healthwatch Cheshire West

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People's views on the NHS Long Term Plan

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Executive summary

Background

This report provides the local NHS with people's views about the NHS Long Term Plan. It is designed to feed into work on producing a health and care strategy within the Cheshire and Merseyside Health and Care Partnership (HCP).

With growing pressure on the NHS – people living longer, more people living with long-term conditions, and lifestyle choices affecting people's health – changes are needed to make sure everybody gets the support they need.

The NHS has produced a Long Term Plan, setting out all the things it wants health services to do better for people across the country. The research presented within this report is based on what people in Cheshire East told Healthwatch about what those changes should look like in our communities.

The Long Term Plan sets out what the NHS wants to do better, including making it easier for people to access support closer to home and via technology, doing more to help people stay well, and providing better support for people with cancer, mental health conditions, heart and lung diseases, long-term conditions, such as diabetes and arthritis, learning disabilities and autism, and for people as they get older and experience conditions such as dementia. The Long Term Plan can be viewed in full online at www.longtermplan.nhs.uk.

What is Healthwatch?

Healthwatch are independent consumer champions for health and care. There are 152 local Healthwatch who work within local authority boundaries forming part of the national network of local Healthwatch across England. Our role is to make sure that those who run health and care services understand and act on what really matters to local people.

Local Healthwatch undertake continuous engagement activities with the public to hear about concerns and compliments regarding health and care services. The information we gather is then analysed so that we can identify and act upon trends and common themes by presenting our findings to decision makers in order to improve the services people use. We also share people's views locally with Healthwatch England who make sure that the government put people at the heart of care nationally.

Cheshire West and Chester

The Local Authority of Cheshire West & Chester covers approximately 350 square miles and is the fourth largest unitary authority in the North West. The Borough includes the historic city of Chester and the industrial and market towns of Ellesmere Port, Frodsham, Helsby, Malpas, Neston, Northwich and Winsford; as well as a patchwork of rural villages. Over 335,000 people live in Cheshire West and about a third live in rural areas.

Quality of life is generally good for many people across the Borough, with lower levels of deprivation, higher incomes and generally good health. However, there are pockets of significant disadvantage, where residents experience poorer health outcomes, living conditions, educational attainment and economic prospects.[1]

[1] Source: *Cheshire West & Chester Council Borough Profile, July 2018. Produced by Insight & Intelligence.* http://inside.cheshirewestandchester.gov.uk/find_out_more/datasets_and_statistics/statistic

What we did

On production of the Long Term Plan, NHS England commissioned Healthwatch England to gain the views of the public. In turn, Healthwatch England asked the 152 local Healthwatch throughout the country to work with their Sustainable Transformation Partnerships (STP) or HCPs, to engage with people to find out what was important in regard to the way services will be delivered in the NHS under the Long Term Plan. This research was to be conducted through two surveys and a minimum of two specific focus groups per local authority area, and took place following the publication of the Long Term Plan from mid-March to the end of May 2019. The surveys were designed nationally by Healthwatch England, with the first entitled 'People's general experiences of health and care services', and the second survey looking at 'NHS support for specific conditions'.

As the coordinating local Healthwatch for the nine within Cheshire and Merseyside who conducted the research, Healthwatch Cheshire (consisting of East and West) oversaw the research across Cheshire and Merseyside and brought the information together to produce final reports. Healthwatch Cheshire were also responsible for liaising with the Cheshire and Merseyside HCP regarding the work. There are nine local Healthwatch within the Cheshire and Merseyside HCP area. These are:

- Healthwatch Cheshire East
- Healthwatch Cheshire West
- Healthwatch Halton
- Healthwatch Knowsley
- Healthwatch Liverpool
- Healthwatch Sefton
- Healthwatch St Helens
- Healthwatch Warrington
- Healthwatch Wirral.

Each local Healthwatch then discussed with their relevant area leads within the HCP in regards to which areas or issues were deemed to be a priority at HCP level for focus group activity. Each local Healthwatch worked with focus groups that best fit key issues and priorities in their area.

People in Cheshire West and Chester were asked a series of questions to ascertain:

- How would you help people live healthier lives?
- What would make health services better?
- How would you make it easier for people to take control of their own health and wellbeing?
- What would you do to make support better for people with long-term conditions?

Surveys were available both online and in paper copy. Healthwatch Cheshire West promoted the survey using our website, social media, and engagement activity based on local links and expertise. At least two focus groups with a minimum of 10 attendees at each were also conducted. The format guidance from Healthwatch England enabled Healthwatch Cheshire West to structure our focus groups to suit our local area and participants, which provided a richness of information that would have been lacking with a one size fits all approach.

In Cheshire West and Chester, we received 253 survey responses, consisting of 230 general surveys and 23 specific condition surveys. There were also 20 attendees across two specific focus group events with students and people with autism.

Summary of Findings:

What matters most to people in Cheshire West and Chester?

- When people were asked to consider what was most important to them to help them to lead a healthy life the predominant factor was having **access to the help and treatment they need when they want it**, accounting for 40% of responses. A quarter of people stated that **professionals that listen to them when they speak about their concerns** was the second most popular answer.
- However, it is important to note that when respondents were asked to rate each statement according to importance, **professionals that listen** rated slightly higher than **access to services when needed.**
- Additionally, when asked to think of one thing that would help them to lead a healthy life, respondents primarily focused on factors relating to **prevention**, a **joined-up approach** to accessible service, **environment and infrastructure** and easier access to **GP appointments**.
- When asked about keeping independent and staying healthy in later life, the overwhelming response was the ability to be able to **stay in their own home** for as long as it was safe to do so, accounting for 57% compared to the second highest answer relating to convenient ways to travel to health and care services, which was given by 13% of respondents.
- **Home support** and **community support**, a **holistic approach** to care, **financial stability** and **good transport** were all emerging themes when respondents were asked to think of one thing that would help them to retain their independence and live long and healthy lives.
- When asked to think about managing and choosing support and treatment, the most important factor by far was that choosing the right treatment was a **joint decision** between the individual and the relevant healthcare professional.
- When asked to rate this however, **timely communications** were also deemed as very important.
- When asked to think of one thing that would help them to manage and choose the NHS support needed, **communication** was a dominant theme. Respondents also mentioned **information and advice**, **support** and **funding**.

What are the experiences of people with specific conditions?

- Feedback from people with or caring for someone with autism concerned long **waiting times** for diagnosis, **limited support following diagnosis** and **inconsistent communication**.
- A respondent with a learning disability found that care and support met their needs, but **better communication** from services and health professionals would have been more beneficial.
- All four respondents with a heart and/or lung disease felt that they had had a positive experience in terms of accessing help and support in a timely manner. The majority of the respondents also felt that help to lead a healthy life through **early intervention** would be beneficial.
- The majority of respondents with a mental health condition felt that the support they had received did not meet their needs. Although some respondents stated that they had not received any ongoing support, those who did felt that **waiting times** were too long. Once support was accessed, some found it to be ***"dismissive"***.
- People with long-term conditions such as diabetes and arthritis found that the support they received was mixed, and believed that communications they received were **not timely enough**.

Survey results

The following sections now break down the results of the 253 responses across Cheshire West and Chester to the surveys designed by Healthwatch England. The first sections use the 230 responses to the general 'People's general experiences of health and care services' survey, before breaking down the 23 survey responses from people discussing support for specific conditions.

In the responses to the general surveys, people were asked questions around:

- Living a healthy life
- Keeping independence and staying healthy in later life
- Managing and choosing support and treatment
- Interacting and engaging with the NHS.

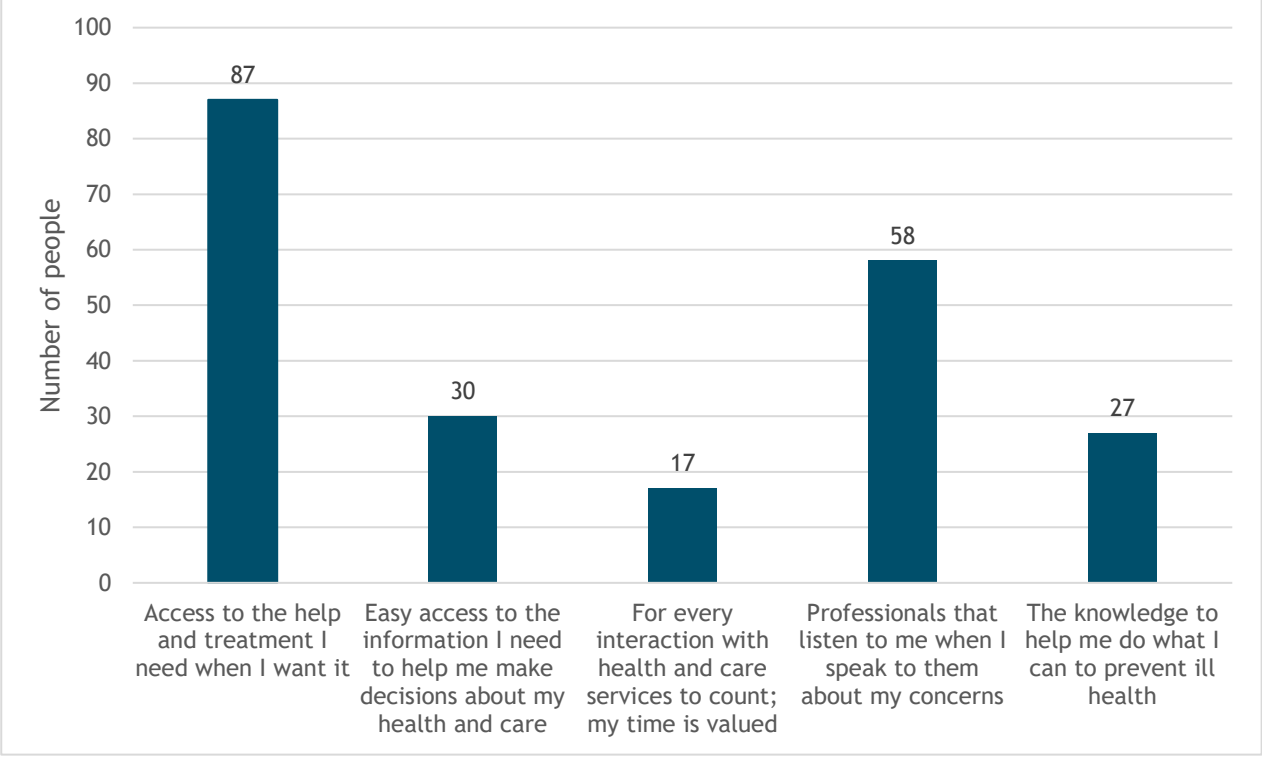
For each of these, people were asked to choose which of a number of options was most important to them. Following this, people were asked to rate each of the options on a scale of 'very important' to 'not important at all'. Therefore, more than one option could be considered 'very important'. Finally, respondents were then asked to elaborate on what works well and what could be improved in these areas.

What is important to people about health and care services

Living a healthy life

When considering how to live a healthy life, having access to the help and treatment needed when it is wanted was deemed to be most important by people responding to the survey (see **Chart 1**). 219 people responded to this question.

Chart 1: What is the most important to you to help you to lead a healthy life?



