healthwatch

NHS Long Term Plan Report

Cheshire and Merseyside

Contents

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 and Merseyside 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.

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.

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

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.

People in Cheshire and Merseyside 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. Each local Healthwatch promoted the survey using their websites, social media, local press, 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 in each area. The format guidance from Healthwatch England enabled all local Healthwatch to structure their focus groups differently in order to suit their local area and participants, which provided a richness of information that would have been lacking with a one size fits all approach.

The table below lists the focus groups conducted by each local Healthwatch.

Healthwatch	Focus Groups
Healthwatch Cheshire East	• Students (p.68) • People with Autism (p.87)
Healthwatch Cheshire West	• Students (p.104) • People with Autism (p.122)
Healthwatch Halton	• 2x Cancer Support Groups (p.155)
Healthwatch Knowsley	• General Public (p.174) • Older People (p.179) • People with Mental Health Conditions (p.201) • People with Learning Disabilities (p.205) • Young People (p.214)
Healthwatch Liverpool	• Older People (p.235) • People with Long Term Conditions (p.253)
Healthwatch Sefton	• General Public (p.268)

	- Children and Young People Starting Well with representatives of local CCGs, local authorities, voluntary and faith groups (p.287)
Healthwatch St Helens	- General Public (p.306) - People with Mental Health Conditions (p.328)
Healthwatch Warrington	- Families of Seriously Ill Children (p.352) - People with Learning Disabilities (p.353)
Healthwatch Wirral	- Carers (p.385) - Deaf Community (p.386)

In Cheshire and Merseyside, we received 2487 survey responses, consisting of 1928 general surveys and 559 specific condition surveys. There were also 320 attendees across 21 specific focus group events. This meant that Healthwatch were able to capture 2807 pieces of information across Cheshire and Merseyside. A breakdown of the demographics of who replied to our surveys is included on page 45.

The results of both surveys are presented at a Cheshire and Merseyside level in Chapter 1. Results at a local authority level and summaries of focus group events are then provided in the following chapters for each of the nine local Healthwatch.

Chapter 1 - Cheshire and Merseyside

Summary of Findings:

What matters most to people in Cheshire and Merseyside?

- The most important factor for people to ensure they are leading a healthy life is to have access to the help and treatment needed when it is wanted. People also want professionals to listen to them.
- Other comments centred on access to healthy lifestyles, better local infrastructure, availability of more self-help information to support the prevention of illness and a more joined up approach to appointments and referrals with more community support.
- People want easy access to quality GP appointments at times to suit them.
- People told us that the ability to stay in their own home for as long as it is safe to do so was the most important factor to helping them stay independent and healthy as they get older.
- Comments also focused on the need for more information on the community support available, more home visits from professionals and carers, more funding for palliative care and the integration of health and social care services to provide better continuity of care. The need to feel financially secure and the impact of poor public transport links on loneliness and isolation were also emphasised.
- Respondents overwhelmingly stated that choosing the right treatment should be a joint decision between the individual and relevant healthcare professional.
- Other dominant themes covered funding, the benefits of continuity of staffing, good quality service information and timely communication.

Interacting with the NHS

- Regarding their interaction with the NHS, most respondents felt that being able to talk to their doctor or health professional wherever they are was most important.
- Other important factors were considered to be confidence regarding security of personal data, clear communication channels and good access to services including GP appointments.
- Comments regarding the use of technology were mixed emphasising that methods of information provision should be varied.

System-wide issues

- People across Cheshire and Merseyside commented on challenges facing them through their treatment journey and the impact that service change and transformation may have on this, including population increases. A number of people feel frustrated with the system but also reflect upon funding and ongoing issues facing the NHS.

Experiences of people with specific conditions

- Those with specific conditions on the whole found their experience of getting help in regard to their condition to be positive.
- People with Cancer were generally the most positive about their experience and waiting times to access assessment and treatment.
- People with Mental Health conditions tended to report poorer experiences and found waiting times for assessment and support to be very slow.
- Responses from those with heart and lung conditions or other long-term conditions such as diabetes or arthritis across Cheshire and Merseyside were often mixed with some people

finding their experience and waiting times to be good and others finding it to be inadequate.

- People with all of the conditions we asked about provided mixed responses about whether they would like to prioritise seeing a professional they had seen before even if it meant a longer wait, or seeing any professional appropriate if it meant they were seen quicker for each stage of their care journey.

Survey results

The following sections now break down the results of the 2487 responses across Cheshire and Merseyside to the surveys designed by Healthwatch England. The first sections use the 1928 responses to the general 'People's general experiences of health and care services' survey, before breaking down the 559 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.

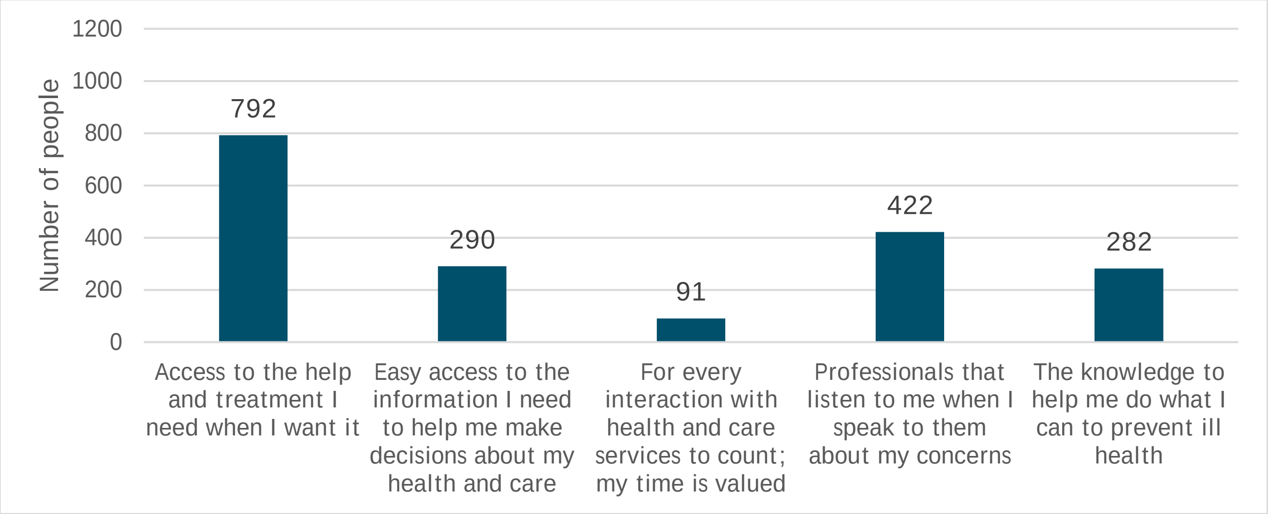
For each of these, people were asked to choose which of a number of options was most important to them. Following this, people were asked to rate each of the options on a scale of 'very important' to 'not important at all'. Therefore, more than one option could be considered 'very important'. Finally,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

What is important to people about health and care services?

Living a healthy life

We asked people to tell us about what is most important to ensure that they are leading a healthy life. When considering how to lead a healthy life access to the help and treatment needed when they wanted it was deemed as being the most important aspect by respondents (see Chart 1). 1877 people responded to this question.

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



When asked to rate this on a scale of very important to not important at all (see Table 1) access to help and treatment needed when they wanted it was still seen as being the most important aspect. However, professionals that listen to people when they speak about their concerns was also rated extremely high. 1874 people responded to this question, though not everyone responded to all options.

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
Access to the help and treatment I need when I want it	1533	317	18	4	2
Professionals that listen to me when I speak to them about my concerns	1516	323	27	2	2
Easy access to the information I need to help me make decisions about my health and care	1256	519	79	10	5

Having the knowledge to help me do what I can to prevent ill health	1211	556	89	10	4
For every interaction with health and care services to count; my time is valued	1200	535	91	16	5

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 common themes and key points from across Cheshire and Merseyside, and are summarised below using comments illustrative of others received:

Healthy lifestyles and prevention

A key theme that emerged from this question was the importance of healthy lifestyle intervention and prevention services:

- *"Easier access to support health walks, support groups, etc. especially in early evening or weekends, variety of times of day/week."*
- *"Regular health checks for adults that could detect problems at an early stage and be prevented from causing long term illness."*
- *"Information on lifestyle regarding diet and exercise. Then being able to consult with an expert for appropriate services both for currently healthy people and people with long term conditions."*
- *"Access to healthy cooking course, health walks, more outdoor activities."*
- *"Access to health provision e.g. cheaper offers for gymnasium, swimming to enable a proactive lifestyle."*
- *"An annual invitation for a general check-up. This would help to pick up any problem more quickly and efficiently."*

Access to services

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

- *"More routine outreach services in the community so that [there is no] need for long car journeys, finding someone to drive and limited but expensive parking at hospitals."*
- *"Acceptable wait times for GP and A&E services."*
- *"Easy access [to] the first line consultation then quick response from referral, at present I am waiting seven weeks for a physio referral which in the meantime means I am causing more problems to my health."*
- *"Local services that are accessible. I currently miss out on treatment for long standing health issues because I cannot get to the clinics, they are very far away and inaccessible. Better resourced services, more money for staff, sites and equipment needs to be allocated to both primary and secondary care as waiting times for both are appalling. I have been on waiting lists for several services that are essential for many months."*
- *"Joined up care pathways which prevent isolated GP/hospital/clinic visits."*

Person centred and self-help

Respondents also told us that information should be more readily accessible regarding any self-help and educational health information, which would contribute to a more person-centred approach to care:

- *"Somewhere to go for professional advice about health matters which may not be serious, but can be concerning to myself."*
- *"Joined-up treatments - being treated as a whole person, you are always treated as though you only have one thing wrong with you."*
- *"Better awareness of regulated support services available in the area, to avoid having to ask my GP for them first."*
- *"Health Education is vital through our life, from school to care home. Everybody should understand what is needed for our health and wellbeing, especially at a young age."*
- *"Giving ownership of health back to patient."*

Environment and infrastructure

Another key theme to emerge across Cheshire & Merseyside was the importance of infrastructure that supported a healthy lifestyle, and a cleaner environment:

- *"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."*
- *"The council putting more effort into making public open spaces safe and pleasant spaces to spend time in."*
- *"Affordable and easier transport to self-help activities."*
- *"More safer cycle routes."*
- *"Less takeaways and fast food outlets would help (less temptation)."*
- *"A healthier environment free from carcinogenic, as found in our water and food."*
- *"Less traffic, very concerned about rising air pollution."*

