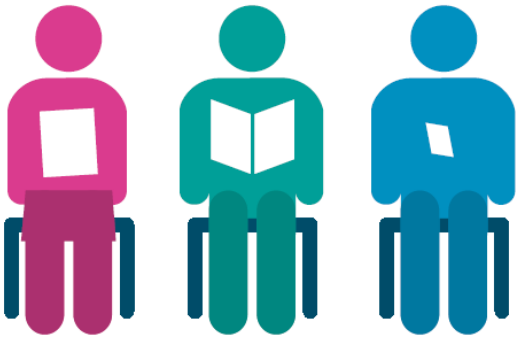
- Feedback from a carer also noted that they did not feel supported to care for the person they cared for who was "high-risk"

- Of those who told us about their experiences of using services for **Autism**, every respondent felt that the support they received "did not meet their expectations". Generally, people had mixed experiences of care but often felt that waiting times between diagnosis and treatment was long and support received was minimal. This was often specifically in relation to support from CAHMS.

- The limited number of responses we received about people with **heart and lung conditions** was generally positive. People felt that support met their expectations, but this was often paired with long-waits for care.

- Respondents with a range of long-term conditions discussed concerns about access to appointments and waiting times for referrals to specialists. A minority of respondents also discussed feeling like medical professionals did not take their health concerns or condition seriously.

  "Had the doctor listened to me when first reported in September I could have seen the correct professional much sooner"



Focus on: Implementing Cancer Services

We spoke to a group of local people with experiences of using cancer services to understand what currently works, what areas should be improved and understand how cancer services should be implemented locally in the future. The findings below are based on discussions with 5 people who have experience of using cancer services.

What Works Well?

People told us about a range of positive experiences when using cancer services.

> ***"[In North Tyneside] Particularly lucky to have excellent hospitals and university working together on improving treatment, it's a terrific place to be ill"***
>
> ***"The Bobby Robson is Magic, Brilliant, I didn't want to leave"***
>
> ***"Maggie's centre is great although the centre manager is very busy and not as focused on local services now, she manages other places too"***
>
> ***"The specialist nurses phone line is available 24/7 and that's really important"***

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

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

What Could be Improved?

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

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

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

   "I thought I was just getting old"

   "Blokes are particularly good at ignoring things"

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

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

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

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

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

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

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

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

   Therefore, people discussed the value of taking another person to appointments with you or making sure information was relayed in a way that meant you could revisit it at a later point. Positive experiences of consultants listening to patients individual research and treatment options were described, although, frequently people noted that the level to which people wanted to be involved in decisions about their treatment was varied.

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

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

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

5. **Support for carers and family** was described as minimal and inadequate. This was a key concern for patients who felt their families were not supported and felt more signposting to support groups and local charities such as the carers centre would be incredibly beneficial.

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

Suggestions for Improvement

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

- Improving ways to find out about access to support for patients.
- Significant development in the way that carers and families are supported, involved and signposted to further services for further support.

- Supporting people to understand the treatment options and support available to them, whilst understanding that each person may want different levels and types of support to suit their needs.
- Improving awareness about screening and post screening whilst supporting those who are too worried about being screened or seeking further investigation to engage with services early.
- Increased support with practical issues that change post-treatment. For example, how you can manage your waterworks.
- Increasing peer support networks to ensure that people have the opportunity to discuss their lived experience with someone who has experienced cancer too.

Focus on: Implementing Mental Health Services

We also spoke to people with experiences of using services to support their mental health needs. We discussed what currently works, what areas should be improved and how mental health services should be implemented locally in the future. The findings below are based on discussions with 6 people who have experience of mental health conditions themselves or who support someone who has.

What Works Well?

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

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

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

Existing Insights: Supporting People in Crisis

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

We found that:

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

What Could be Improved?

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

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

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

3. **People discussed the binary options of treatment being offered.** These options were often CBT or medication. The use of CBT or medication which were often not helpful and did not meet the person's needs. People perceived these options to be available because they were 'easy' options and 'cheap'.

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

for people with multiple conditions or substance use issues.

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

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

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

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

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

What Should Support Look Like?

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

Who?

- There should be a choice of which people should be involved and support needs to be delivered in a co-ordinated approach whereby professionals work together and share information accurately so that they can see the whole picture.
- The person should have the time and skills to listen to you and work decisions out together and staffing should be consistent and someone you can develop a rapport with.
- NHS 111 was not viewed as the right place for a single point of access.

- Specific roles identified included: school nurses, health visitors, community support, someone who understands mental health, physical health and other related issues.

Where?

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

When?

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

Access, Information and Digital Solutions

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

A key issue was raised about a number of services where the requirement is telephone centred access (such as talking therapies). This is a significant barrier for people with limited verbal communication.

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

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

Engagement in Health Service Delivery

During our focus group we also asked people how they felt local people should be engaged in health service delivery.

"NHS to have a customer focus"

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

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

The importance of being engaged at multiple levels was highlighted:

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

Methodology and Demographics

Healthwatch North Tyneside received **144 survey responses** from local people telling us what matters most to them and about their experiences of living with a number of long term conditions. We used the two national surveys provided by HWE in order to ensure consistency and utilise optimum comparison both locally and nationally.

Here is a breakdown of the demographic information relating to those who shared their feedback through surveys:

Row Labels	Age
Under 18	1
18-24	2
25-34	9
35-44	16
45-54	17
55-64	33
65-74	38
75+	27
Grand Total	**143**

Row Labels	Gender
Female	97
I'd prefer not to say	2
Male	36
Grand Total	**135**

Row Labels	Ethnicity
Any other mixed background	1
Other	6
White British	129
Grand Total	**136**

Row Labels	Sexuality
Asexual	2
Gay or lesbian	2
Heterosexual	46
I'd prefer not to say	7
Other	2
Grand Total	**59**

Row Labels	Religion
Christian	30
I'd prefer not to say	3
No religion	23
Other	3
Grand Total	**59**

Row Labels	Carer
No	121
Yes	21
Grand Total	**142**

Row Labels	Disability
I'd prefer not to say	8
No	77
Yes	57
Grand Total	**142**

Row Labels	Long Term Condition
No	45
Yes	35
Yes, I have a long term health condition	33
Yes, I have more than one long term health condition	28
Grand Total	**141**

Long-term condition Based Survey Only:

Condition	Count
Dementia	1
Autism	4
Cancer	7
Lung and Heart	2
Long-term Condition	11
Mental Health	12

We also spoke to 11 people through two focus groups about their lived experiences of mental health services and cancer services. This included both service users, patients and carers. The cancer related focus group was only attended by men so this will influence the findings.

Acknowledgements

We would like to thank the local people who shared their views for this project. Thanks also go to our volunteers who continue to support us when engaging with local people.

Thank you to Healthwatch England and Healthwatch Darlington who coordinated the work across the North East and Northern Cumbria ICS area. The feedback from this project links to work we will be carrying out over 2019/2020:

- Talking to more people about their experiences of cancer services;
- Completing our project about access to GP appointments;
- Understanding older people's experiences of accessing mental health support;
- Exploring where local people go when they are ill

To find out more about our future work see annual report: https://healthwatchnorthtyneside.co.uk/wp-content/uploads/2019/06/HWNT-Annual-Report-1819-Final.pdf