However, in **Table 1** when asked to rate on a scale of very important to not important at all respondents to the survey felt that 'Professionals that listen to me when I speak about my concerns' was ranked as being the most important, followed by access to the help and treatment needed when it is wanted. However, it is also important to note that all five statements were deemed as very important or important, as the table below shows. Up to 226 people responded to this question, but not everyone responded to each option:

Table 1: Rate how important the following things are to you when it comes to living a healthy life

	Very Important	Important	Neutral	Not Important	Not Important at all
Professionals that listen to me when I speak to them about my concerns	196	27	1	0	0
Access to the help and treatment I need when I want it	183	37	1	1	0
For every interaction with health and care services to count; my time is valued	151	60	9	2	0
Having the knowledge to help me do what I can to prevent ill health	144	67	11	3	0
Easy access to the information I need to help me make decisions about my health and care	141	72	9	3	1

We also asked respondents to think about one more thing that would help them to lead a healthy life. This was a free text question and so answers were collated into themes and summarised below:

Environment and infrastructure

Many people commented on the impact that wider determinants have on leading a healthy lifestyle, such as the provision of sport and leisure facilities, better transport and infrastructure, as well as the quality of the environment:

- *"Access to good shops selling healthy food"*
- *"Better places for walking"*
- *"Less worry about my finances, with all the rocketing prices for everything"*
- *"Easy access to a leisure centre (price wise)"*
- *"Better local infrastructure. Developers have built around 5000 new homes locally, yet there has been an utter failure to meet the needs of the community by providing a new medical centre, or any other community facilities."*
- *"Cheaper healthy food"*
- *"More time to exercise around the working day"*

- *"Outside environment where I live being safer in the evenings if I want to go out on the bike or for a run"*
- *"Cleaner air"*
- *"Tackle poverty."*

Prevention services

Another emerging theme from respondents centred around the need for prevention advice and support and provision of services that meet this requirement (including regular health checks):

- *"Annual 'well women' checks for blood pressure, cholesterol, etc"*
- *"Regular health checks for adults that could detect problems at an early stage and be prevented from causing long term illness"*
- *"Information about healthy eating and exercise"*
- *"More information about the cause of some illnesses and how to prevent them"*
- *"Give more promotion to information that helps to prevent ill health. Cancer, Diabetes, Obesity etc"*
- *"For my GP surgery to offer me health checks/MOT as a late 30's apparently I am too young to qualify for this."*

Joined up approach to accessible services

Respondents commented upon there being a joined-up approach to services and in particular the offer that is available to support them in the community:

- *"More community-based services and continuity of staff"*
- *"More linking in of services and not long waiting i.e. doctor/hospital for physiotherapy and doctor for mental health"*
- *"More routine outreach services in the community so that the need for long car journeys, finding someone to drive and limited but expensive parking at hospitals [is avoided]."*
- *"Professionals that will give me the right services when required"*
- *"More local services 24/7 so I don't need to go to A&E"*
- *"More support groups to help people get healthy then stay healthy"*
- *"Mental health support that was available on the day I need it and easy to access"*
- *"Better information about groups in the area i.e. walking groups"*
- *"Access to a support group where I can learn about complimentary alternatives rather than take medication."*

GP appointments

The majority of comments regarding GP appointments centred around the ability to get a timely appointment:

- *"Easier to make GP appointment"*
- *"To be able to make Drs appointment within 2 days of request"*
- *"Getting doctor appointments when I want them"*
- *"For access to GP to be easier. My GP has made it almost impossible to get appointments."*

However, a number of respondents also commented on the quality of the appointment such as length of appointment and content:

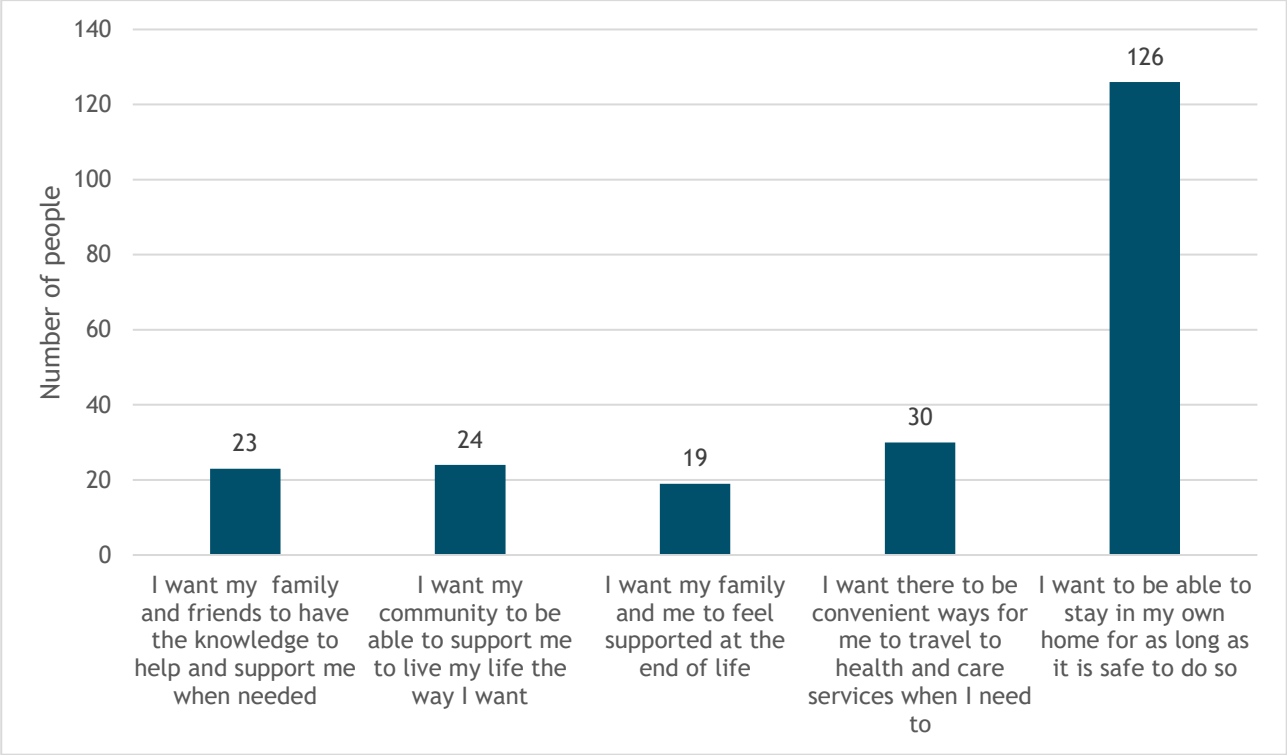
- *"Increase local Doctors appointments times from 10 minutes to 15 minutes or even longer."*
- *"Longer appointments with the professional, so that more than one condition or problem can be thoroughly dealt with."*

- *"Extra time allowed at appointments. Just GPs who are so overstretched. Possibly more GPs."*
- *"Continuity of care at the GP. Seeing different doctors means explaining other conditions repeatedly. Frequently I am prescribed something that, when I read the contra-indications, will aggravate one of my other four long term conditions."*
- *"Some respect for my existing knowledge would be a good added extra."*

Keeping independence and staying healthy in later life

We asked people to tell us about what they feel is important about keeping independence and staying healthy in later life. Being able to stay in their own home for as long as possible was by far the most important factor (see **Chart 2**). 222 people responded to this question:

Chart 2: What's most important to you to help you to keep your independence and stay healthy as you get older?



In **Table 2** when asked to rate this however, although being able to live independently in their own home is rated as the most important, all of the other statements identified were also rated as very important or important. Up to 226 responded to this question, but not everyone responded to each option.

Table 2: Rate how important the following things are to you when it comes to keeping your independence and ageing healthily:

	Very Important	Important	Neutral	Not Important	Not Important at all
I want to be able to stay in my own home for as long as it is safe to do so	188	26	4	3	3

I want my family and me to feel supported at the end of life	172	42	6	3	2
I want there to be convenient ways for me to travel to health and care services when I need to	159	51	12	2	1
I want my family and friends to have the knowledge, to help and support me when needed	139	66	13	3	4
I want my community to be able to support me to live my life the way I want	114	79	21	8	4

We also asked respondents to think about one more thing that would help to retain their independence and live healthily for as long as possible. Again, this was a free text questions so answers were collated into themes and summarised below:

Home support

The most prevalent theme with regards to what people feel would help them to live independently was related to support to stay at home and also provision of quality housing:

- *"Having properly trained carers at home"*
- *"Help with housework"*
- *"Regular visits from a health professional, not only carers, when living in own home with support"*
- *"Better support to stay in own home"*
- *"To live in accommodation to enable myself to be able-bodied for as long as possible"*
- *"Being able to access help with household cleaning etc free or at a reasonable price within my means"*
- *"Good housing with accessible bathroom"*
- *"Affordable housing"*
- *"Advice about adapting a home."*

Community support

A number of respondents commented on the need for community support to enable them to stay healthy as they get older:

- *"More community feeling. Groups and places to meet. Services that are suited for the ages."*
- *"I believe community programmes involving volunteers would be a great help."*
- *"Perhaps the NHS could stop assuming that everyone has a battalion of friends and family to provide the help and support that the NHS is properly supposed to provide - I live alone and I do not have family to take up the slack."*
- *"Local community hubs, a part of doctor's surgeries/clinics where health information and services are available."*

Holistic care and prevention

A preventative approach to healthcare and a more holistic offer was also seen as important:

- *"Someone to be aware of me and to unobtrusively monitor my way of living, offering help if needed."*
- *"Respect and the ability to stay in control of my life for as long as possible."*
- *"Offering alternative healthcare i.e. Reiki & discounted Brio Leisure"*
- *"Staying fit, reduce costs at council gyms. Promote keeping fit and healthy eating."*

Transport

A concern for a number of respondents related to the provision of a quality transport service being available to enable them to remain independent in later life:

- *"Better local transport services"*
- *"I don't drive or have much money so cheaper public transport to and from NHS services - or make services more local"*
- *"There is a local free shuttle bus that runs from Halton Hospital to Warrington Hospital which is vital for a lot of patients. But there seems to be priority given to NHS staff to board before patients/other users. If this service is needed for staff then they should have their own shuttle put on for them, then there wouldn't be any issues of patients/ other users missing out on transport."*
- *"Independent means of personal transport to places where I feel safe"*
- *"Good public transport so that I can access clinics etc when I can no longer drive" "Some clinics should be run locally."*
- *"When there is no family living near it is a real worry getting to appointments. Hospital transport is very wearying, taking a long time especially for the aged, waiting around for hours."*

Communication and information provision

How people are communicated to and provided with information was also seen as pertinent to leading a long, independent and healthy life. In particular:

- *"Good communication between providers of healthcare and social services"*
- *"Being listened to and my family being part of the discussions"*
- *"Knowledge of what support is there and means tested, have that removed so all are treated the same"*
- *"There needs to be a local central point with the information of what care is available, what is free or paid, and how to access it. There are several old couples around us who need some help with care or respite and yet they don't know where to go. The GPs help out when it's a crisis but the crisis could be avoided, if there was a clear process of somewhere to ask what is available."*