GP appointments

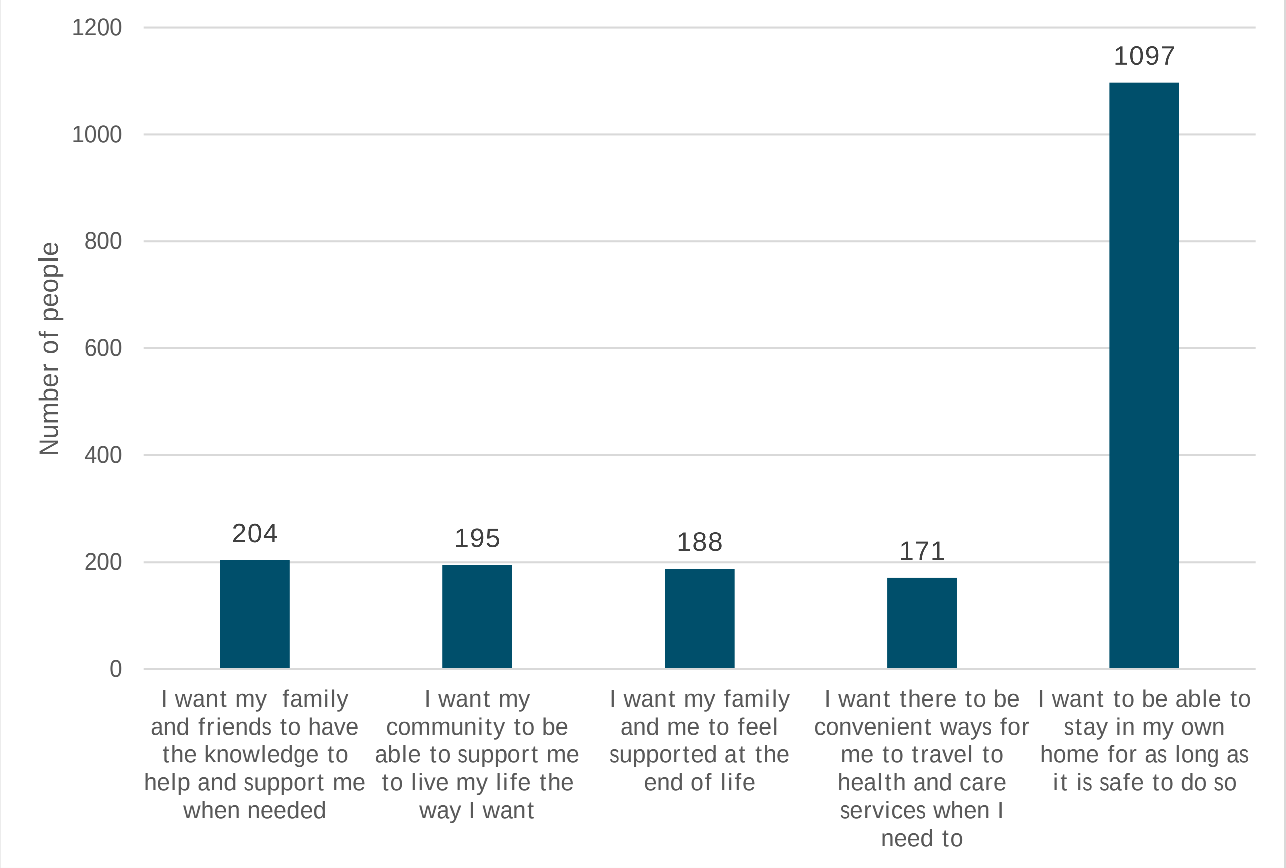
Across all surveys people talked not only about making GPs more accessible but also about the length of the appointment when visiting:

- *"Increase local doctor's appointments times from 10 minutes to 15 minutes or even longer."*
- *"More time to discuss problems by getting more staff to help people."*
- *"Being able to access GP appointments outside working hours, e.g. evenings and weekends."*
- *"Access to doctor's appointments when required. Consultant telephone appointments (similar to GPs). Cross-hospital communication."*
- *"The ability to have access to my GP or health practitioner in a reasonable time. The time spent trying to contact the surgery by telephone at 8am is often very long and having re-dial a necessity. Then to be told no appointments left and ring at 8am tomorrow is a frustration."*

Keeping independence and staying healthy in later life

We asked people to think about what is most important to them to ensure that they keep their independence and stay healthy in later life. Chart 2 shows that there is an overwhelming number of respondents who felt that the most important thing to helping them to stay independent and healthy as they get older is the ability to stay in their own home for as long as it is safe for them to do so. 1855 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?



We also asked people to rate how important these issues were from very important to not important at all. Being able to stay in their own home for as long as possible was still rated the highest amongst respondents, however all aspects were considered as very important or important by the majority (Table 2). 1864 people responded to this question, though 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	1529	264	52	12	7
I want my family and me to feel supported at the end of life	1425	354	47	12	9
I want there to be convenient ways for me to travel to health and care services when I need to	1300	462	81	15	3
I want my family and friends to have the knowledge, to help and support me when needed	1182	555	97	13	11
I want my community to be able to support me to live my life the way I want	1032	603	169	37	8

Staying independent

People felt that their independence could be maintained by support in their community, from services and individuals:

- *"I want to be able to stay in my own home for as long as it is safe to do so - most important as they get older. All others either important or very important too."*
- *"Staying fit, reduce costs at council gyms. Promote keeping fit and healthy eating."*
- *"Frailty is a really important consideration for the aging population and is the key factor for falls. Routine assessment and access to strength and balance series should be put into place."*
- *"My neighbours and community help to retain my independence."*

Home visits and support

An ability to stay at home and receive health and care services and general help was a common theme amongst respondents:

- *"Extra support at home, independent living skills for those that are less able."*
- *"Regular visits from a health professional, not only carers, when living in own home with support."*
- *"Being able to access help with household cleaning etc free or at a reasonable price within my means."*
- *"Better availability of things to allow independent living. Alterations to home etc."*
- *"To be confident in knowing that if I wished to stay at home, I would receive a constant and appropriate level of care."*

- *"We need more accessible housing and proper funding for social care if we want more people to live safely at home and be supported to die there with dignity when the time comes."*
- *"Stop making elderly residents move location to access their care at the end of their lives… we don't provide adequate home care so they move to residential care… then as they deteriorate, they have to be moved to a nursing home…. and if there is further deterioration they are moved again at the very end into hospice or hospital. What's wrong with escalating care up and down appropriately in a person's own home… it would be a lot cheaper and better for the people involved."*

Community services and information

More information provision was regularly mentioned as a key theme, including the importance of community services being offered and offered in different formats:

- *"Make sure information of available services, support, community resources are shared effectively."*
- *"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."*
- *"Contact with other people is important, sometimes you need to speak to people who aren't in your family or who aren't that close to you, this is tricky if you're housebound, how about 'mobile support groups' or organised 'E support groups' that 'meet' online at set times/webinars/WhatsApp support groups."*
- *"By providing people with information about non-commissioned services and focus on their own strengths and assets."*
- *"More care in the community tailored to individual needs."*
- *"Greater support in the community, longer GP opening hours."*

Links between health and care

The continuity of care and communication between health and care services was also considered to be an important factor:

- *"Joined-up care between health and social care and voluntary sector. Talking to each other."*
- *"The availability of non-profit making care homes is slim and the very worst of patients are given second rate provision. A complete state funded system needs to be instigated even if it means income tax is increased. This should be available regardless of income as it is grossly unfair that patients who have worked hard to provide for their children are penalised when it comes to healthcare in old age."*
- *"The specialists that we see all have such different knowledge and work that we accept that there will be travel to see experts and duplication in some areas. However, where appointments are linked to such areas as education, health and social care there is much to do to ensure we have less repetition as services are working better together, i.e. joined up administration single records and access for all of the agencies involved."*
- *"Services must work together to achieve better outcomes."*
- *"The interface between council care and the NHS needs to be smoother and not be a matter for the patient to sort out. In political terms, there shouldn't be a tussle between local government and the NHS over who pays for what. Perhaps it is time to fix individual patient budgets which can be allocated to hospital/GP/council, rather than setting overall budgets."*

Loneliness and isolation

Many people felt that as they got older, they felt more socially isolated. An ability to get out and about and socialise was seen as important to many:

- *"More community clubs for the elderly and not run by volunteers to go out and meet other people spend more money on supporting the elderly."*
- *"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."*
- *"To be able to get out more. Before I got my wheelchair, I was really depressed."*
- *"Stop ignoring people who need support. I have no family here and rely on the services to assist me. [Assistance] has not happened in my case and my physical and mental health as a 68-year-old man living alone is suffering because of it."*
- *"Access to exercise facilities. People such as Community Connectors to alleviate loneliness."*

Public Transport

Linking in to loneliness and isolation was the theme around public transport and how poor public transport impacts upon independence:

- *"[I would like that] Appropriate help is available to stay in my own home and travel around where I live. The bus services are not good and I know of non-drivers who are stranded."*
- *"I don't drive or have much money so cheaper public transport to and from NHS services - or make services more local."*
- *"Free community transport for older people."*

Palliative care

Palliative and End of Life Care were considered to be very important and some of the comments we received reflected a desire for more funding to enable more nursing hours:

- *"My recent experience of having a terminally ill husband at home with 'end of life' palliative care which amounted to one 20-minute visit by a district nurse each week was not impressive."*
- *"To be well informed and have documents in place that make the medical profession aware of views. My father had an end of life advance directive and these should be in place for all people not just at end of life as family can then support the wishes of the individual in case of medical emergencies."*
- *"Be able to choose when and where to die when I'm older."*