Financial issues

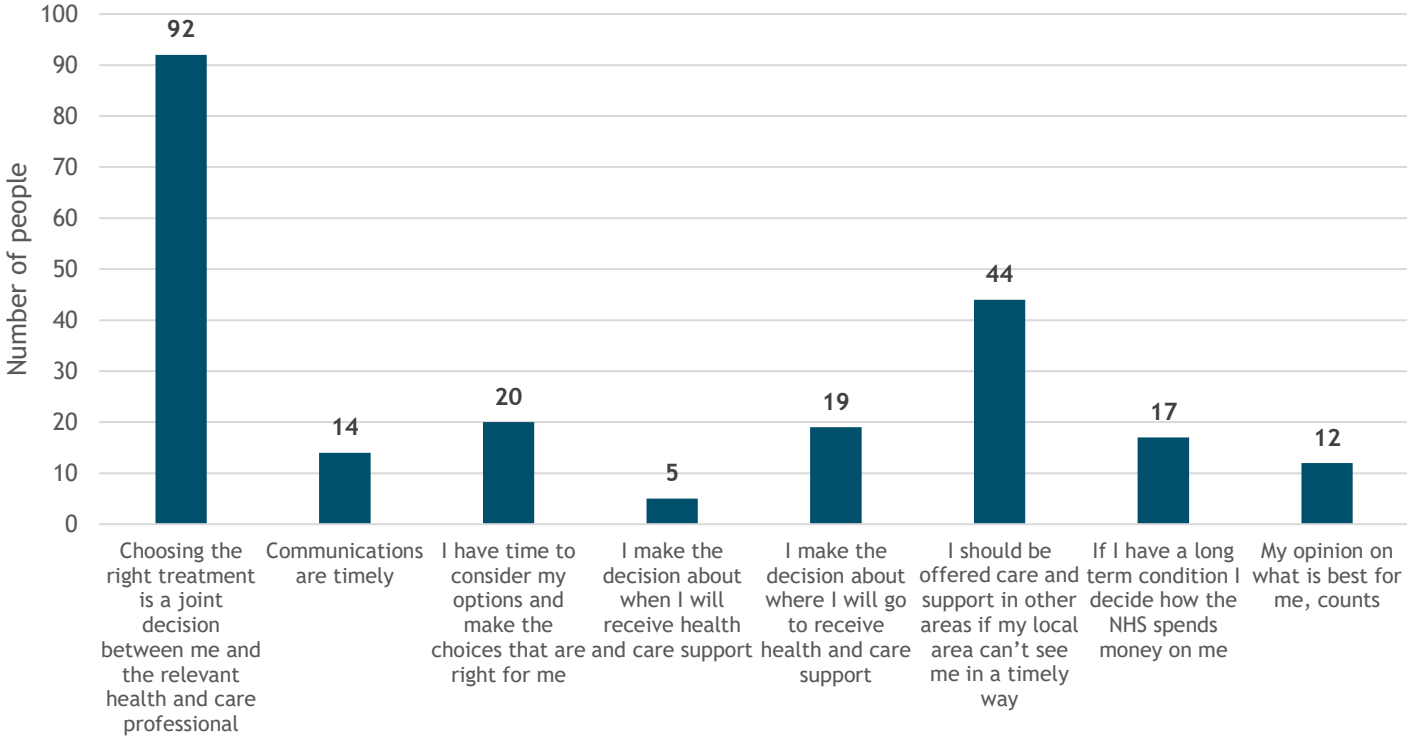
A number of respondents felt that more financial security was the most important element when it came to leading a long and healthy life.

- *"Not to struggle so much financially that sometimes a choice has to be made between prescription or food as on single low income"*
- *"The cost of carers and at home care is prohibitive and needs to be sorted out"*
- *"Care at home is a massive expense"*
- *"Being written off by our government because I am a pensioner, if they cannot get us because of our disabilities, now they think we should not get our perks"???"*
- *"Cheaper prescriptions."*

Managing and choosing support and treatment

Chart 3 shows that people we spoke to in Cheshire West and Chester told us that choosing the right treatment being a joint decision between them and the relevant health and care professional is most important to them in managing and choosing support and treatment. Being offered care and support in other areas if people cannot be seen in a timely way locally was deemed as the second most important option. 223 people responded to this question.

Chart 3: What's most important to you to be able to manage and choose the support you need?



As **Table 3** shows, when asked to select how important different factors were on a scale of very important to not important at all, people also deemed timely communications, having time to consider options and make choices that are right for them as very important. It must be noted that all options offered to people were overwhelmingly considered to be very important or important in their responses, although people deciding how the NHS spends money on them if they have a long-term condition was perhaps considered less important as the relatively high number of neutral responses shows. This is detailed in the table below, in order of the options that most people classed as being very important. Up to 227 people responded to this question, but not all responded to each option.

Table 3: Rate how important the following things are to you when it comes to managing and choosing the support you need

	Very Important	Important	Neutral	Not Important	Not Important at all
Choosing the right treatment is a joint decision between me and	148	65	11	2	1

the relevant health and care professional					
Communications are timely	146	64	12	1	0
I have time to consider my options and make the choices that are right for me	128	84	7	0	1
My opinion on what is best for me, counts	123	79	23	0	1
I make the decision about where I will go to receive health and care support	120	74	26	4	2

Communication

A common theme stemming from people's comments was the need for better communication both within the NHS and when talking to patients and people's desire to feel listened to. People told us that they would like their GP to have more time available to them in order to speak to their patient. There was also a feeling that more information should be provided to increase people's awareness of what support options are available to them. Comments included:

- *"To have medical professionals that listen to my views about my condition"*
- *"Having access to a doctor who is willing to work with me and my condition/symptoms. Not being fobbed off."*
- *"Being able to talk to a doctor about health concerns without feeling rushed and without the trials of getting an appointment"*
- *"That the various arms of the NHS would communicate and share with one another. So much money and time is wasted because exactly the same tests etc already done are repeated by different professionals in different places."*
- *"Link up between departments would be very helpful, as I constantly get conflicting advice and people who do not understand my problems/conditions."*
- *"Listen to patients more, through past experience I waited for many years to get my message through so in the meantime I suffered for many years. There should be a triage system to listen to patient's concerns."*

Information and advice

People also told us that they would value more information and advice about support options available, for example:

- *"I would like to know what services are available within the NHS or if there is a private option so I can choose."*
- *"What is there available?"*
- *"Better information of websites. Statistics that I can look over. Testimonials."*
- *"It's all very well saying we have a free choice of where we go for appointments and surgery but we don't actually have the information as to who is the best or shortest waiting list. I always ask who would you go to? We have to rely on the information the specialists/GPs have and accept that."*

- *"Clear options on treatment and clear and available information on how to keep healthy."*

Guidance and ongoing support

People told us they would also like to see more ongoing support and guidance from health professionals. Comments included:

- *"Guidance and navigation, I need an expert to guide me, I don't know what to do for the best and it puts pressure on me being asked to make all these decisions."*
- *"Ongoing support, when you are first diagnosed, sometimes you are just given the diagnosis and left to find your own way through."*
- *"To offer thorough advice and options about my care from the beginning, and explains conditions in some more detail."*

Funding for, and availability of services locally

Furthermore, people told us that they would like to see funding for more services provided locally with good public transport links to make them easy to travel to and from. This also linked into comments that called for more investment in frontline services. For example:

- *"Increase the number of medically trained and qualified staff at all levels; GP surgeries, hospitals, walk-in centres, opticians, dentists, audiologists, podiatrists, pharmacists and many others."*
- *"Increased options for care of my particular condition, there are so few clinics specialising, there should be satellite clinics locally - gender dysphoria."*
- *"Services that don't rely on post code - e.g. good services such as Visyon (young people's mental health support) offered in Cheshire East but not in Cheshire West."*
- *"All services should be available in an NHS area. Cross-boundary treatment should be the exception especially in the case of multiple repeat appointments."*
- *"More minor injuries clinics. More nurses available in doctor's practices to see with minor ailments rather than take up doctor's time."*

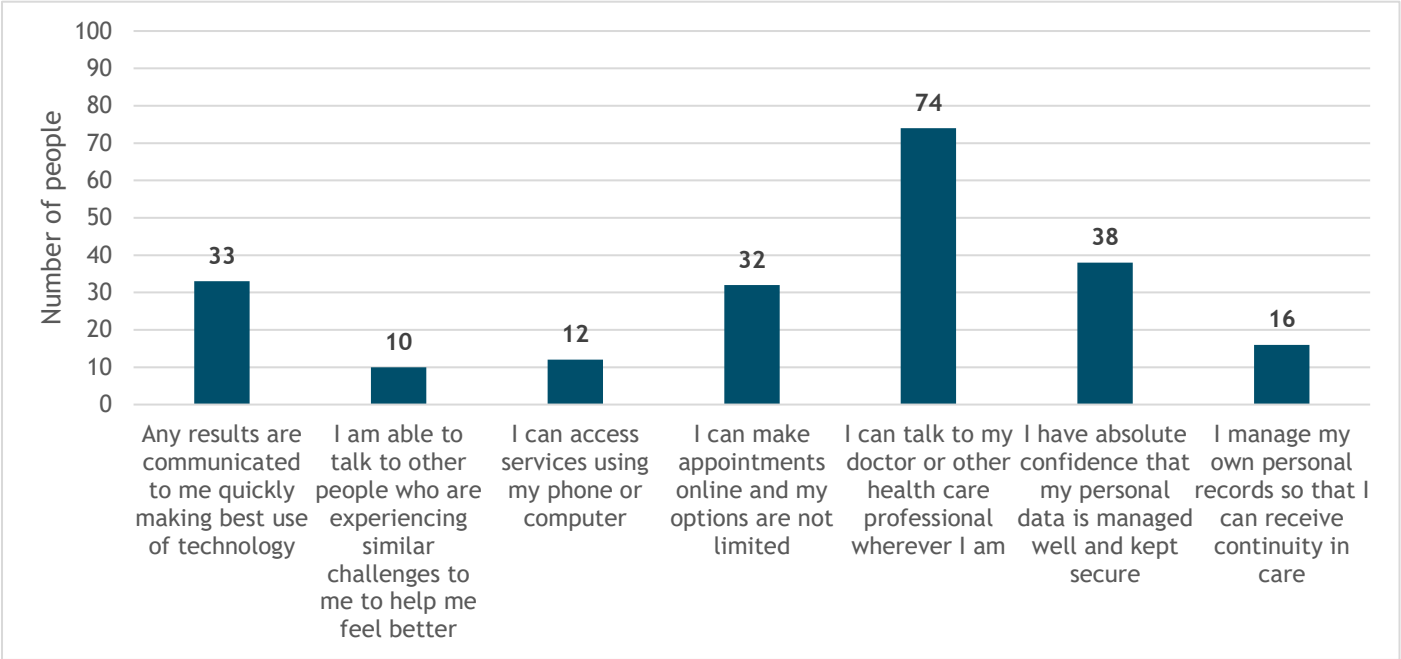
Engaging people in health service delivery

This section of the report summarises how people told us they would like to be engaged in health and care.

Engaging people is considered to be an enabler of service change and improvement within the Long Term Plan. This provided an opportunity for people to make suggestions about what good and appropriate engagement can look like.

As **Chart 4** shows below, people in Cheshire West and Chester told us that being able to talk to their doctor or other health care professional wherever they are was the most significant important factor in being engaged in health service delivery. Having any results communicated quickly making best use of technology and having absolute confidence that personal data is managed well and kept secure were also considered important by people. 215 people responded to this question.

Chart 4: What is most important to people when interacting with the NHS



When asked to select how important different factors were on a scale of very important to not important at all, people deemed that communicating results via technology was very important and that personal data was well managed and kept secure, along with being able to talk to a doctor wherever they are. It must be noted that all options offered to people were generally considered to be very important or important. People talking to other people who are experiencing similar challenges to feel better and people managing their own personal records so that they can receive continuity in care, can perhaps be shown to be not as important as other factors as evidenced by the higher number of neutral answers from people in regard to these options. This is detailed in **Table 4** below, in order of the options that most people classed as being very important. Up to 227 people responded to this question, though not everyone responded to each option.