Financial issues

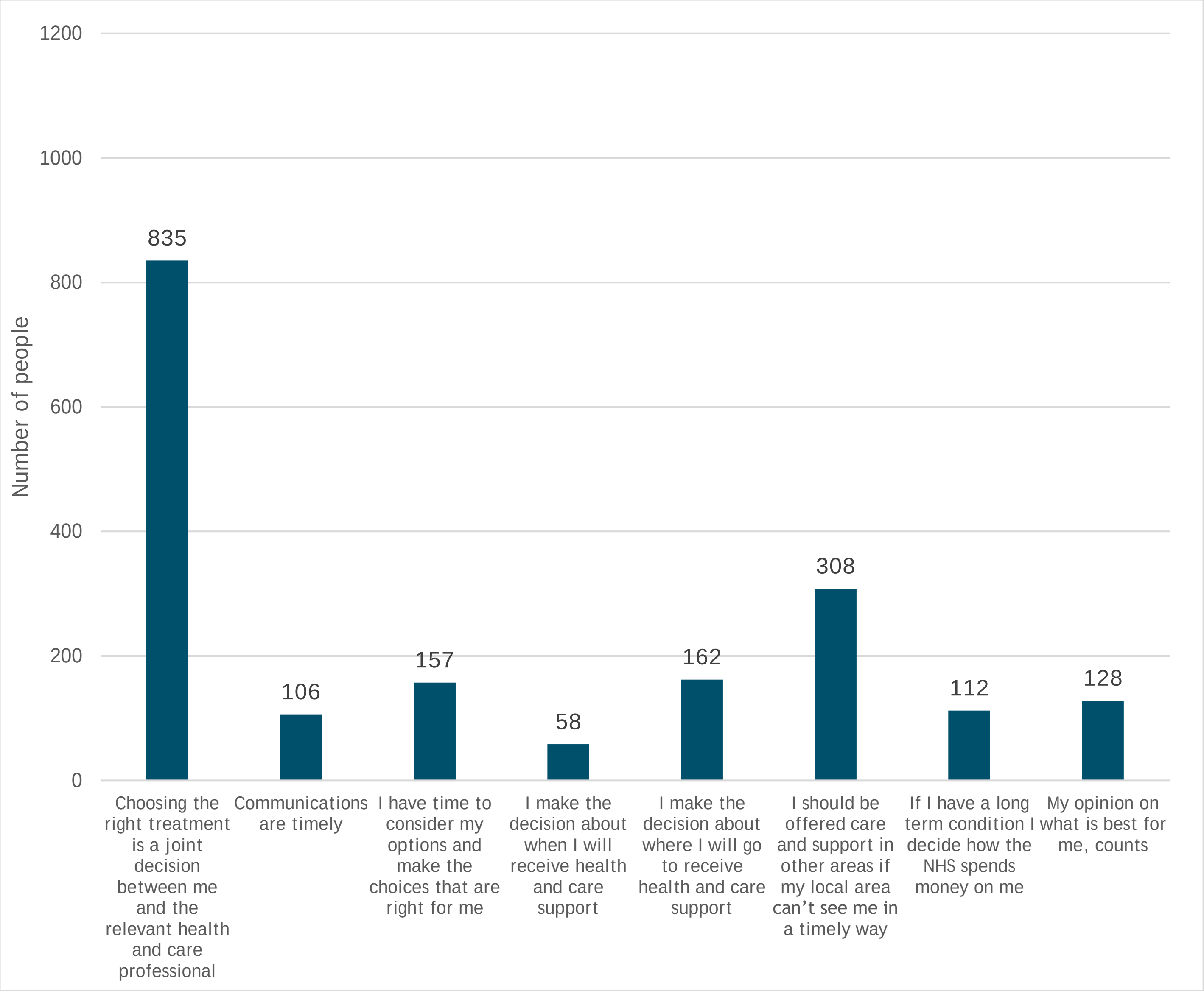
A number of respondents felt that more financial security was the most important element when it came to leading a long and healthy life.

- *"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?"*
- *"Financially viable and comprehensive home support with living."*
- *"Stop the cuts to social care. They are currently so underfunded as a consequence of government austerity that they can no longer meet statutory duties. Combined with cuts across all public services, transport, etc. vulnerable people are being left behind and the harm suffered is directly proportional to how many public services are relied upon."*

Managing and choosing support and treatment

We asked people what was important to them when managing and choosing support and treatment. Chart 3 shows that overwhelmingly respondents stated that choosing the right treatment should be a joint decision between them and the relevant health and care professional. 1866 people responded to this question.

Chart 3: What's most important to you in managing and choosing support and treatment?



We also asked people to rate how important these issues were from very important to not important at all. Making a joint decision regarding the right treatment with the relevant health and care professional was still rated the highest amongst respondents, however all aspects were considered as very important or important by the majority (Table 3). 1887 people responded to this question, though not everyone responded to all options.

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

	Very Important	Important	Neutral	Not Important	Not Important At All
Choosing the right treatment is a joint decision between me and the relevant health and care professional	1223	565	87	7	5
Communications are timely	1181	559	101	6	3
I have time to consider my options and make the choices that are right for me	1022	700	109	6	3
I should be offered care and support in other areas if my local area can't see me in a timely way	949	731	145	35	6
My opinion on what is best for me, counts	940	702	191	20	5
I make the decision about where I will go to receive health and care support	909	699	213	36	10
I make the decision about when I will receive health and care support	806	737	269	40	8
If I have a long term condition, I decide how the NHS spends money on me	657	685	408	58	22

We then gave respondents an opportunity to tell us more about managing and choosing support in treatment using a free text question. For ease this has been summarised into themes below:

Funding for local services

A number of respondents commented on funding issues for services and the impact that lack of funding has on the availability of services, and what they think is needed to improve this:

- *"Acceptable wait times for GP and A&E services."*
- *"Sharing of budgets between the NHS and local authorities for care at home or in respite or in hospital when recovering from an operation or illness should make better use of resources. The Government has reduced local authority grants more than those of the NHS. Poorer councils cannot raise enough from Council Tax to adequately fund social care."*
- *"In thyroid illness people are just being left to rot, very ill. The basics need to be done right. Adequately staffed, financed and respected psychological services."*
- *"Services that don't rely on postcode - e.g. good services such as Visyon (young people's mental health support) offered in Cheshire East but not in Cheshire West."*

- *"Accountability by those who hold the budgets - too much power by the CCGs and LMC- The balance of power needs to return to the patient and be less about the GP budget."*
- *"[Would like] more investment in front line services. Happy to see things like fertility being private only."*

Communication

Another emerging theme concerned communication, in terms of how communication can be improved, and in knowing who to communicate with and how this happens:

- *"Communication is the key between me and the health care professional and I feel they do not tell you about options for treatment itself or the place it can take place."*
- *"Carers need to be fully included and considered in all discussions, decisions and actions associated with NHS support."*
- *"It is essential that all health professionals involved in my care communicate with each other and with me so in a timely manner to enable a holistic approach to my care."*
- *"Understanding how health is structured so I know who to contact. Too many changes and when living on a border with two local authorities, nightmare, as often referred to wrong provider."*
- *"Better communication - more timely correspondence, linked up with primary and secondary services. Make use of holistic therapies for example acupuncture and pain management - much more cost effective than medication."*
- *"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."*
- *"[Would like] continuity of any health professionals seen and any info to be shared in simple language as patients don't always think about any questions they may have until later."*

Information and Advice

Many respondents stated that they needed quality information and guidance to enable them to make choices. Knowledge of the available services and their locations was also a key theme. Comments included:

- *"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."*
- *"Ongoing support, when you are first diagnosed, sometimes you are just given the diagnosis and left to find your own way through."*
- *"Clear point of access from which we can be signposted/navigate the system so that we aren't lost in the system... the NHS app has great potential to be this for the majority of people. Those unable to use the app should be able to access someone who can use the app for them."*
- *"I would like if someone would explain test results to me and where to go from there. I don't think they should only call if there is a problem with the results. Should discuss them with you."*
- *"Individuals do not always know what is best and I think NHS professionals should advise and offer guidance as required."*
- *"I think GPs should always say to their patients 'If your symptoms don't settle within a few days come back and see me.'" This does not always happen. Also, if*

investigations/blood tests, etc. are ordered there should be a structured way of patients obtaining their results in a timely manner."

Staff

There were a number of mixed comments relating to staffing. Whilst there was an understanding of staff pressures, there were also comments about how this could be improved:

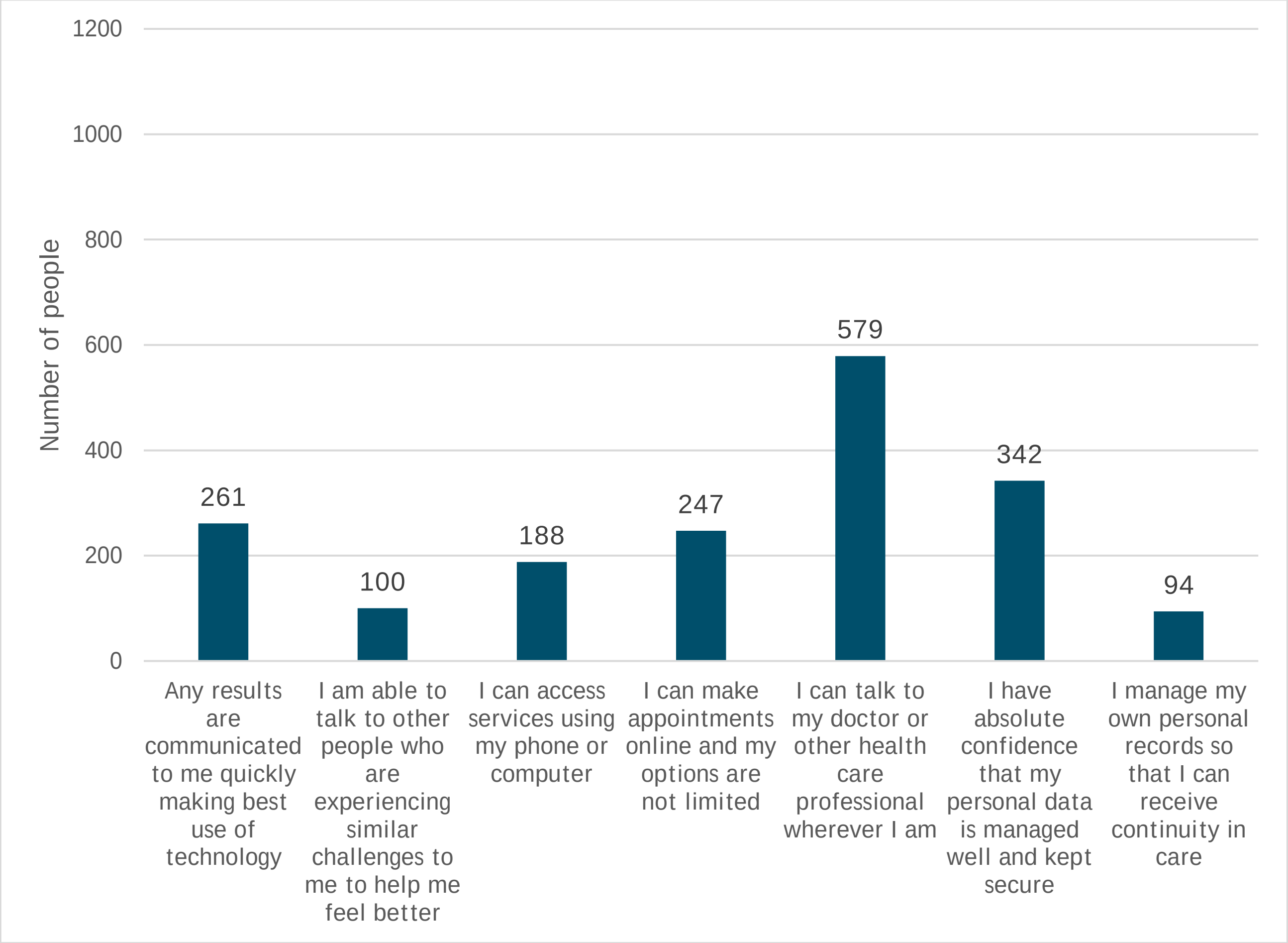
- *"Consistency of nursing/doctors. By this I mean having the same District Nurse visiting me for my treatment each week. Having the same nurse/doctor* would provide *compassion and a better all-round relationship feeling, with better health care service."*
- *"I think the NHS do a fantastic job, they're under such pressure and strain. Any dealings I've had with them I can only praise."*

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. Chart 4 indicates that being able to talk to a doctor or health professional wherever they are is the most important factor when engaging in health service delivery. 1811 people responded to this question.