Table 4: Rate what is most important to you when interacting with the NHS

	Very Important	Important	Neutral	Not Important	Not Important at all
Any results are communicated to me quickly making best use of technology	144	62	14	6	0
I have absolute confidence that my personal data is managed well and kept secure	137	55	28	5	2
I can talk to my doctor or other health care professional wherever I am	131	71	18	5	1
I can make appointments online and my options are not limited	119	71	22	12	2
I can access services using my phone or computer	116	77	21	8	2
I manage my own personal records so that I can receive continuity in care	95	82	35	10	3

Accessibility

Responses regarding the use of accessibility in health and care were mixed; some people told us that they would like to see faster referrals and quicker access to their GP. They also commented that they would like to manage their own medical reports and results. Comments included:

- *"Access to all my records and results from home as part of a routine annual service"*
- *"Continuity of care at GP, regular and easier scheduled check-ups (yearly/6 monthly)"*
- *"That I could gain faster access to my GP. The wait is usually two weeks and more. Appointments need to be available same week when you are not well, not wait weeks."*
- *"Quicker access to healthcare professional and results, not having to wait on the phone making call after call on a busy line. It can take too long to get through, front line receptions can be so busy and sometimes downright obstructive and unpleasant, especially in some urban/city practices."*
- *"More drop-in centres."*

Technology and online services

Responses regarding the use of online technology in health and care were mixed. Some people told us that they would like to see more online or accessible appointments or being able to easily access records and results, whereas others felt that they would like to see less technology and more face to face communication. Comments included:

- *"A fast and reliable broadband service and better website access"*

- *"Allow me to enter the results of tests I have carried out into the GP surgery information system (EMIS) from a PC or handheld device"*
- *"For NHS to remember that not everyone has access to technology and technology loses the personal touch which can cause further distress and ill health"*
- *"To be able to speak to a doctor in person, not phone calls; it is bad when you are on the phone and your doctor is telling you about how unwell you are"*
- *"Promoting online chat sites for those with similar health worries, as currently with Health Unlocked"*
- *"More resources so patients can be seen in a timelier manner e.g. consultants - have to wait months for appointments, scans, etc."*

Home and community

Responses regarding the use of home and community in health and care were again mixed. Some people told us about the activities they would like to see, others commented on the home healthcare provision, homelessness and community engagement. Comments included:

- *"More understanding over homeless issues and more health workers for them"*
- *"Help with cost to the gym or other outdoor activities"*
- *"Great links between school and health - healthcare in schools is very poor"*
- *"Some way of letting neighbours know if you live alone and are not well"*
- *"Children have a health visitor supporting parents, could there be a similar person visiting elderly e.g. 80 or more at home supporting them, keeping them healthy and making known what services are available to them."*

Staff and communication

Responses regarding staff and communication in health and care again were mixed. Some people commented on staff training, and better communication with patients. Comments included:

- *"Lack of red tape or poorly trained staff"*
- *"The same team, doctors or specialists as they always change and I have to repeat everything"*
- *"Ability to see GP of choice on day of need and for the appointments not to be limited to one complaint at a time"*
- *"I want to be able to communicate with the NHS regardless of where I am, with effective cross departmental communication – the heart department should talk to rheumatology"*
- *"We need to be made aware of exactly what help & support is available to us just like these refugees get. Pensioners are kept in the dark as to what is available to us yet refugees and visitors to this country are given every help needed."*

What people expect during service change and transformation

People in Cheshire West and Chester commented upon challenges facing the health system locally, including population increases. Comments included:

- *"That all hospital trusts operate from a standard national policy, without exception and without any 'local' interference as far as CHC is concerned. Time limits should be set on response to all correspondence, my own experience is that this is simply not complied with. My personal experience is that so-called independent panels are far from 'independent'."*
- *"Due to chaotic confusion and shortage of resources of all kinds in the NHS, increasing numbers of people who can afford it are moving to private healthcare, but the NHS, like*

other organisations I could mention, thinks it is still the only healthcare service on the planet. The NHS needs to learn how to cooperate better with privately-provided healthcare and how to exchange data and information using modern technology instead of Dickensian pieces of paper."

- *"Northwich and surrounding areas need another hospital and GP surgeries to accommodate the increasing population."*
- *"An extra hospital in Cheshire West. Spent time at A&E Leighton and waited almost 12 hours for a bed. the population is growing but still only served by this one hospital. Good care given; staff can't be faulted but supply is insufficient to cope with demand. The area is still expanding and extra resources are needed."*

In focus: what is important to students about health and care services?

As part of our research activity, Healthwatch Cheshire West conducted a focus group with students from University of Chester in order to gain the views and experiences from young people who can struggle to have their views heard in regard to health and care. This focus group took place on the morning of 2nd May 2019, and was attended by 10 health and social care students. Below is a summary of the themes and issues they raised:

Awareness of the Long Term Plan

One of the main issues raised by the students was a lack of knowledge of the Long Term Plan as they did not know anything about it prior to the session. There was a concern that as an age group they are being missed out and feel they should be involved in consultations and engaged with more.

Clarity in communication

Consistently, the students raised that they wanted to be spoken to in plain English when using health and care services. There was a feeling that too much jargon was used by health and care professionals.

Accessing information and advice

It was stressed by students that a reliance on information being supplied digitally should not be seen as the paramount source as it often fails to reach all parts of the community. When information is shared online it should not be seen that it is "*job done*".

Access to information, especially for those in rural areas, needs to be improved and there is an opportunity for more community involvement.

Students said that information should be available in every format and the NHS should always be prepared to supply information in different languages and to suit the needs of people with a disability. NHS staff or agents should deliver information in all communities through face-to-face contact, in news form, via local media, schools, community groups, Healthwatch, surveys, consultations, libraries and community hubs. Local government and local councillors should also take a more prominent role in the delivery of important health-related news. Students suggested the NHS team up with mobile companies to deliver public information through free messages at times of need or outbreak of illness.

It was felt by attendees that the NHS needs to be more direct in signposting people to other services such as pharmacies, clinics, GPs, NHS 111 and walk-in centres. People said that the

Accident & Emergency department should be seen as the last resort and if it is not an emergency people should be turned away.

Community role of GP practices

People suggested that GP Practices should become a community within the community and associate with other hubs such as centres and libraries. They thought that GP Practices should consider volunteering teams who can offer peer support as lived-experience buddies.

It was suggested that GPs assist in the reduction of loneliness and isolation by interrogating their address/mailing list to see who has not accessed services for a while and, if appropriate, make contact to see how they are.

Accessibility of services

Students felt that there is a need for all primary care to be accessible by local or community transport. There is an expectation that primary care can remove pressure from A&E, and that it should provide a true reflection of its community, recognising language and culture differences. Primary care should provide education regarding health or forge relationships with schools, colleges or universities to drive forward improvements.

Some of the services which students prioritise are Mental Health support, sexual health, scanning facilities, speech services, bloods, dietician and physiotherapy services. They believe there should be little or no wait for services across the country. If there is a wait for a service then staff should continue to engage with the patient, bring them into their own care plan, set goals, standards that have to be met to ensure that the treatment can be delivered and stand the best chance of success.

Students could not comprehend how one GP Practice could operate a first-class appointments system yet its neighbour cannot. They feel there is need for a best practice review. They would like to see students and young people engaged with as part of future work.

Training

The group identified that they wished to seek careers within the NHS but highlighted that finance was a barrier. They would like to see new methods of entry being looked at, assisting with the financial aspect which is putting people off, but without lowering standards of training. It was reported that a planned course was cancelled setting back training and recruitment. It was seen to be not cost effective that people on bank support can earn much more money coming in to assist than if they were working full-time for a service.

Mental Health services

Mental Health was identified by the group as having a major effect within the student environment, and whilst it is appreciated that student union and mentors offer a service, they fail to meet demands. Students would like to see a service similar to the sexual health provision when services base themselves in the university for mental health to meet demand. Delivery of mental health first aid and more contact would be seen as a major step to reducing issues at early stages.

People's experiences of NHS support for specific conditions

People with specific conditions were asked to complete a separate survey on their experiences of the NHS support they had received in relation to that condition. This included discussion on the three stages of the care journey; assessment, diagnosis and treatment; the provision of ongoing care and support; and prevention and/or early intervention. We received 23 responses in total to this survey. This section breaks down the responses we received in terms of number of people by specific condition:

Table 5: Respondents with specific conditions

Condition	Number of people
Autism	3
Cancer	0
Dementia	1
Heart and lung diseases	4
Learning disability	1
Long-term condition e.g. diabetes, arthritis	7
Mental Health	8

Table 6: Who are you responding on behalf of?

Condition	Myself	Someone else
Autism	1	2
Cancer	0	0
Dementia	0	1
Heart and lung diseases	4	0
Learning disability	1	0
Long-term condition e.g. diabetes, arthritis	7	0
Mental Health	6	2

Table 7: Has the condition you are telling us about started within the last three years?

Condition	Yes	No
Autism	1	2
Cancer	0	0

Dementia	0	1
Heart and lung diseases	2	2
Learning disability	0	1
Long-term condition e.g. diabetes, arthritis	4	3
Mental Health	4	4

Experience of getting help and support

Table 8: When you first tried to access help, did the support you received meet your needs?

Condition	Yes	No	Somewhat
Autism	0	3	0
Cancer	0	0	0
Dementia	0	1	0
Heart and lung diseases	1	1	2
Learning disability	1	0	0
Long-term condition e.g. diabetes, arthritis	0	5	2
Mental Health	0	6	2

Autism:

- *"In Cheshire West and Chester, if you are with West Cheshire CCG they don't commission post diagnosis support for Autistic Adults you are discharged from the service after diagnosis."*
- *"Too long waiting list for help. No diagnosis originally due to both Paediatrician and CAMHS involvement and then not collaborating effectively. Eventually diagnosis given 4 years later once my son was at crisis point and suffering extreme anxiety and expressing suicidal thoughts."*

Heart and lung diseases:

- *"I kept track of all my appointments and did my own research so that I knew what tests I might need. I discussed this intelligently with my Consultant and their various teams and was able to come to a mutual decision. I felt my opinions and worries were considered but had a minor concern - because I work in a hospital there was an element of them thinking that I knew more than I did: I had to remind them that there were distinct areas that I knew little or nothing about."*
- *"I was told by telephone that I had Pulmonary Fibrosis, and I would be referred to the respiratory clinic."*
- *"Two months later not had any help from my doctor and have not had a date from the clinic. I feel frightened and alone, surely this is not good enough."*
- *"I have AF, started in Rochdale, then I moved to Wales, then to Northwich, so my treatment has differed in places."*

- *"More availability of support and advice especially on weekend."*

Long-term condition e.g. diabetes, arthritis:

- *"I was diagnosed with fibromyalgia. The doctors were very understanding but I knew nothing about it and the doctors gave me very little information."*
- *"GP totally dismissed me having Lyme disease and still does. I have to access treatment privately."*
- *"Investigations and information provided by GP initially felt good."*
- *"Not a lot of help for osteo-arthritis, it is 'old age'."*
- *"Took too long."*

Mental Health:

- *"By the time I got up the courage to talk to my GP about why I had such prolonged mental health issues and my functioning had got to a level I could no longer cope with day to day life funding for mental health services had been cut that much that after my initial referral for talking therapy and my assessment I waited 16 months for my first IAPT appointment. I couldn't be referred to a psychiatrist in the NHS as I hadn't attempted suicide. If having to attempt suicide is the bar you set to enable someone to get proper help, then it's not difficult to see how you could improve services."*
- *"I experienced very poor access to services. I was told my symptoms were too severe for short term therapy so had to wait over two years for further assessment. IAPTS did not work."*
- *"Long waiting list for counselling, by the time appointment comes crisis over, counselling offered not very effective, was over the phone."*
- *"Alternative ways of managing anxiety, depression, menopause not offered on NHS, just medication or counselling - therapies such as exercise, meditation, massage, aromatherapy not available."*
- *"Quick response from mental health team."*
- *"The Five Year Forward View for Mental Health was very limited in the support for people with SMI. The Long Term Plan has identified opportunities to enhance support for people with SMI but on a local level 3 months on from the publication of the Long Term Plan very little engagement to seek the views of family members supporting a family member with disabilities, I wonder how parity of esteem will be established given that people with SMI life expectancy is 20 years less than general population, is this in line with the NHS Constitution?"*
- *"GP seemed unsure about first next steps for mental health concern."*

Table 9: How would you describe your overall experience of getting help?

Condition	Very Positive	Positive	Average	Negative	Very Negative	Don't know
Autism	0	0	0	0	3	0
Cancer	0	0	0	0	0	0
Dementia	0	0	0	0	1	0
Heart and lung diseases	1	2	0	0	1	0
Learning disability	0	1	0	0	0	0

Long-term condition e.g. diabetes, arthritis	0	2	2	0	1	2
Mental Health	0	1	2	2	3	0

Table 10: Do you have any other/additional conditions including long term conditions or disabilities?

Condition	Yes	No
Autism	2	1
Cancer	0	0
Dementia	0	1
Heart and lung diseases	2	2
Learning disability	1	0
Long-term condition e.g. diabetes, arthritis	2	3
Mental Health	3	5

Table 11: If so, how would you describe the experience of seeking support for more than one condition at a time?

Condition	It made getting support easier	No difference	It made getting support harder	I don't know	Not applicable
Autism	0	0	1		1
Cancer	0	0	0	0	0
Dementia	0	0	0	0	0
Heart and lung diseases	0	1	0	1	0
Learning disability	0	0	0	0	1
Long-term condition e.g. diabetes, arthritis	0	1	1	0	0
Mental Health	0	0	3	0	0

The health and care support received after initially seeking help

Table 12: How would you describe the time you had to wait to receive your initial assessment or diagnosis?

Condition	Very slow	Slow	Ok	Fast	Very fast	Don't know
Autism	3	0	0	0	0	0
Cancer	0	0	0	0	0	0
Dementia	0	0	1	0	0	0
Heart and lung diseases	1	0	2	1	0	0
Learning disability	0	0	0	1	0	0
Long-term condition e.g. diabetes, arthritis	2	1	2	0	0	0
Mental health	3	3	2	0	0	0

Autism:

- *"Waited 15 months for an Autism assessment as the CCG has a numbers cap for Adult Autism Assessments."*
- *"Nobody listens and there is too much repeating of information to different services. It was a constant fight to get my son the support he needed, unfortunately not everybody in society is capable of doing that, meaning they are left in a terrible situation."*

Heart and lung diseases:

- *"I had to wait a while to get my referral to Liverpool Heart and Chest because it was intra-Trusts. I also had to have a lot of tests repeated because the Heart and Chest Hospital could not access them electronically - this, I felt, was largely a waste of money. There should be a way for this sort of process of ensuring that the patient's full information is transferrable between Trusts in a timely manner like Radiology departments can do with X-Rays through PACS."*
- *"I waited 2 months"*
- *"Initially I had to wait 3 months. I paid for a private consultation to get diagnosed in the end."*
- *"My first call to the doctor was positive, they have knowledge of me and want to help."*

Long-term condition e.g. diabetes, arthritis

- *"I was off work for 5 months whilst I was diagnosed with neurocardiogenic syncope. I was threatened with dismissal due to the time it took to eventually diagnose it. I was becoming more and more depressed and came close to a nervous breakdown."*
- *"I had to access help privately as my GP wouldn't help"*
- *"Within a week following blood tests."*
- *"Thumbs - trapezieoctomy. Both fast."*
- *"Shoulder problem - don't recognise weight as an eating disorder/addiction (sugar)."*
- *"12 months from Dr to specialist."*

Mental Health:

- *"I waited 6 weeks to receive my initial assessment where I was diagnosed with CPTSD, depression, severe anxiety - I needed intensive step 4 treatment. This would take at least 4 months, I was told. That felt like too long, I couldn't eat, sleep, I was constantly dizzy, crying and shaking. I had no professional support, only support from family."*
- *"The wait to actually receive treatment was 16 months, an absolutely disgusting length of time to leave someone in severe mental distress."*
- *"Over two years after referral I was still awaiting more thorough assessment. When it came it was hurried and seemed like the assessor was jumping to conclusions. I did not get reasonable adjustments from the person treating me and had to complain formally to get anywhere with them. It seemed I was pigeon-holed into what the therapist was wanting to do rather than being assessed. A further seven months after complaint I was assessed yet again but they didn't even use the full range of IAPTS questionnaires. This doesn't give me confidence in any of the primary or secondary care services nor the professionals I met. A number of professionals gave contradictory views and once I complained I got less help and was passed around with no real assessment. I have had mental health problems for 40 years and as this referral has not found any, it seems hopeless."*
- *"Literally years with GPs suggesting one thing, giving meds, temporary relief for the back again. GPs are not psychiatrists nor do they have the time to try and listen. every person should be able to have rapid psychiatric assessment to support mental health, you literally have to have attempted suicide to see a psychiatrist and even then, you will wait and get referred back to your GP."*
- *"I waited 6 weeks"*
- *"It took several years to get proper treatment."*
- *"Took time for referral letter to go and then for CWP to get in touch."*

Table 13: How would you describe the time you had to wait between your initial assessment/diagnosis and receiving treatment?

Condition	Very slow	Slow	OK	Fast	Very fast	Don't know
Autism	2	0	1	0	0	0
Cancer	0	0	0	0	0	0
Dementia	0	0	1	0	0	0
Heart and lung diseases	1	1	1	1	0	0
Learning disability	0	0	0	0	0	1
Long-term condition e.g. diabetes, arthritis	1	2	0	1	1	0
Mental health	4	1	2	1	0	0

Table 14: After being diagnosed or assessed, were you offered access to further health and care support?

Condition	Yes	No
Autism	1	2
Cancer	0	0
Dementia	0	1
Heart and lung diseases	2	2
Learning disability	1	0
Long-term condition e.g. diabetes, arthritis	1	3
Mental health	3	5

Autism:

- *"Cygnet sessions for parents and therapy sessions for son at CAMHS to assist with anxiety."*

Heart and lung diseases:

- *"I had to go for specialist allergy tests as I have a fish allergy and they have to give you a fish-based product after you have been on bypass. This was arranged very quickly and my Consultant at the Heart and Chest hospital was checking regularly for the results even when she was not in her Trust."*
- *"The treatment went well."*

Learning Disability

- *"More clear explanations, more focused people."*

Long-term condition e.g. diabetes, arthritis

- *"Operation - removed bone - pain relief."*

Mental Health:

- *"Mind (organisation) has helped me a lot."*
- *"Third sector support, but the CCG has cut grant funding by 20% locally in recent years."*
- *"Individual support."*

What could be improved?

Autism:

- *"Everything is treated in isolation by different areas when in fact each area of concern impacted upon another, therefore treating all symptoms and conditions together would have been more successful and cost effective to the NHS."*

Heart and lung diseases:

- *"Pace of appointment making, you seem to be left in a void."*

Learning Disability:

- *"More clear explanations, more focused people."*

Mental Health:

- *"Crisis care, inpatient environment and setting and safety on wards. More senior staff with more experience."*

Table 15: Were you referred to a specialist? For example, a hospital consultant, psychiatrist or physiotherapist

Condition	Yes	No
Autism	2	1
Cancer	0	0
Dementia	0	1
Heart and lung diseases	4	0
Learning disability	1	0
Long-term condition e.g. diabetes, arthritis	3	2
Mental health	4	3

Table 16: How would you describe the time you had to wait between the initial appointment and seeing the specialist?

Condition	Very slow	Slow	OK	Fast	Very fast	Don't know
Autism	1	1	0	0	0	0
Cancer	0	0	0	0	0	0
Dementia	0	0	0	0	0	0
Heart and lung diseases	1	0	1	2	0	0
Learning disability	0	0	1	0	0	0
Long-term condition e.g. diabetes, arthritis	0	2	0	1	0	0
Mental health	1	1	1	1	0	0

Autism:

- *"I waited 15 months."*
- *"I think it was approximately nine months to one year that I waited."*

Heart and lung diseases:

- *"No more than six weeks."*

- *"I have waited 2 months for an appointment and I am still waiting."*
- *"Once I had my diagnosis it has been quite quick - my GP has helped with this."*
- *"About 3-4 months."*

Learning Disability:

- *"Not very long."*

Long-term condition e.g. diabetes, arthritis:

- *"From referral to operation - couple of months – quick."*

Mental Health:

- *"I waited a couple of days."*
- *"Consultant psychiatrist of 11 years has just been moved to another area of the Trust because of Trust shortages in Neston and Ellesmere Port. Approximately 600 people now without a consultant."*
- *"Because of poor mental health the wait made anxiety worse."*

Table 17: If you needed it, how easy did you find it to access ongoing support after you were diagnosed or assessed?

Condition	Very easy	Easy	OK	Difficult	Very difficult	Don't know	Not applicable
Autism	0	0	0	0	2	0	1
Cancer	0	0	0	0	0	0	0
Dementia	0	0	0	0	1	0	0
Heart and lung diseases	0	0	1	0	1	1	1
Learning disability	1	0	0	0	0	0	0
Long-term condition e.g. diabetes, arthritis	1	1	2	0	1	0	0
Mental health	1	0	2	1	4	0	0

Table 18: Did the support option you were offered meet your expectations?

Condition	Yes	No	Somewhat
Autism	0	3	0
Cancer	0	0	0
Dementia	0	1	0
Heart and lung diseases	1	1	0
Learning disability	0	0	0
Long-term condition e.g. diabetes, arthritis	1	1	3

Mental health	1	5	2

Autism:

- *"No support offered as none commissioned for adults with Autism."*
- *"Services wanted to get rid of the problem by placing my son in a residential setting rather than keeping him with his family, due to his behaviours. Please be aware services had no concerns with our family setting or treatment of our son but yet we still had to fight to keep him at home. Cost was constantly mentioned."*

Heart and lung diseases:

- *"I have had no care. I was told I had been referred to a chest clinic and I am still waiting for an appointment."*

Learning Disability:

- *"The care did meet my needs. But more communication [would improve it]."*

Long-term condition e.g. diabetes, arthritis:

- *"I received no care from my GP."*
- *"Blood tests and treatment for my autoimmune condition is very limited by the NHS."*
- *"Hand therapy - easy to access, on-going if I thought I needed."*

Mental Health:

- *"I asked to see a psychiatrist and was told 'no' by the GP."*
- *"I was just given different anti-depressants which didn't help. Complained numerous times to the GP about the wait and was just told it's because the lists are so long."*
- *"Delays and dismissive attitudes. Superior attitudes and hostility from other practitioners. One crisis team member said I wasn't experiencing flashbacks when I mentioned them, she told me I had bad memories but didn't actually explore my experiences. Two years later I was told yes they were flashbacks and I had PTSD ...this, from the same mental health department."*
- *"Poor quality counselling without ever having a diagnosis of why my mental health is poor."*
- *"Quicker response and out of hours helpline, i.e. until 10pm not office hours."*
- *"The CQC's concerns on safety within mental health units is warranted."*
- *"Poor returning of phone calls when help requested."*

Table 19: 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?