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



Respondents were also asked to rate what is most important to them when interacting with the NHS, from very important to not important at all. The rating shows that having confidence that their personal data is managed well and kept secure has the highest rating for very important. Although being able to talk to a doctor or health professional wherever they are was deemed very important this was rated below another number of factors (Table 4). 1865 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
I have absolute confidence that my personal data is managed well and kept secure	1128	506	209	15	7
Any results are communicated to me quickly making best use of technology	1120	553	140	30	13
I can talk to my doctor or other health care professional wherever I am	980	646	200	26	11
I can make appointments online and my options are not limited	899	585	234	87	42
I can access services using my phone or computer	887	661	234	55	24
I manage my own personal records so that I can receive continuity in care	709	646	389	82	32
I am able to talk to other people who are experiencing similar challenges to me to help me feel better	606	641	434	137	44

Respondents were then asked to think about one more thing that needs to change to help them to successfully manage health and care. These answers have been categorised under emerging themes.

Technology

There was a mixed response to the use of technology in health services, with some praising its use, whilst others have concerns about how different groups cope with the ever-increasing use of technology:

- *"I feel for the older generation(s) who did not experience computers. If the NHS went totally down the road of using technology to deliver to a patient's home desk, where does that leave those who do not use the technology? It is the way ahead for the future, but for now it should be a gentle introduction."*
- *"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."*
- *"I am dyslexic so could not manage my own records, there would be too much to read or [difficult to] use a computer."*

- *“To have a health care app with interactive advice.”*
- *“I would like to see test results online including health tests so I can see improvements over time following routine health checks, e.g. weight, cholesterol levels, blood pressure, blood results that will give me an indication and motivation overtime whether I am improving my health or it is deteriorating. An 'App' for this would be very useful."*
- *“Options in communication not everyone is comfortable with today's technology.”*
- *“More secure systems in place to protect notes. Mine were missing for six months.”*
- *“I would like to be notified of my results and not having to ring up to get them”*
- *"Access to appointments are helped by texts. You can access GP appointments or consultation. Unfair you don’t get the same options if you do not use internet to make appointment.”*
- *“Knowledge for confident use of NHS website.”*

Accessibility

Many people felt that a more flexible approach to service accessibility would be useful. Additionally, comments showed that respondents felt that services could also be more accessible either by being closer at hand or that means of transport to get to appointments are improved. Comments included:

- *“Continuity of care at GP, regular and easier scheduled check-ups (yearly/six monthly).”*
- *“More drop-in centres.”*
- *“Weekend appointments. I work all day every weekday and find it impossible to take time off.”*
- *“For all departments to have a joined-up approach, making information on the individual accessible across the NHS. This would provide a better understanding of the patient, particularly those with more than one condition.”*
- *“It is difficult for working people to make appointments to see medical professionals, particularly if it is not an urgent matter but you do need to see someone. There are limited appointments and everyone, no matter who you speak to or where they live, is having problems getting an appointment. You are told to ring 8-8.30 am for an appointment, but this is when a lot of people are travelling to work. The system does not work very well for the working population. In my experience, I received a letter for a health check. There was a limited number of places available. I phoned when I got in from work only to be informed that I was too late and all the places had been taken. I am a widowed, working single parent and am trying to be responsible about my health. I don't want to be ill or go into hospital but the system doesn't help people like me.”*
- *"Whilst access to services and support in a timely manner is important, this should not be at the expense, or instead of, face-to-face consultations.”*

Communication

A number of respondents stressed the importance of clear communication channels when dealing with medical professionals. People told us they wanted to feel listened to and their wishes taken into consideration. For example:

- *“To improve the ability for healthcare professionals to communicate important messages in a timely and clear way. It often feels like messages are rushed or just not given because of pressures on individuals time.”*
- *“The same team, doctors or specialists as they always change and I have to repeat everything.”*
- *“Ensure all communication platforms have ease of use and are not overly wordy or complicated.”*

- *"Better communication between patients and health services around multiple and long-term conditions."*
- *"Clear options - discussed slowly at my own pace and clarifying my understanding."*
- *"Advising people of preventative steps and healthy active lifestyle activities that they can do to help prevention."*
- *"The NHS really needs to think about how it interacts with people like me with disabilities and put as much investment into people who have the times necessary to engage with patients with limited understanding and not just rely on new technology."*
- *"I would like the services to be able to communicate better as I don't have to tell my history multiple times."*

GP Appointments

- *"Better access to doctors' appointments to suit me. My doctors currently offer over the phone hoping to save appointments which puts me off."*
- *"Access to my GP. This front-line service is extremely important to me. He knows me well and also my family and circumstances within this family which may help at some time with the decisions made about my health and wellbeing."*
- *"I would like making appointments with my GP to be an easier process. Due to how difficult it is I often delay accessing GP care."*
- *"I often encounter difficulty when requesting medical appointments and feel screening methods are employed that are completed by reception staff. I do not feel this is appropriate."*

Information provision

- *"I would like to see clear instructions and education and training in the various on line and appointment systems. These should be appropriate to the people involved, as not all people have a phone/computer or are IT literate."*
- *"Knowledge of available services and groups."*
- *"Clear patient information on different health conditions and options, written with patients in mind, or signposting to the NHS website. I can find accurate information myself - a lot of people can't and google a symptom or condition."*
- *"Knowledge is the key."*

What people expect during service change and transformation

People across Cheshire and Merseyside also commented on challenges facing them through their treatment journey and the impact that service change and transformation may have on this, including population increases. A number of people also feel frustrated at the system but also reflect upon funding and ongoing issues facing the NHS:

- *"My concern is living in an area with massive new housing developments - population will almost double - without any addition to services. Surgery is always busy - 4 to 6 week waits for appointments and blood tests. It will only get worse."*
- *"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 simply not complied with. My personal experience is that so-called independent panels are far from 'independent'."*
- *"There is an assumption that the family will be involved. In my case, apart from my wife, I have no blood relative within 200 miles and do not want to bother them except when it is necessary."*

- *"Last week I had two appointments one early afternoon, one late afternoon but at different hospitals… After nearly two hours I had to leave without being seen in order to get to the next appointment."*

People's experiences of NHS support for specific conditions

People with specific conditions were asked to complete a separate Healthwatch England designed 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 559 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	21
Cancer	86
Dementia	42
Heart and lung diseases	88
Learning disability	11
Long-term condition e.g. diabetes, arthritis	192
Mental Health	115

Table 6: Who are you responding on behalf of?

Condition	Myself	Someone else
Autism	8	13
Cancer	71	15
Dementia	13	29
Heart and lung diseases	74	13
Learning disability	7	4
Long-term condition e.g. diabetes, arthritis	169	21
Mental Health	88	27

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

Condition	Yes	No
Autism	16	5
Cancer	22	63
Dementia	19	23
Heart and lung diseases	55	30
Learning disability	8	3
Long-term condition e.g. diabetes, arthritis	118	72
Mental Health	61	51

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	Not applicable
Autism	15	1	2	2
Cancer	8	1	13	63
Dementia	7	1	18	16
Heart and lung diseases	10	1	18	56
Learning disability	3	0	4	4
Long-term condition e.g. diabetes, arthritis	38	2	44	104
Mental Health	52	0	40	22

Tell us whether the support met your needs and how it could have been improved.

Autism

- *“We were not signposted to support services. Assessments were not undertaken due to funding issues. Families are left without support.”*
- *“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.”*

Cancer

- *“Could have been quicker to receive the support.”*
- *“10 minutes with the GP is not long enough.”*
- *"I spent three months going to the GP and was repeatedly given antibiotics but no blood test. My friend took me to A&E”*

- *“When I was first diagnosed with cancer, I saw a consultant 10 days later, the operation and radiotherapy plan was put in place and commenced two weeks later.”*
- *“GP could have requested an MRI which would have diagnosed the spinal tumour, instead of offering physiotherapy. We had months of surgery visits that never made any difference.”*
- *“Further options for treatment were not explored. Only treatment offered was a surgical intervention but on pushing the consultant a different treatment.”*
- *“Original referral made to secondary care, within two weeks and appointment was made with consultant and initial tests done within appointment, this was amazing and we couldn't have asked for a better service.”*
- *“Needs not always met. Information about my condition was poor. Felt unsupported at times.”*
- *“There seemed to be a lack of communication between the hospital and other services involved.”*
- *“Lack of support when not accessing cancer services (i.e. basic NHS).”*
- *“Felt that once I got diagnosis of terminal cancer, I was left as abandoned, nothing can be done.”*
- *“Multi-disciplinary team has provided excellent support.”*

Dementia

- *“I got all the information I required from Alzheimer's Society.”*
- *“It took a long time to get a diagnosis as they had to do a lot of tests, I think it could of been quicker.”*
- *“The Dementia Reablement Service were not very effective - it would have been helpful to have some further contact after the initial assessment.”*
- *“There could have been a better link made between the effects of arthritis on the dementia. Deal with the whole person not just the condition.”*
- *“The condition of dementia was not very well supported at first. It was hard to get a diagnosis and when we did get the diagnosis, we didn't know what support was available.”*
- *“From the first diagnosis it was six months before any support arrived.”*
- *“Having a regular carer would have been good. Different girls each time was not good for my husband and tiresome for me telling them over and over what we needed.”*