Condition	Yes	No	Somewhat
Autism	0	3	0
Cancer	0	0	0
Dementia	0	1	0
Heart and lung diseases	0	1	2

Learning disability	1	0	0
Long-term condition e.g. diabetes, arthritis	2	3	0
Mental health	1	5	2

Autism

- *"No contact as no support commissioned."*
- *"Information wasn't passed between services therefore there was a lot of repetition and constant explaining to be done by the family."*

Heart and Lung Diseases

- *"I have had no care from the doctor or a Hospital appointment."*
- *"Appointments can be given out and cancelled in the same day and the professionals can disagree."*
- *"Sometimes a call or message expected didn't arrive on time."*

Learning Disability

- *"The care did meet my needs, but better social communication would be helpful."*

Long-term condition e.g. diabetes, arthritis

- *"Having further bloods tests and variety of treatments for under active thyroid. Instead of only one option."*
- *"Steps from referral to operation to after-care met all expectations fully."*

Mental Health

- *"I was not told by anyone that I could be assessed for ADHD by Gateway. Any information I found I sourced myself. I had to pay to see a private psychiatrist. I'm now receiving psychotherapy, which is good, the therapist is good and it's helping but I have a lot of issues and I have the constant threat of it being taken away due to funding cuts."*
- *"Unless I was in crisis, I had no access to help or support. Crisis team said they couldn't find a role for them, so I was left with severe symptoms for two years. I have no confidence in the IAPT services to actually assess patient need. After I formally raised matters once I was back with psychology professionals... their qualifications were always something they were vague about when I asked... I felt I was being directed to other areas because I complained. I use the term professional loosely...I found this conduct unprofessional and it amounted to hostility."*
- *"I would like a proper evaluation and a care plan that is holistic, not just medication."*

Time spent travelling to access support and care

Table 20: What is your main means of transport?

Condition	Own car	Another person's car	Bus	Train	Bicycle	Taxi	Other
Autism	1	0	1	0	0	0	1
Cancer	0	0	0	0	0	0	0
Dementia	0	0	1	0	0	0	0
Heart and lung diseases	3	1	0	0	0	0	0
Learning disability	0	1	0	0	0	0	0
Long-term condition e.g. diabetes, arthritis	3	2	0	0	0	0	0
Mental health	6	0	2	0	0	0	0

Table 21: How much time would you be willing to travel for to receive a quick and accurate diagnosis?

Condition	Less than 30 minutes	30 minutes to 1 hour	1 - 2 hours	Over 2 hours
Autism	0	1	0	2
Cancer	0	0	0	0
Dementia	1	0	0	0
Heart and lung diseases	1	1	2	0
Learning disability	0	0	1	0
Long-term condition e.g. diabetes, arthritis	0	2	2	1
Mental health	2	3	3	0

Table 22: How much time would you be willing to travel for to receive specialist treatment or support?

Condition	Less than 30 minutes	30 minutes to 1 hour	1-2 hours	More than 2 hours
Autism	0	0	1	2
Cancer	0	0	0	0
Dementia	1	0	0	0

Heart and lung diseases	0	1	3	0
Learning disability	0	0	1	0
Long-term condition e.g. diabetes, arthritis	0	1	1	2
Mental health	3	3	2	0

Your expectations at each stage of your care

Table 23: What is most important to you when first seeking help?

Condition	Seeing a health professional you normally see but you may have to wait	Seeing any medically appropriate health professional who is free immediately	Don't mind
Autism	0	1	1
Cancer	0	0	0
Dementia	0	0	0
Heart and lung diseases	0	4	0
Learning disability	1	0	0
Long-term condition e.g. diabetes, arthritis	3	1	0
Mental health	3	5	0

Table 24: What is most important to you when you first received a diagnosis and explanation of treatment or support options?

Condition	Seeing a health professional you normally see but you may have to wait	Seeing any medically appropriate health professional who is free immediately	Don't mind
Autism	0	1	1
Cancer	0	0	0
Dementia	0	0	0
Heart and lung diseases	0	4	0
Learning disability	1	0	0
Long-term condition e.g. diabetes, arthritis	3	1	0
Mental health	3	5	0

Table 25: What is most important to you during your initial treatment or support?

Condition	Seeing a health professional you normally see but you may have to wait	Seeing any medically appropriate health professional who is free immediately	Don't mind
Autism	0	1	1
Cancer	0	0	0
Dementia	0	0	0
Heart and lung diseases	0	4	0
Learning disability	1	0	0
Long-term condition e.g. diabetes, arthritis	2	2	0
Mental health	2	5	0

Table 26: What is most important to you during your long term support?

Condition	Seeing a health professional you normally see but you may have to wait	Seeing any medically appropriate health professional who is free immediately	Don't mind
Autism	1	0	1
Cancer	0	0	0
Dementia	1	0	0
Heart and lung diseases	1	3	0
Learning disability	1	0	0
Long-term condition e.g. diabetes, arthritis	1	2	1
Mental health	5	3	0

Supporting you to have more control over your own care

Table 27: What level of support do you want the NHS to provide to help you stay healthy?

Condition	A lot of support	Some support	I don't need support	Don't know
Autism	1	2	0	0
Cancer	0	0	0	0
Dementia	1	0	0	0

Heart and lung diseases	1	3	0	0
Learning disability	1	0	0	0
Long-term condition e.g. diabetes, arthritis	1	3	1	0
Mental health	4	3	0	1

Autism

- *"At 72 with a diagnosis of Autism at 70, help with my mental health."*
- *"Be there when a problem has been identified and don't wait until it reaches crisis point."*

Heart and Lung Diseases

- *"To explain if there is any treatment for pulmonary fibrosis and how can I manage my everyday life living with it."*
- *"Make sure the basics - easy access to GP and following on hospital appointments."*

Learning Disability

- *"Set up more healthy eating courses."*

Long-term condition e.g. diabetes, arthritis

- *"More varied blood tests and not just the limited TSH, also another option for other medications if needed."*
- *"Recognise that long term morbid obesity is a disorder/addiction - not a lazy feckless lifestyle."*
- *"Speed up."*

Mental Health

- *"Be honest from the beginning about what options are and talk through those options. If I'm seeing a different GP at least read through my last few visits so they have an idea of why I'm there."*
- *"Not rush me or make me feel like I'm wasting their time."*
- *"Give me the money I would be allowed in NHS talking therapy to see someone privately."*
- *"Let me get a quick, accurate diagnosis and stop fobbing me off with 'you don't need labels' to avoid giving me extra support."*
- *"A thorough reform of professional standards. Better access through reasonable adjustments training to ensure that patients who complain are assured of fully professional conduct and treatment. In all honesty, I would say the culture among a majority of 'health professionals' in mental health is poor and there needs be a thorough grass roots change. Mere training won't be enough if the poor attitudes are ingrained."*
- *"I was laughed at, demeaned and subjected to hostility and left hanging for months when I complained. I think the whole service here needs replacing"*
- *"Discounted Brio leisure fitness & alternative therapy i.e. Reiki or Reflexology."*
- *"More staff are urgently needed in adult mental health, as current staffing levels place too much strain on both professionals and service users. Lack of staff is a definite barrier to both accessing care/treatments and continuity of care."*
- *"More investment in the third sector and personal health budgets."*

Further comments

Long-term condition e.g. diabetes, arthritis

- *"More support groups, 1-2-1's, counselling and medical intervention for obesity."*

Mental Health

- *"Access support for my mental health. I can never see the same GP twice in a row. I can't get any continuity of care from the GP. The IAPT stepped care is a joke. I was made to wait 16 months for the most intensive treatment step 4, I was never offered any help in the meantime. I asked numerous times for help, I had to keep returning letters to say I wanted to stay on the list, if I didn't reply I was informed I would be removed immediately. No leeway or excuses. You can't treat mentally ill people like that even if you do need the lists to be brought down."*
- *"Parity of esteem is a nice to have but not a reality."*

In focus: what is important to the parents and carers of families with autism about health and care services?

As part of our research activity, Healthwatch Cheshire West conducted a focus group with parents and carers of children with autism to gain insight into their experiences of accessing health and social care services. The focus group was hosted by ChAPS (Cheshire Autism Practical Support) and was held at the New Creation Centre in Ellesmere Port on the 2nd May 2019. 10 people were in attendance.

Experiences of Health Care services

We asked the group to think about their experiences of health care services in terms of positive and negative experiences as well as any other neutral comments. The group talked about a number of different health services that they have accessed including GPs, hospitals and dental services. A number of GPs were cited as providing a positive experience with excellent paediatric support and good listening skills when engaging with the parent and child; making adjustments to make sure that the child is heard. Both Boughton Clinic and Neston Surgery were mentioned as providing positive experiences; well listened to and quickly referred.

A number of different departments at the Countess of Chester Hospital were also mentioned as providing good support and communication. Awareness of autism was good in the Children's Ward; at the Ophthalmology Clinic a quiet room was provided and the staff were very helpful in making them feel comfortable. The Paediatric team were quick and thorough with their diagnosis.

However, in reference to negative experiences the group were more focused on much broader issues, such as length of time waiting for a diagnosis, training issues and a lack of service provision. A number of the group felt frustrated with how long they were having to wait to get a formal diagnosis. In terms of the service provided by CAMHS two of the group mentioned that they felt communication and understanding was lacking. One parent said;

"I was referred to CAMHS when my daughter was six. They told me she was ok and that there was nothing wrong and that I should go to a parent group instead." Her daughter later received an autism diagnosis.

Again, in reference to misdiagnosis, but in relation to when her child received the 2-year check by her Health Visitor a parent commented that;

"*At the 2-year check at clinic we were accused of being bad parents and having the wrong toys for our child* [to help them develop]*, instead of investigating why he couldn't build blocks".*

The group also discussed the importance of training and how a better understanding of autism across services would have been helpful. The group talked about more training and support for them as parents, particularly around speech and language – one parent talked about being made to feel like it was their fault that their child couldn't talk properly. Another mentioned their experience with a dental service;

"The dentist didn't understand that you can't get him to brush his teeth and that he can't eat full meals. Needs more training."

What's different about accessing services when you have autism?

We then asked the group to reflect on how it is different accessing health services when you have a child with autism. One of the key issues that arose during the discussion related to communication, in terms of how the practitioner communicates but also how difficult it is for the child to communicate their needs. One parent stated;

"Practitioners don't necessarily ask enough questions about your personal conditions/ requirements before commencing treatment" and that for the patient *"the ability to explain pain/illness is difficult."*

The group felt there was a lack of tactfulness in communicating by some practitioners. NHS 111 was mentioned by two of the group who felt that they were *"reading from a script"*, both mentioned that NHS 111 had sent out an ambulance when it was not required as they were not listening to them properly.

In terms of GP surgeries there was a general discussion around who they communicate with at the GP surgery when trying to get an appointment (i.e. receptionist or triage nurse) and whether they have a good understanding of autism. One parent stated;

"When ringing the doctors, it's trying to get past the receptionist. They don't understand why you are ringing if you say your child is not great."

"My child has anxiety and OCD, but it is impossible to get past the nurse on the phone."

When accessing services, it is felt that there is a blanket approach adopted, which doesn't necessarily take into account specific conditions such as autism. One parent talked about their experience at the Countess of Chester Hospital when her child was due to have a tooth extraction. Better training would have made this more straightforward, particularly if there had been a better plan on how to support the child through this procedure.

What matters to you?

We asked the group to think about what matters the most to them in terms of support for accessing services. A number of themes arose throughout this discussion primarily relating to diagnosis, funding, support and training.

A number of the group talked about the length of time it takes to get a **diagnosis** as it was felt that early treatment would give their child the best start in life and would also help their child to get more support in the school setting.

In terms of **funding**, there was a frustration with the lack of funding for mental health services but also a lack of funding to provide community support. It was felt that there was little funded support provided (and if it was provided it did not take into account work commitments), and that support provision was reliant upon the voluntary sector. This led into a discussion about the location of **community support**, how it was lacking in rural areas and was not flexible in terms of timing and locations. All of the group felt that there should be more support groups for parents and carers as following diagnosis they can feel quite isolated.

Training of all staff was also seen as very important to the group, ensuring that all settings were autism aware to enable a smoother use of the service.

How would you like to be involved in future service developments?

We asked the group to think about how they would like to be involved in any future service developments with particular reference to autism. The groups felt that it was important that there was a co-production approach, that they should be involved in the design and implementation of services, including trialling them and being consulted on location and timings of support services.

More generally, being informed as services progress and change, communication is key.

Who responded to the surveys

Below is a breakdown of the demographics of the people across Cheshire West who responded to one or both of our surveys.

Table 28: Gender

Of the 253 people who responded to the survey across Cheshire West, 250 responded to this question:

	Female	Male	Other	I'd prefer not to say
Cheshire West	175	73	0	2

Table 29: Age

Of all respondents to the survey, 249 provided age profile information. 142 respondents were aged 55+, whilst those under 24 accounted for 20 respondents:

	Under 18	18-24	25-34	35-44	45-54	55-64	65-74	75+
Cheshire West and Chester	3	17	23	27	37	64	50	28

Table 30: Do you consider yourself to have a disability?

Of the 252 people who answered this question, just over two-thirds (70%) stated they did not have a disability:

	Yes	No	I'd prefer not to say
Cheshire West and Chester	67	177	8

Table 31: Ethnicity

All respondents answered this question. Of these 233 classed themselves as White British:

	African	Arab	Asian British	Bangladeshi	Black British	Caribbean	Indian	Pakistani	White British	Any other white background	Any other mixed background	Other
Cheshire West and Chester	0	0	0	1	4	0	5	0	233	6	0	4

Table 32: Are you a carer?

246 people surveyed responded to this question:

	Yes	No
Cheshire West and Chester	44	202

Table 33: Do you have a long-term health condition?

Of the 244 people who responded to this question, around a third (83) said that yes, they had a long-term health condition, with a further 43 saying that they had one or more health condition:

	Yes, I have a long-term health condition	Yes, I have more than one long term health condition	No
Cheshire West and Chester	83	43	118

Table 34: Which of the following best describes you?

Of the 253 people who responded to the survey, 243 answered this question:

	Heterosexual	Gay or lesbian	Bisexual	Asexual	Pansexual	Other	I'd prefer not to say
Cheshire West and Chester	213	10	2	1	1	4	12

Table 35: Your religion

Across Cheshire West 252 people responded to this question:

	Buddhist	Christian	Hindu	Jewish	Muslim	Sikh	Other	No religion	I'd prefer not to say
Cheshire West and Chester	2	160	3	0	1	0	6	67	13

Next steps

Next steps for Healthwatch Cheshire West

Healthwatch Cheshire West will share this report with the people of Cheshire West and Chester, Cheshire West and Chester Council, the Health and Wellbeing Board, West Cheshire and Vale Royal Clinical Commissioning Groups, Cheshire West Integrated Care Partnership, Voluntary and Community sector partners and statutory stakeholders. This will ensure the views on what matters to the public help inform local planning, commissioning and delivery of health and care services in our communities.

The findings will help identify priority areas for Healthwatch Cheshire West to focus on, and themes for future engagement, research and Enter and View activity.

Below is a contribution from the Cheshire and Merseyside Health and Care Partnership about how the findings will influence their next steps in progressing the Long Term Plan:

Cheshire and Merseyside HCP next steps

The work to produce this report done by our local Healthwatch is the biggest of its kind ever undertaken in Cheshire and Merseyside, with nearly 3000 people providing their feedback. We are immensely grateful for the time and effort that has gone into this report by all concerned. We would like to thank Healthwatch Cheshire (East and West) for their work in coordinating the research and for compiling the report, and we would also like to thank all of the Healthwatch that conducted the research and engagement activity in each area, specifically:

- *Healthwatch Cheshire East*
- *Healthwatch Cheshire West*
- *Healthwatch Halton*
- *Healthwatch Knowsley*
- *Healthwatch Liverpool*
- *Healthwatch Sefton*
- *Healthwatch St Helens*
- *Healthwatch Warrington*
- *Healthwatch Wirral.*

What shines through is the passion that our local Healthwatch representatives, and those who participated in the workshops and survey, have for health and care in general and the NHS in particular. To be able to tap into this, and the ideas that people are brimming with, and the understandable concerns they still have, gives us an invaluable, comprehensive insight into how, together, we can continue to improve health and care in Cheshire and Merseyside over the next five years and beyond.

The wealth of information contained in the report will now enrich the development of the system-wide strategy. The report, and the work that lies behind it, is an integral piece of our plan for public engagement around our five-year strategy. The strategy will be an aggregation of our nine Place plans, and it is essential that those plans meet the needs and requirements of their local communities. That is why Healthwatch work in each Place has been so important because it gives each Place a proper sense of what the priorities of local people are. I'm delighted that many of our Places are already incorporating their tailored reports into their thinking of their own plans.

This report is so important, but it won't be the only engagement on our plans and strategies. Alongside the work of Healthwatch, we also intend partnering with VCS North West and be likely

to be partnering with a local media partner to reach their audiences in Cheshire and Merseyside. And in our Places, considerable work will be getting underway to ensure all local stakeholders are engaged. Finally, we want to ensure the health and care workforce are also provided with the opportunity to have their say.

We have now received the report and will require some time to digest its findings. For us though, there are two findings from the report which immediately stand out and which will need to be comprehensively addressed in the five-year strategy. The first is access – ensuring that local people can get the help they need much more quickly and easily than they can at present. The second is a service that is much more responsive to people's needs and the way they live their lives today.

Because of the importance we attach to engagement, and our ongoing relationship with Healthwatch, we intend repeating this engagement exercise in Place at least once before the launch of the strategy. This will allow us to explore these issues again but will also allow us to test whether the work we are identifying in our strategy that needs to happen to address these issues goes far enough.

Our intention is to produce drafts of Place plans in September, alongside the system strategy draft. It will be then that we can re-engage with communities to test our ideas and see whether there is more that needs to be done.

Neil Skitt
Head of Communications, Cheshire and Merseyside Health and Care Partnership

Appendix 1 - People's experiences of NHS support for specific conditions

This appendix discusses the experiences presented in the last section in more detail.

Autism

Assessment, diagnosis and treatment

Out of the three people with autism or caring for somebody with autism who responded to this survey, two of those were commenting on behalf of someone else and one person had been diagnosed in the past three year. All three felt their needs for support were not met, one quoting "*In Cheshire West and Chester if you are with West Cheshire CCG they don't commission post-diagnosis support for Autistic Adults, you are discharged from the service after diagnosis.*" Another said "*Too long a waiting list for help. No diagnosis originally due to both Paediatrician and CAMHS involvement and then not collaborating effectively. Eventually, a diagnosis was given four years later once my son was at crisis point and suffering extreme anxiety and expressing suicidal thoughts.*" It was said that "*[support] did meet my needs but [I would have liked] further details about what it might mean to have autism.*"

All three people described their overall experience of getting help as very negative. Two out of the three people have additional health conditions and/or disabilities; one said they thought seeking support was more difficult because of this. They all described the waiting time for an assessment and/or diagnosis as being very slow. One quoted; "*Waited 15 months for an Autism assessment as CCG has a number cap for Adult Autism Assessment.*" Whilst another said "*Nobody listens and too much repeating of information to different services. It was a constant fight to get my son the support he needed, unfortunately not everybody in society is capable of doing that meaning they are left in a terrible situation.*"

Two people said they are prepared to travel over two hours to receive a quick and accurate diagnosis, while the other person said 1-2 hours.

Two people would travel more than 2 hours to receive specialist treatment, whilst the other person would travel 1-2 hours.

When first seeking help, one person said seeing any medically appropriate health professional, who is free immediately is most important to them.

One person said they would rather see any medically appropriate health professional who is free immediately when being given their diagnosis and an explanation of treatment or support options.

During the initial treatment and or support one person would rather see any medically appropriate health professional who is free immediately.

The provision of ongoing care and support

Two people said the time scale between receiving treatment from their assessment/diagnosis was very slow and they were not offered further health and care support. The other person said the waiting time for treatment was satisfactory, and were offered Cygnet sessions for the parents and therapy sessions for the son at CAMHS to assist with anxiety. In relation to any improvement of the support received they quoted; "*Everything is treated in isolation by different areas when in fact each area of concern impacted upon another therefore treating all symptoms and conditions together would have been more successful and cost effective to the NHS.*"

Two out of the three people were referred to see a specialist, however the waiting time from referral to actually seeing the specialist was slow/very slow. One person said they waited 15 months whilst the other person waited nine months to a year. They both found assessing ongoing support very difficult once diagnosed. All three people said their support options did not meet their expectations, one quoting "*No support offered as not commissioned for adults with Autism.*" Another stated "*Services wanted to get rid of the problem by placing my son in a residential setting rather than keeping him with his family, due to his behaviours. Please be aware services had no concerns with our family setting or treatment of our son but yet we still had to fight to keep him at home. Cost was constantly mentioned.*"

During the long-term support, one person would prefer to see a health professional they normally see even though a wait could be possible.

Prevention and/or early intervention

Throughout the duration of care/services, all three people thought their experience in the support they received was not timely and the communication was not consistent. One person stated "*There is no contact because there is no support commissioned.*" Another said "*Information wasn't passed between services therefore there was a lot of repetition and constant explaining to be done by the family.*"

Two out of the three people who responded, said they would like some support from the NHS to help them stay healthy and the other person said they would like a lot of support.

When asked what could the NHS do to help you stay healthy or manage any condition you have, one person said "*At 72 with a diagnosis of Autism at 70 help with my mental health.*" Another said "*Be there when a problem has been identified and don't wait until it reaches crisis point.*"

Dementia

Assessment, diagnosis and treatment

Only one response was received in relation to dementia. This person felt their needs for support were not met and described their overall experience of getting help as very negative. The time waiting for their initial assessment and/or diagnosis was okay and so was the waiting time for treatment after diagnosis.

The provision of ongoing care and support

This person was not offered access to further health and care support after their diagnosis. They were not referred to a specialist and found it very difficult to access ongoing support after they were diagnosed/assessed. The support options did not meet their expectations.

Prevention and/or early intervention

During their whole experience of getting support they felt they did not receive consistent communication from all of the services they came into contact with and not in a timely manner.

This person would travel up to 30 minutes to receive a quick and accurate diagnosis and to receive specialist treatment. During their long-term support, they would prefer to see a health professional they normally see even though a wait could be possible. This person said they would like a lot of support from the NHS to help them stay healthy.