Heart and lung diseases

- *“Easier access to the same GP.”*
- *"I was told by telephone that I had Pulmonary Fibrosis, and I would be referred 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."*
- *“There was a lack of communication between hospital departments which resulted in long term inconvenience.”*
- *“More information needs to be provided some people need more than others.”*
- *“Less waiting time for consultant. Appointments are constantly being cancelled.”*
- *“Accessing help was very difficult it took two years. Once accessed the system was very helpful.”*
- *“Waited too long before getting appointment to see consultant after undergoing relevant tests, scans etc. Therefore, suffered a heart attack.”*
- *“More availability of support and advice especially on weekend.”*

Learning Disabilities

- *“Could have been told, what was out there, told who to take to.”*
- *“Long time getting the right support. Information given about my daughter's condition in a very blunt manner.”*

Long-term condition e.g. diabetes, arthritis

- *“My GP did not listen to me and my records became incorrect due to his write up of the appointment. I was given incorrect test results which meant delays to medication. I've had to go back numerous times to try and discuss the conditions with different GPs until one GP finally listened and put the correct plan in place for testing.”*
- *“Referrals to specialists were approved and appointments carried out within timescale.”*
- *“Very kind doctor who had plenty of time to listen to my worries and complaints. He didn't make me feel I was on a time limit at all.”*
- *“It is very difficult to get an appointment at your local GP as all appointments have gone when you ring in the morning.”*
- *“Getting a diagnosis was too long and took over six months before a consultant decided to do some bloods.”*
- *“No coordination in care between primary and secondary care, no continuity of care, no looking at the whole picture.”*
- *“Between the diagnosis of cancer and waiting for a specialist opinion was a period of anxiety. There was no support. I ended up paying for a private consultation to try to get some information sooner to help with the anxiety of receiving such a diagnosis.”*
- *“Felt that I didn't get time to ask questions and that was a big rush when I was first diagnosed. Have never seen a doctor about my condition only practice nurses.”*
- *“I was referred to a consultant quite quickly.”*

Mental Health

- *“Too long waiting lists and then a limited time for appointments. I felt just as I was becoming used to the counsellor and opening up, my sessions were over and was told if I needed anymore, I would have to go back on the waiting list.”*
- *“Daughters first episode with psychosis she was not offered any ongoing support, and has still not been able to access ongoing support. Everything happens in a knee jerk response such as leave well alone until she reaches crisis point yet again.”*
- *“My boyfriend attempted suicide and was taken to hospital by ambulance. He was given a leaflet and told to self-refer to adult mental health. I think they should have asked him for permission to refer at hospital. He hasn't referred himself yet, although he says he wants help. It has been one month since then, and I'm worried about him.”*

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

Condition	Very Positive	Positive	Average	Negative	Very Negative	Don't know
Autism	1	4	2	2	12	0
Cancer	40	25	12	6	2	1
Dementia	7	12	16	5	1	1
Heart and lung diseases	31	25	20	6	4	2

Learning disability	1	2	5	3	0	0
Long-term condition e.g. diabetes, arthritis	40	64	46	21	12	6
Mental Health	6	20	35	30	22	2

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

Condition	Yes	No
Autism	10	11
Cancer	45	41
Dementia	21	20
Heart and lung diseases	66	22
Learning disability	8	3
Long-term condition e.g. diabetes, arthritis	130	58
Mental Health	54	60

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	1	1	5	1	1
Cancer	9	23	4	2	5
Dementia	2	10	5	3	1
Heart and lung diseases	16	25	20	3	1
Learning disability	2	1	3	0	2
Long-term condition e.g. diabetes, arthritis	19	60	36	9	5
Mental Health	3	25	22	2	2

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	15	3	0	1	0	2
Cancer	7	11	19	27	22	0
Dementia	2	14	14	9	3	0
Heart and lung diseases	9	20	26	25	8	0
Learning disability	0	5	1	4	0	1
Long-term condition e.g. diabetes, arthritis	23	37	58	47	16	7
Mental health	31	33	27	14	5	3

Please tell us about the length of time you waited.

Autism

- *"We are actually still waiting. It's been three years and we have another six months to wait, at the least, for a first appointment."*
- *"12 months- and case notes were ' lost'."*
- *"Over 13 months and still waiting."*
- *"12 months wait for assessment to diagnosis."*
- *"Due to a GP error it took a while to get an appointment."*

Cancer

- *"Diagnosed July, operated August & radiotherapy during November."*
- *"One week."*
- *"Three months."*
- *"I was on fast track pathway for Cancer I waited two weeks from going to my GP to seeing specialist."*
- *"Hospital fast and efficient."*
- *"Within one month of diagnosis I had had the operation and started radiotherapy."*
- *"The waiting time is now 10 months."*
- *"From initial discovery to being seen by a Consultant took about four weeks."*
- *"Long wait for results after surgery."*
- *"There was no delay at all from seeing my GP through specialist examination CT scan, etc. All very timely."*
- *"I was waiting for a number of weeks to see a haematologist after I received the diagnosis of lymphoma."*

Dementia

- *"After waiting for a test/assessment appointment about six weeks."*

- *“It took more than one year between consulting GP and getting an appointment with the dementia consultant.”*
- *“We waited six months to go to the memory clinic.”*
- *“A memory test had to be requested twice, this caused months of delay.”*
- *“Initial referral came quickly. Diagnosis took long time.”*
- *“My dad didn't know what was available and was very much in the dark as to what the diagnosis meant and where to go for help.”*
- *“The initial diagnosis took time, as expected really but getting care and respite break was good.”*

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 [Picture Archiving and Communication System].”*
- *“One month.”*
- *“Over one year.”*
- *“Six weeks.”*
- *“It took months to get a diagnosis."*
- *“I got support as soon as I left the hospital, so didn't have to wait.”*
- *“Immediate at first then regular short periods. First class support.”*
- *“From registering with urgent care, describing symptoms, immediately being seen, then transferred to hospital coronary care unit.”*
- *“Waited over six months. Paid privately to see consultant before seeing NHS consultant. I had my heart attack a day before finally getting appointment for NHS consultant waiting nine months since diagnosis.”*
- *“My first call to doctor was positive, they have knowledge of me and want to help.”*
- *“Although the patient is supposed to be beginning their discharge plan more or less as soon as a proper diagnosis is given this woefully falls below expectation. Even when an initial Social Services Plan was supposed to be in place and meeting needs, prior to hospital admission and the diagnosis of two further life changing conditions, Mum is still waiting for a comprehensive holistic approach to her long-term management and care plan.”*
- *“In general, pretty well. I had two cancellations whilst awaiting a triple A (aneurism repair).”*

Long-term condition e.g. diabetes, arthritis

- *“The x-ray and diagnosis were very quick.”*
- *“I had to access help privately as my GP wouldn't help.”*
- *“Probably about two weeks, I saw some physio and consultants, very impressed.*
- *I was seen straight away.”*
- *“For diabetes health check quite a while.”*
- *“12 months to see a Lipoedema nurse, and now for bariatric surgery and counselling for my eating issues it’s also a 12 month wait,”*
- *“Symptoms started in January, was diagnosed in the August.”*
- *“The first GP I saw kept deferring referral and then referred me to somewhere that only deals with life threatening conditions, so naturally I was rejected. My correct GP is excellent.”*

- *"Waited two years for operation."*
- *"About nine months between first seeing GP to the time that Multiple Sclerosis was diagnosed."*
- *"I am waiting to see a physio and was initially told this would be within two weeks. It has been almost six months and the condition has worsened."*
- *"Service fragmented not able to get to what is needed."*
- *"Six months between each appointment."*

Mental Health

- *"Waiting over a year for support."*
- *"When the NHS would help, it would be about six months. Now, they just refer you to charities, which then take six months too, just for basic counselling."*
- *"I waited three months for my mental health assessment, and then waited another two months to get my log in details to start my online CBT [Cognitive Behavioural Therapy]. I've now been waiting two weeks so far for an appointment to start my new therapy."*
- *"I waited so long I ended up going to another agency."*
- *"After calling the GP surgery I had an appointment within a week."*
- *"12 months or more."*
- *"Each admission was timely but follow up was poor and difficult to access."*
- *"Wait was not too long but back up has not happened."*
- *"Diagnosis quick, aftercare poor and length of wait unacceptable- particularly for a child."*
- *"I self-referred in and waited two weeks before I was 'assessed' by phone."*
- *"Still waiting (eight weeks)."*
- *"I waited a few weeks for my first appointment."*
- *"I had to pay a local charity to get one to one counselling."*
- *"It was going to be over 12 months which was ridiculous, so we pursued another avenue and went private."*
- *"We are still waiting after two and a half years."*

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	13	2	1	2	0	2
Cancer	3	5	16	37	22	1
Dementia	0	11	18	10	0	2
Heart and lung diseases	7	22	21	20	13	5
Learning disability	1	3	4	1	1	1
Long-term condition e.g. diabetes, arthritis	20	40	59	42	15	9
Mental health	33	26	28	16	4	7

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

Condition	Yes	No
Autism	6	14
Cancer	59	24
Dementia	32	10
Heart and lung diseases	56	30
Learning disability	6	5
Long-term condition e.g. diabetes, arthritis	105	75
Mental health	60	51

What could be improved?