Heart and lung diseases

Assessment, diagnosis and treatment

Out of the four people who responded to the survey who had a heart and/or lung condition, two people were diagnosed with the condition within the last three years, whereas the other two have had the condition for over three years. One person found that they could access initial support in a timely manner, whilst two people found it somewhat slow and another did not receive support to fit their needs. One person recommended that there should be "*more availability of support and advice especially on weekends.*" Another said "*I felt my opinions and worries were considered but had a minor concern because I work in a hospital and there was an element of them thinking I knew more than I did*."

There was an overall positive consensus in regards to experiences of getting help and the respondents felt that there was no difference in seeking support for more than one condition at a time. A mixed view of the respondents described the timescale for the initial assessment as being 'okay', where one person said "*initially I had to wait three months. I paid for a private consultation to get diagnosed in the end*." Another said "*I had to wait a while to get my referral to Liverpool Heart and Chest because it was intra-Trusts. I also had to have a lot of tests repeated because the Heart and Chest Hospital could not access them electronically*." From the respondents there were mixed views for considering their waiting time acceptable.

The provision of ongoing care and support

Two of the four respondents were offered access to further health and care support, one quoted that "*I had to go for specialist allergy tests… This was arranged very quickly and my Consultant at the Heart and Chest hospital was checking regularly for the results even when she was not in her Trust*." When respondents were asked what could be improved if they accessed support, one said, "*pace of appointment making, you seem to be left in a void*."

All respondents were referred to a consultant or specialist, most were satisfied with their waiting time and one found it very slow, commenting that "*I have waited 2 months for an appointment and I am still waiting*." Whilst another said they waited "*three to four months*." Another said they were waiting "*no more than 6 weeks*." When asked how their expectations could be improved, one respondent said, "*I have had no care. I was told I had been referred to a chest clinic and I am still waiting for an appointment*." During the whole experience of getting support, the majority of the respondents stated that they somewhat receive timely and consistent communication; one stating that "*Appointments can be given out and cancelled in the same day and the professionals can disagree*." Whilst another respondent said they did not receive consistency throughout the duration of care and said "*I have had no care from the Doctor or Hospital appointment*."

Two people said they were prepared to travel 1-2 hours to receive a quick and accurate diagnosis, while another said they would be willing to travel less than 30 minutes and another 30 minutes to 1 hour. Three people said that they would be willing to travel 1-2 hours to receive specialist treatment or support, while another stated 30 minutes to 1 hour.

All four of the respondents said it was more important to them to see a medically appropriate health professional who is free immediately when first seeking help and when they received a diagnosis and explanation of treatment or support. During the long support, one person would prefer to see a health professional they normally see but may have to wait, while the other three respondents preferred seeing any medically appropriate health professional who is free immediately.

Prevention and/or early intervention

Three people who responded said they would like some support from the NHS to help them stay healthy, one would like a lot of support and another didn't need any support.

When asked what the NHS could do to help people stay healthy or manage conditions, one person responded that the NHS should "*explain if there is any treatment for pulmonary fibrosis and how can I manage my everyday life living with it.*" While another said that the NHS must "*make sure they have easy access to GP and following on hospital appointments.*"

Learning disability

Assessment, diagnosis and treatment

One person with a learning disability responded to the survey. The support they had met their needs when they first accessed help. Their overall experience was positive and they found that they could access initial support in a timely manner; stating that it took just 12 minutes to wait for support.

When asked what could be improved when accessing support; it was quoted that there could have been "*clearer explanations and more focused people.*" The respondent was referred to a specialist and the waiting time was specified as "*not very long*".

The provision of ongoing care and support

When asked how easy it was to access ongoing support after diagnosis or assessment, the person said it was very easy, but quoted that even though "*the care did meet my needs, more communication*" would have been beneficial.

During the whole process of getting support, the respondent said that they received timely and consistent communication from services and commented that "*the care did meet my needs with better social communication.*"

The respondent specified that they were prepared to travel 1-2 hours to receive quick and accurate diagnosis and also said they would be willing to travel 1-2 hours to receive specialist treatment or support.

The respondent said it was important seeing a health professional you normally see but may have to wait when first seeking help and when they received a diagnosis and explanation of treatment or support.

During long term support, the person would prefer to see a health professional they normally see but may have to wait.

Prevention and/or early intervention

The respondent said they would like a lot of support from the NHS to help them stay healthy.

When asked what the NHS could do to help people stay healthy or manage conditions, the respondent said that the NHS should "*set up healthy eating courses*".

Long-term conditions, i.e. diabetes and arthritis

Assessment, diagnosis and treatment

Seven people with long-term conditions responded to this subject area of the survey. The majority of people reported that the support they had received did not meet their needs (five) whilst two people said that the support 'somewhat' met their needs. Comments given in this area included that support "*took too long*" or was otherwise described as being insufficient, however, one person stated that the "*Investigations and information provided [by their GP] initially felt good*".

Two respondents reported that they felt the time they had to wait to receive their initial assessment or diagnosis treatment was 'very slow', one said it was 'slow' and two people said it was 'okay', one receiving a diagnosis "*within a week*". Two of the respondents elaborated on the result of a 'very slow' waiting time; one stating that they were "*becoming more and more depressed and came close to a nervous breakdown*", another saying "*[I] had to access help privately as my GP wouldn't help*".

Two people reported their overall experience of getting help to be 'positive', two average' and one person said it was 'very negative'.

The provision of ongoing care and support

The majority of people who responded (three of four) told us they were not offered any follow up health and care support, however, three out of five respondents were later referred to a specialist, although two told us the time that they waited for this appointment was too long.

For most respondents, the ease of accessing ongoing support after diagnosis/assessment was a positive experience (four out of five), with the support 'somewhat' meeting their expectations. However, one person reported access to be 'very difficult', expressing dissatisfaction with the limited support offered by their GP.

During the whole experience of getting support, three people reported that they did not receive timely and consistent communication from all of the services that they came into contact with, two people told us that they did.

In terms of transport, three people told us that they used their own car as a means to get to appointments, one person willing to travel up to two hours to receive a quick and accurate diagnosis and two others willing to travel 30 minutes to one hour. Two people reported that they used someone else's car and both would be willing to travel 1-2 hours, for this purpose.

When first seeking help and receiving a diagnosis and explanation of treatment and support options one person thought it was most important to see any medically appropriate health professional who is free immediately, whilst three other people would prefer to a see a health professional, they would normally see, accepting that they may have to wait. During initial treatment and support, there was an equal response to both options, whilst during long term support, two people would prefer to see any medically appropriate health professional who is free immediately, one would prefer to wait and see their normal GP, and one person did not mind either way.

Prevention and/or early intervention

When asked what they expected from the NHS to help them stay healthy, three people said that they expected some support, one person would expect a lot of support and one person said they did not know what level of support they wanted to receive.

Mental health

Assessment, diagnosis and treatment

Eight people responded to this subject area of the survey, of which, four had been diagnosed with mental health issues within the last three years. Three people told us that they had an additional health condition alongside a mental health concern, which made the experience of seeking help harder.

The majority of people reported that the support they had received did not meet their needs (six) whilst two people said that the support 'somewhat' met their needs. Comments given in this area included that support "*took too long*" or was otherwise described as being insufficient i.e. one GP "*seemed unsure about first next steps for Mental Health concern*". One person told us that a wait of 16 months "*prolonged*" their mental health issues stating "*my functioning got to a level [where] I could no longer cope with day to day life*". Another individual told us "*[there was a] long waiting list for counselling, by the time the appointment comes, crisis over*". However, one person stated that the "*Investigations and information provided [by their GP] initially felt good*".

Three respondents reported that they felt the time they had to wait to receive their initial assessment or diagnosis was 'very slow', three also said it was 'slow' and two people said it was 'okay', waiting times ranging from six weeks to two years. Two of the respondents elaborated on their 'very slow' waiting time; one stating that they felt that their assessments were becoming "*hurried*" and they were worried that they were being "*pigeon-holed*" into unsuitable services. Another person told us the waiting time worsened their condition, elaborating; "*[I] couldn't eat, sleep, I was constantly dizzy, crying and shaking*".

Post initial assessment/diagnosis, respondents told us that their waiting time for treatment was mixed. Four indicating that it was 'very slow', one 'slow', one 'fast' and two 'okay'.

The majority of people who responded told us that after being diagnosed or assessed, they were not offered access to further health and care support (5 out of 8). Two people elaborated that third sector support was helpful to their situation. Those that were referred to a specialist experienced mixed waiting times for this service. One individual's wait was very short at two days; one other person's wait was 'slow' however, telling us that this "*worsened my anxiety*".

The provision of ongoing care and support

Over half of respondents (5 out of 8) found it 'difficult' or 'very difficult' to access follow up health and care support, however, three respondents found this process to be 'very easy' or 'okay'. In most cases (5 out of 8) the support did not meet people's expectations one individual describing the service as "*dismissive*", a view supported by others who told us that they were denied access to a service when requested, or experiences such as having 'flashbacks' were dismissed. One person told us that the support did meet their expectations, two more telling us that it somewhat met their expectations.

During the whole experience of getting support, five people reported that they did not receive timely and consistent communication from all of the services that they came into contact with, one said they did and two respondents reported they 'somewhat' received timely and consistent communication. Respondents expressed concerns regarding the availability of information and services no longer being made aware of services which they had experienced in the past.

In terms of transport, most people told us that they used their own car as a means to get to appointments (6 out of 8), and were equally willing to travel the distances specified to them (up to 30 minutes, 30 minutes to 1-2 hours). Those individuals who used the bus were also willing to travel mixed distances (under 30 minutes and 1-2 hours, respectively). Most respondents were

willing to travel less than an hour for specialist treatment or support, with two willing to travel longer, at 1-2 hours distance.

When first seeking help, receiving a diagnosis and explanation of treatment and support options or during initial treatment and support, five people thought it was most important to see any medically appropriate health professional who is free immediately, whilst three other people would prefer to a see a health professional they would normally see, accepting that they may have to wait. During long term support the results were reversed – three people thought it was most important to see any medically appropriate health professional who is free immediately, whilst five other people would prefer to a see a health professional they would normally see, accepting that they may have to wait.

Prevention and/or early intervention

When asked what they expected from the NHS to help them stay healthy, half of respondents (4 out of 8 people) said that they expected a lot of support, whilst three people said they expected some support and one person did not know what level of support they wanted to receive.

In regard to what the NHS could do to help people stay healthy or manage their condition, people urged the need for better communication. For example:

- *"Be honest from the beginning about what options are and talk through those options. Give me the money I would be allowed in NHS talking therapy to see someone privately."*
- *"If I'm seeing a different GP, they could at least read through last few visits so they have an idea of why I'm there."*
- *"Not rush me or make me feel like I'm wasting their time."*
- *"Let me get a quick accurate diagnosis and stop fobbing me off with 'you don't need labels' to avoid giving me extra support."*
- *"The culture among a majority of 'health professionals' in mental health is poor and there needs be a thorough grass roots change."*
- *"I was laughed at, demeaned and subjected to hostility and left hanging for months when I complained. I think the whole service here needs replacing."*

In the future, people stated that they would like to see more support for families during mental health illnesses, more access to community-based services, and changes in the way health records are managed. For example:

- *"Greater support for family members during mental health problems, greater understanding from local GP. Face to face rather than telephone conversation when finally get through to a mental health professional."*
- *"Mental health services and elderly care to be funded on a national basis not on a county level so all receive the same."*
- *"There needs to be more support for people of all ages, counsellors etc. I am my Mother's carer; my husband has been recently diagnosed with cancer and I work in a school. Unfortunately, I see on an almost daily basis people struggling with mental health and it has shocked me by how many young people are really struggling. We all need easier access to professionals who will actually listen and help rather than just instruct."*

Notes

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