Autism

- *"Time waiting."*
- *"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."*

Cancer

- *"The nurses are over-worked and need more staff."*
- *"Chemotherapy could have delivered in Leighton not Manchester - less travel, less stressful."*
- *"More counselling offered."*
- *"Computerised systems should be interlinked."*
- *"Support services should be available from the outset."*
- *"More holistic support required: e.g. massage, Reiki, reflexology, etc. Oncology."*

Dementia

- *"I was satisfied with the support offered."*
- *"Being told what is around. I myself found a rare dementia group in Stockport, no one suggested it."*
- *"An opportunity at regular checks for both of us to discuss progress of the disease and possible help."*
- *"More practical support."*
- *"No improvement needed."*
- *"Someone to monitor what is working and what is not working."*
- *"There was a long delay between diagnosis and post diagnostic support."*

Heart and lung diseases

- *"Better communication between healthcare groups."*
- *"The support I received could not be improved for me."*
- *"Information not available to consultants on hospital computer records."*

- *"Improving availability of NHS consultant appointments."*
- *"Pace of appointment making, you seem to be left in a void."*

Long-term condition e.g. diabetes, arthritis

- *"The support could be more accessible locally so I don't have to travel as far to my appointments."*
- *"Service was very good."*
- *"More information and support about how I can best improve my own self-care to improve my health and wellbeing, improving or reducing my symptoms."*
- *"Waiting times for appointments."*
- *"Different medical experts didn't work together, care fragmented, no one coordinating care, communication between primary care and out of borough specialist hospitals/medics very poor."*
- *"Answering phone calls on the numbers we are given instead of voicemail."*
- *"Each time I went, I saw a different specialist and information was not passed on."*
- *"More medical staff."*
- *"Improving availability of NHS Consultant appointments."*

Mental Health

- *"Waiting time appalling."*
- *"Waiting times for appointments just causes more anxiety and stress."*
- *"I would have found it more helpful to be offered different treatment options sooner rather than persistently being given CBT. I would have preferred to be able to see the secondary care team for longer rather than being discharged while I still felt I would benefit from more sessions."*
- *"Choice of clinicians, psychiatric input, more intensive treatment options, e.g. day/inpatient."*
- *"Better training to identify when a person is desperate for mental health treatment. Less waiting times. More trained staff. More signposting to mental health charities and websites."*
- *"More time on appointments needed and groups could be an option."*
- *"Nothing could have been improved."*

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

Condition	Yes	No
Autism	5	14
Cancer	80	5
Dementia	33	8
Heart and lung diseases	76	10
Learning disability	9	2
Long-term condition e.g. diabetes, arthritis	144	44
Mental health	67	45

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	2	1	0	1	0	1
Cancer	4	5	18	34	18	0
Dementia	0	7	18	7	0	0
Heart and lung diseases	6	19	21	17	10	1
Learning disability	2	2	3	2	0	0
Long-term condition e.g. diabetes, arthritis	13	27	47	37	13	5
Mental health	18	16	20	11	0	2

Please tell us more about the length of time you waited

Cancer

- *“Three weeks.”*
- *“I was seen within a day as an inpatient.”*
- *“Six months.”*
- *“Once started it got moving, problem was getting started.”*
- *“From initial diagnosis to results one week.”*
- *“Pretty much immediately.”*
- *“I was completely satisfied.”*

Dementia

- *“Dementia treatment is still slow compared to other illness.”*
- *“More than the 18 weeks.”*
- *“Initial waiting time for seeing consultant was quite quick. Waiting time when consultant referred me to a second consultant was met by logjam which needed intercession from my MP to resolve”.*
- *“Around six weeks was suggested but it turned out to be nearer eight.”*

Heart and lung diseases

- *“I have waited two months for an appointment and I am still waiting.”*
- *“About three weeks.”*
- *“Waited five months for follow up appointment.”*
- *“Over two months and still not arranged, even though progress meetings were organised by the hospital.”*
- *“Once I had my diagnosis it has been quite quick - my GP has helped with this.”*
- *“About three - four months.”*

Long-term condition e.g. diabetes, arthritis

- *“From what can remember it was no more than six weeks.”*
- *“Referred to hospital within two months of diagnosis.”*

- *"Over nine months."*
- *"Most I have waited is two weeks."*
- *"Waited four weeks and got a cancellation."*
- *"I was seen quickly and was diagnosed quickly too. Waiting times in the clinic are always running late. I once asked for an early appointment and was given the first slot at 8am. They were running 40 minutes behind even then."*
- *"I waited several months to be seen, when I was in severe pain and not sleeping all night."*
- *"Three months."*
- *"Once started it got moving, problem was getting started."*
- *"Poor accountability as to delays."*
- *"From referral to op - couple of months - quick."*

Mental Health

- *"My care had been transferred between teams and if I had not proactively contacted them, I would have waited even longer as my details hadn't been passed over."*
- *"I see a psychiatrist whilst I am waiting for psychological services. However, he was not apparently aware that I was not on the waiting list."*
- *"Usually months. Up to a year."*
- *"I think it only took a month or so to see the psychiatrist once I'd been referred."*
- *"Made me more anxious."*
- *"Six months between GP and psychiatrist."*
- *"I understand they have waiting lists but sometimes with mental health it is urgent."*
- *"It wasn't long before I saw a psychiatrist."*
- *"I was assessed and treated within a couple of weeks."*
- *"When I complained to our GP about my concerns regarding my wife's mental state, things moved on pretty quickly from then on."*
- *"Six months."*
- *"Once started it got moving, problem was getting started."*
- *"The length of the wait further intensified symptoms."*

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	1	2	3	11	2	1
Cancer	20	16	17	12	0	6	12
Dementia	3	3	19	5	5	4	3
Heart and lung diseases	14	11	31	12	5	4	10
Learning disability	1	1	2	5	1	1	0
Long-term condition e.g. diabetes, arthritis	22	28	61	23	17	17	18
Mental health	6	7	32	27	29	3	9

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

Condition	Yes	No	Somewhat
Autism	3	14	2
Cancer	44	11	18
Dementia	15	12	11
Heart and lung diseases	49	19	12
Learning disability	2	3	4
Long-term condition e.g. diabetes, arthritis	85	41	54
Mental health	22	54	34

Please explain how the care did or did not meet your expectations and how it could have been improved.

Autism

- *“My daughter used to get support, and when it was decided that group meetings would be best, she was excluded. It was ludicrous to expect someone with Autism to attend groups. it is a communication and social disorder what were they thinking?”*
- *“It could have happened quicker. The waiting was frustrating.”*
- *“I expected to be referred to other specialists.”*
- *“The only support available was with the third sector, Space4Autism. I don't know what we would have done without their support. The NHS only offer help to those in crisis.”*

Cancer

- *“Only found out about local cancer support charities after accessing a psychology referral.”*
- *“The care for my cancer diagnosis met all my expectations, I just felt overwhelmed with it all.”*
- *“I did not know what to expect and felt a little lost. I do not feel I got any support.”*
- *“Everything was explained clearly and I felt more at ease.”*
- *“Having spent time in a hospital away from home and two close to home, I have experienced a lack of sharing information.”*
- *“Felt abandoned.”*
- *“Not been much support. Lots of passing around different departments and hospitals and nobody taking total ownership of the case.”*
- *"Communication an ongoing support has been excellent so far.”*
- *“I have not experienced any areas needing improvement."*
- *“Was allocated a specialist nurse who was extremely supportive.”*
- *“I expected to have surgery or radiotherapy but I am on chemotherapy tablets which is marvellous.”*
- *“The support for cancer patients is thorough and beneficial to the patient.”*
- *“Need more support after diagnosis.”*
- *“I was completely satisfied.”*

- *"Symptoms were showing in June however was not taken seriously until September. Once it was diagnosed all scans and consultants' reviews were very quick."*
- *"It exceeded my expectations."*
- *"Was never given a care plan, not signposted to support services."*

Dementia

- *"It met my expectations, we had three information sessions about dementia."*
- *"The system is stretched to the point of breaking. Social Workers are massively overloaded and can't get support to those who need it. Far too much paper pushing and form filling resulting in less one-to-one support."*
- *"I was satisfied with support given."*
- *"Nothing offered. Found various care day centres and pay for it ourselves."*
- *"At the beginning we were offered day care which was good, but when the situation got worse, a diagnosis of residential care was given. The time given to agree to the place was not enough to properly assess and consequently the care was not good."*
- *"I know places are limited, but a little more time to look and visit, without pressure would be good."*
- *"Only one service from Age Concern. I'm not old. where's the choice."*
- *"It was hard to find out what support was available."*
- *"The service seems very disjointed and we had to tell our story to each professional."*
- *"I had to request medication, it was not offered and I was not informed about the options or educated about what can be tried."*
- *"More information needs to be advertised in all areas of the hospital and GP surgeries. Help should be automatic and then should come to the house of the person diagnosed."*
- *"I felt supported and relieved to be listened to."*

Heart and lung diseases

- *"Better information sharing between healthcare groups."*
- *"I received excellent care from my GP and practice nurse and continue to do so."*
- *"They never followed up with what they said they would do after my appointments."*
- *"Once the system was accessed the help and advice was available and helpful. It was the initial access that was difficult and information is still difficult to access."*
- *"No ongoing support for COPD [Chronic Obstructive Pulmonary Disease] could have exercise classes."*
- *"Only found out about exercise classes from Healthwatch."*
- *"Results not available to progress my "urgent" symptoms after months."*
- *"Excellent Care - No change needed."*
- *"Seeing the same doctor more than once."*
- *"Speedier access to Consultant via NHS."*
- *"Could not have had better care."*
- *"I have been explained what options for treatment are available and been involved with treatment."*
- *"Very little information. Need more information at diagnosis."*

Long-term condition e.g. diabetes, arthritis

- *"Offer longer home care support after surgeries."*
- *"Very good, fast reactions, impressive."*
- *"Trying to get to see the same doctor that found your diagnosis."*
- *"Time taken to see specialist could have been shorter."*

- *"Problems getting appointments at GP surgery."*
- *"Provision of the support given would be better if provided nearer to our home and not limited to just a few visits then being discharged to manage alone."*
- *"I have no complaints."*
- *"I am happy with the NHS and the care/continue to receive."*
- *"Arthritis care; cannot fault it."*
- *"Fantastic care. The consultant was lovely, recognised instantly that it was a scary experience for someone at just 16 years of age."*
- *"Misdiagnosed and left without medication."*
- *"Length of time waiting - could be improved and some attitudes of the consultant as he tended to see me as an employee as I worked at the hospital. Never referred for pain management."*
- *"Support is ongoing and the practice nurses are very efficient."*
- *"I was quickly given the physio and the surgical support which the consultant recommended."*
- *"It met my expectations I was given equipment to help me."*
- *"I was well looked after."*
- *"Waiting times."*
- *"The consultant did not give me enough information or answer my questions. I was told to see my GP regarding the medication I was to take."*

Mental Health

- *"Felt very let down and abandoned, didn't know who else to turn to."*
- *"No ongoing support other than self-care."*
- *"The GP did not do a lot for me but the crisis team were fantastic."*
- *"More understanding, not to be passed around."*
- *"There has been no support as the assessment I had has led to me going on a waiting list for over a year. Now it appears I came off the waiting list and no one realised so I have a further assessment."*
- *"Needed one to one support such as weekly support visits to check on wellbeing."*
- *"No support has been offered."*
- *"Not tailored to needs of individual."*
- *"The consultant helped with the shock of having surgery."*
- *"If you ring for help/appointment can take weeks to be seen."*
- *"Poor quality counselling without ever having a diagnosis of why my mental health is poor."*
- *"Very good."*
- *"More available appointments and quicker appointments."*
- *"The care met my expectations as the staff were very helpful and gave me information that I needed. It could not have been improved."*
- *"Shorter waiting lists needed. More money needs to go into mental health."*
- *"I was given medication but not offered counselling."*
- *"Too long to wait and not easy to access."*
- *"There does not seem to be the help for mental health in this area and something needs to be done."*

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	3	14	3
Cancer	46	11	21
Dementia	12	15	11
Heart and lung diseases	44	23	16
Learning disability	4	6	0
Long-term condition e.g. diabetes, arthritis	89	57	32
Mental health	20	70	22

Please explain how the care did or did not meet your expectations and how it could have been improved.

Autism

- *“Letters not received; appointments changed without notice.”*
- *“No communication between professionals.”*
- *"No communication at all.”*
- *“All reports have to be repeatedly requested. One report took two months to type. More admin staff would be better."*
- *“Information wasn’t passed between services therefore there was a lot of repetition and constant explaining to be done by the family.”*

Cancer

- *“More continuity between departments.”*
- *“I think someone explaining everything the outcomes as I was shocked from the diagnosis.”*
- *“Hospital excellent.”*
- *“Once we had had initial appointment at second hospital communication improved. We saw a specialist nurse how gave us the information we required. If initial letter could have been sent out, explaining timescales, etc. that would have improved experience by managing expectations”.*
- *“Everything really good.”*
- *“One to one care of all agencies has been excellent.”*
- *“Communication between different departments and hospitals non-existent at times. Poor at other times.”*
- *“Triage helpline very useful."*
- *“First class treatment.”*
- *“Needed to push to be treated.”*
- *“I was completely satisfied.”*
- *“Often had to chase up appointments.”*
- *“Better notification of test results.”*

- *"Anyone receiving a diagnosis of serious cancer should have an appointment within 48 hours to discuss possible implications for that individual. To have to wait a number of weeks is too long."*

Dementia

- *"Staffing shortages in social care and lack of awareness of what dementia is in some areas of the health service."*
- *"I feel as though everything has worked well for me."*
- *"It couldn't have been improved."*
- *"I think the doctors need to talk to each other."*
- *"Phone calls are often difficult - having to leave messages - then not hearing from services."*
- *"People don't seem to communicate with each other. Often the case is 'left hand doesn't know what the right hand is doing'. Services/care not joined up."*
- *"The service from my GP and practice is first class."*

Heart and lung diseases

- *"No communication between departments in hospitals."*
- *"More individualised."*
- *"More consultation in the beginning."*
- *"Everything really good."*
- *"The care met and continues to meet my expectations very well."*
- *"Could not have been improved."*
- *"It always seems very difficult to access."*
- *"Not much support when I left hospital."*
- *"Departments don't communicate. Each department say we can do this but for that service you need such and such. Just the fact you have a life changing condition is traumatic enough which is compounded by the fact you do not have any one person who could deal with the various specialities and services. An ongoing written record that the patient has so if they forget anything or are confused, they have something to refer to."*

Long-term condition e.g. diabetes, arthritis

- *"Getting the right information straight away. Didn't hear news as it went along."*
- *"Have had good care but not the assurance of continuity of care from GP. Important to see the same person during flare ups of condition."*
- *"It was impossible to get answers to questions from a doctor/consultant, as appointments were not offered."*
- *"Very supportive, helpful staff, explanation of treatment, etc."*
- *"I am happy with the NHS and my ongoing care."*
- *"Access to my records digitally so I can see what's said."*
- *"I never saw the same doctor."*
- *"Less waiting time."*
- *"I strongly felt that I was being given the care which was needed."*
- *"Never received feedback of test results from hospital or GP."*
- *"Nothing to complain about."*
- *"Poor communications."*
- *"Needed to push to be treated."*

Mental Health

- *"Seeing a different professional at each appointment doesn't help at all as you have to go through your situation each time and its exhausting."*
- *"Phones often on answerphones. Appointments made - but not communicated by either letter or phone. Huge gap between a general enquiry and crisis team."*
- *"A week is a long time for someone with mental health issues to wait - rash decisions may have been made within that sort of time frame."*
- *"Not having to wait too long for appointments."*
- *"Was supposed to have regular appointments and discharged without my knowledge with mental health service. Not discharging patients when they need help the most. Regular appointments should be kept not discharging patients without their notice."*
- *"Mental health needs more communication and better ways to speak to someone instead of voicemail."*
- *"I received consistent communication from all of the services that I came into contact with. They were very helpful and supportive. It could not have been improved."*
- *"If sessions were cancelled you were not always told, also the right to obtain a copy of letters was not always fully explained."*
- *"Never get an appointment when needed."*
- *"Counselling non-existent support or communication."*

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	11	3	4	0	0	1	1
Cancer	56	19	3	1	0	3	2
Dementia	17	14	6	1	1	1	1
Heart and lung diseases	40	18	19	0	0	8	3
Learning disability	6	1	3	0	0	0	1
Long-term condition e.g. diabetes, arthritis	86	34	35	4	0	23	6
Mental health	50	19	29	2	0	6	7

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	4	8	2	6

Cancer	11	41	10	19
Dementia	11	20	6	4
Heart and lung diseases	24	38	16	8
Learning disability	3	4	1	3
Long-term condition e.g. diabetes, arthritis	45	100	21	21
Mental health	22	53	26	8

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	3	7	6	4
Cancer	5	32	19	25
Dementia	7	20	8	6
Heart and lung diseases	12	42	20	13
Learning disability	2	3	3	3
Long-term condition e.g. diabetes, arthritis	27	87	45	27
Mental health	15	51	31	14

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	4	9	2
Cancer	25	45	5
Dementia	13	19	5
Heart and lung diseases	35	35	11
Learning disability	6	1	2

Long-term condition e.g. diabetes, arthritis	82	70	25
Mental health	24	65	18

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	3	9	3
Cancer	26	45	3
Dementia	10	23	3
Heart and lung diseases	32	32	16
Learning disability	2	5	2
Long-term condition e.g. diabetes, arthritis	84	70	24
Mental health	41	40	21

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	5	8	2
Cancer	28	42	3
Dementia	9	24	3
Heart and lung diseases	35	33	12
Learning disability	4	4	1
Long-term condition e.g. diabetes, arthritis	82	65	27
Mental health	35	45	19

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	9	3	3
Cancer	32	37	4
Dementia	17	15	6
Heart and lung diseases	39	28	15
Learning disability	4	3	2
Long-term condition e.g. diabetes, arthritis	89	60	24
Mental health	54	35	16

Supporting you to have more control over your own care

Table 27: What level of support of 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	2	14	1	3
Cancer	17	44	15	6
Dementia	9	30	0	2
Heart and lung diseases	13	61	11	3
Learning disability	5	4	0	2
Long-term condition e.g. diabetes, arthritis	39	118	19	10
Mental health	31	69	6	5

What could the NHS do to help you stay healthy or manage any condition you have?

Autism

- *"Access to specialist teams."*
- *"Easily accessible support services 24/7."*
- *"Get the diagnosis sooner and the follow up sessions sooner."*
- *"Improve almost every aspect of their services. Provide sensible, factual advice and follow it up."*

Cancer

- *“Easier GP appointments with the same GP.”*
- *“Locally available services seven days a week.”*
- *I would like easy access to the services I need.*
- *“Provide specific information regarding illness and treatment available, including side effects.”*
- *“Explain my options.”*
- *"I would love to see more info on living with cancer including lifestyle - i.e. how I can help myself… diet, exercise etc.”*
- *“Speedy access to GP advice - e.g. telephone consultation then face to face appointment if required.”*
- *“The NHS currently gives me a lot of support with ongoing CT scans and chemotherapy tablets.”*
- *“Happy with everything.”*
- *“Offer more wellbeing services for working people over 50.”*

Dementia

- *“I am satisfied as things are.”*
- *“Regular checks on progress of disease. Advice to wife on handling, to save having to research it all out ourselves. My husband is seen once a year better now it's at home and not in the local hospital.”*
- *“Better communication.”*
- *“Easier, accessible appointments to GP.”*
- *“Staff need to be trained to deal with people with dementia. Wards for just people with dementia.”*
- *2Offer more support for family/respite.”*

Heart and Lung Diseases

- *“Employ well trained and optimistic staff who are properly recognised and paid not rushed and clearly stressed by the pressures. Stop asking me the same questions every time I'm seen which don't seem relevant. Simplify getting repeat prescriptions.”*
- *“Co-ordinate between the hospital and the GP where Shared Care is allocated. We have had to ask for copies of letters sent between the GP and the hospital.”*
- *“I am satisfied with my care.”*
- *“Regular health checks to monitor the way the condition is progressing.”*
- *“Provide information of local support groups.”*
- *“To signpost to support groups in the area.”*
- *“Nothing, have been given all the help and support with my condition.”*
- *“Be able to see doctor when needed.”*
- *“Give consistent information.”*
- *“Get them to follow patients through the assessment & treatment stage.”*
- *“Keep promises to triage patients at A&E quickly, not just leave everyone waiting.”*
- *“NHS has done all that I needed.”*
- *“See same doctor more than once.”*
- *“Make sure the basics - easy access to GP and following on hospital appointments.”*

Long-term condition e.g. diabetes, arthritis

- *“More information on self-care as well as referral options available if needed.”*

- *“The GP is usually the first line, there need to be more GPs and their level of training needs to be up to date and consistent. All too often when you see a different GP within the same surgery. The outcome of the consultation is radically different often leaning toward a bias of what that particular GP understands best.”*
- *“Issue more same day appointments. GPs are too often running out of appointments for the same day resulting in a lengthy wait for an appointment.”*
- *“Regular contact with the same doctor during each visit.”*
- *“More information to understand the conditions.”*
- *“More staff to support.”*
- *“Ability to speak to somebody when I need to.”*
- *“Provide more support workers and mental health for those that really need it. Access to social workers and occupational health. Home support for lonely people.”*
- *“The NHS do a wonderful job most of the time.”*
- *“My notes have been confused with another person’s a couple of times - this worries me.”*
- *“Improve communication and streamline processes especially between the GP and hospital and specialist services.”*
- *“Make seeing the doctor easier.”*
- *“No more than is being done at the moment - for which I am most grateful.”*
- *“The district nurses are amazing.”*
- *“See advert after advert saying get checked. Then you cannot get access to services.”*

Mental Health

- *“Long term support and therapy until I feel able to manage my mental health independently. A health professional to explain conditions.”*
- *“Better training for staff re mental health conditions and ability to tailor treatments to individuals.”*
- *“Continue as they are doing.”*
- *“Provide more support workers around mental health for those that really need it. Access to social workers and occupational health. Home support for lonely people.”*
- *“More mental health workers.”*
- *“Put more money into mental health.”*
- *“Make it easy and quick to access support services.”*
- *“Listen to me. Don't ignore my concerns.”*
- *“More investment in the third sector and personal health budgets.”*
- *“Give indication of waiting times.”*
- *“Provide resources to be able to give the guidance and advice immediately when I am concerned or worried about a condition, then prompt treatment thereafter.”*
- *“Group sessions for anxiety.”*

Further comment

Cancer

- *“NHS superb. Just short of staff.”*
- *“I cannot thank staff of NHS enough from consultants to cleaners - all do a vital job.”*
- *“If I had urgent medical need and cannot get an appointment with my GP, I go to the local walk in centre rather than wait for my own GP.”*

Dementia

- *“Receptionists are usually very helpful.”*

- *“We feel the amount of contact from NHS services has been poor. We are unsure of the future and need more support, advice, information.”*
- *“My general opinion of the NHS is a good one. No complaints.”*

Heart and Lung Diseases

- *“Can't get appointments and if you have more than one thing wrong with you and you make a double appointment you are only in the same time as you would be with a single appointment.”*
- *“End up seeing too many doctors at too many different locations. Every doctor has different opinions on the same case.”*
- *“To get advice from doctor by phone when worried.”*
- *“Important need for getting prescriptions on time and not having to wait a week for prescriptions to get from doctor to chemist.”*
- *“Knowing how and where to access support when needed and being confident it will be provided.”*
- *“More GPs are needed so appointments are quicker.”*
- *“I have always had good treatment and support.”*
- *“I would like less of a wait in doctor’s surgeries and hospitals.”*

Long-term condition e.g. diabetes, arthritis

- *“The phone consultations are good and I feel more comfortable asking more questions this way.”*
- *“Takes too long to see a health professional.”*
- *“Not always easy to get advice on phone as difficult to get through.”*
- *“More money should be given to communities to provide services for health and social care really near to our homes. Family doctors who can know the circumstances of people’s lives in the situations they are in.”*
- *“Having recently received surgery, I must commend the NHS for all my treatment and support”*
- *“More support needed to stay healthy and in work."*
- *“What wonderful service the NHS provides, so grateful.”*
- *“NHS superb but short staffed.”*
- *“Need to adapt an 'acting as one' approach. Sometimes, I am in other parts of the country for extended periods of time. It would be comforting to know that if I see a GP in a different area or need to attend a different hospital, they would have access to my records and that for me, as the patient, it would just be like visiting my usual practice/clinic.”*
- *“Visiting your own local hospital is better for my own health wellbeing, it cuts down on stress which doesn't help my condition.”*

Mental Health

- *“Asking for help with mental health is extremely difficult, and to be told there is nothing available and you will be put on a waiting list is devastating, we need support immediately not months down the line.”*
- *“I think the NHS do a great job considering the resources they have.”*
- *“The NHS do a wonderful job most of the time. There are a lot of people suffering with mental health and the situation needs addressing. It is easy to hide mental health and con people into thinking you are fine.”*
- *“My only main concern is waiting times and quick access to specialists. Also takes a long time to speak to someone as GPs have little time and stressful.”*
- *“Parity of esteem is a nice to have but not a reality.”*

Who responded to the surveys

Below is a breakdown of the demographics of the 2487 people across Cheshire and Merseyside who responded to one or both of our surveys.

Table 28: Gender

Of the 2487 people who responded to the survey across Cheshire & Merseyside, 2417 responded to this question:

	Female	Male	Other	I'd prefer not to say
Cheshire East	196	68	0	1
Cheshire West and Chester	175	73	0	2
Halton	170	82	1	3
Knowsley	185	58	2	7
Liverpool	153	57	0	3
Other	1	0	0	0
Sefton	130	82	1	5
St Helens	313	90	2	2
Warrington	137	99	1	9
Wirral	213	92	2	2
Grand Total	1673	701	9	34

Table 29: Age

Of all respondents to the survey, 2443 provided age profile information. 1357 respondents were aged 55+, whilst those under 24 accounted for 214 respondents:

	Under 18	18-24	25-34	35-44	45-54	55-64	65-74	75+
Cheshire East	4	8	14	26	39	67	54	54
Cheshire West and Chester	3	17	23	27	37	64	50	28
Halton	6	10	26	36	45	43	66	25
Knowsley	17	9	13	16	20	24	48	107
Liverpool	5	5	25	17	40	62	37	25

Other	0	0	0	1	0	0	0	0
Sefton	6	8	20	31	34	44	50	32
St Helens	54	27	33	54	82	69	62	30
Warrington	5	12	37	37	49	50	35	27
Wirral	1	17	20	29	41	74	73	56
Grand Total	101	113	211	274	387	497	475	385

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

Of the 2411 people who answered this question, just over two-thirds (1633) stated they did not have a disability:

	Yes	No	I'd prefer not to say
Cheshire East	82	177	4
Cheshire West and Chester	67	177	8
Halton	69	169	16
Knowsley	83	155	14
Liverpool	68	139	6
Other	1	0	0
Sefton	68	136	17
St Helens	107	268	27
Warrington	48	189	11
Wirral	70	223	12
Grand Total	663	1633	115

Table 31: Ethnicity

2413 of all respondents answered this question. Of these 2240 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 East	0	0	0	0	0	1	0	0	255	5	0	3
Cheshire West and Chester	0	0	0	1	4	0	5	0	233	6	0	4
Halton	0	0	0	0	1	0	0	1	248	3	0	3
Knowsley	0	0	0	0	0	0	0	0	237	6	2	3
Liverpool	1	2	2	0	0	0	1	0	185	11	4	6
Other	0	0	0	0	0	0	0	0	0	0	0	1
Sefton	1	0	2	0	4	0	0	1	203	8	0	0
St Helens	0	0	1	0	0	0	0	1	387	5	3	9
Warrington	1	0	12	0	10	1	1	0	211	4	3	5
Wirral	0	0	0	1	3	3	2	0	281	11	1	6
Grand Total	3	2	17	2	22	3	9	3	2240	59	13	40

Table 32: Are you a carer?

2,396 people surveyed responded to this question:

	Yes	No
Cheshire East	71	188
Cheshire West and Chester	44	202
Halton	57	193
Knowsley	39	211
Liverpool	38	176
Other	0	1
Sefton	43	176
St Helens	66	336
Warrington	36	212
Wirral	86	221
Grand Total	480	1916

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

Of the 2394 people who responded to this question, around a third (786) said that yes, they had a long-term health condition, with a further 615 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 East	83	74	102
Cheshire West	4	0	0
Cheshire West and Chester	79	43	118
Halton	88	65	99
Knowsley	68	123	60
Liverpool	70	59	84
Other	1	0	0
Sefton	101	44	78
St Helens	109	124	171

Warrington	57	21	169
Wirral	126	62	115
Grand Total	786	615	996

Table 34: Which of the following best describes you?

Of the 2487 people who responded to the survey, 2374 answered this question:

	Heterosexual	Gay or lesbian	Bisexual	Asexual	Pansexual	Other	I'd prefer not to say
Cheshire East	229	4	2	1	1	7	5
Cheshire West and Chester	213	10	2	1	1	4	12
Halton	235	4	3	0	1	4	8
Knowsley	215	8	7	1	1	2	18
Liverpool	171	8	7	0	1	1	25
Other	0	0	0	0	0	0	1
Sefton	188	7	8	0	1	1	11
St Helens	352	6	16	5	1	7	10
Warrington	206	13	3	1	1	3	22
Wirral	283	5	2	1	1	2	5
Grand Total	2092	65	50	10	9	31	117

Table 35: Your religion

Across Cheshire and Merseyside 2418 people responded to this question:

	Buddhist	Christian	Hindu	Jewish	Muslim	Sikh	Other	No religion	I'd prefer not to say
Cheshire East	1	170	0	0	0	0	6	80	6
Cheshire West and Chester	2	160	3	0	1	0	6	67	13
Halton	2	165	0	0	0	0	7	69	14
Knowsley	0	179	0	2	0	0	3	55	12

Liverpool	5	125	0	2	3	1	11	57	12
Other	1	0	0	0	0	0	0	0	0
Sefton	2	121	0	2	1	1	1	68	26
St Helens	3	242	0	2	0	0	12	130	14
Warrington	2	139	2	0	8	1	6	73	17
Wirral	5	214	1	0	1	0	7	59	18
Grand Total	23	1515	6	8	14	3	59	658	132

Next steps

Next steps for local Healthwatch

Local Healthwatch across Cheshire and Merseyside will share this report with their respective Clinical Commissioning Groups, Local Authorities and Health and Wellbeing Boards to ensure the findings help inform locally developing Five Year Plans; Integrated Care Partnerships; and Care Communities.

The findings in each Healthwatch area will help identify priority areas 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. 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 conducting 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 attached 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

Acknowledgements

The nine local Healthwatch would like to thank all local authorities, local NHS, and third sector organisations for assisting with promotion of the survey. We would also like to thank the following groups and organisations for their assistance in completing focus group activity:

- Be Yourself LGBTQ+, Knowsley
- BIG Group, Knowsley
- Cheshire Autism Practical Support (ChAPS), Ellesmere Port
- Halewood Youth Zone
- Knowsley Youth Cabinet
- Knowsley Youth Mutual
- Merseyside Society for Deaf People, Wirral
- South & West Cheshire College, Crewe
- Space4Autism, Macclesfield
- Speak Up, Warrington
- Sunflowers, Liverpool
- Tree of Hope, Warrington
- University of Chester
- Wheel Meet Again, Liverpool
- Widnes and Runcorn Cancer Support Group

NHS Long Term Plan Report

Chapter 2 - Healthwatch Cheshire East

Cheshire East

The Local Authority of Cheshire East contains the major towns of Crewe, Macclesfield, Congleton and the commuter town of Wilmslow. There are also a number of other significant centres of population in Sandbach, Poynton, Nantwich, Middlewich, Knutsford and Alsager. Much of the northern part of the Borough and a smaller area to the east lie within the Green Belt.

Over 375,000 people live in Cheshire East which is the third largest unitary authority in the North West. In general, the health and wellbeing of the residents of Cheshire East is good. However, there are still very significant challenges that need to be addressed, including reducing the number of people leading unhealthy lifestyles, preparing for an ageing population, improving mental health and addressing some stark differences between life expectancy across Cheshire East.[1]

In Cheshire East, we received 270 survey responses, consisting of 202 general surveys and 68 specific condition surveys. There were also 33 attendees across three specific focus group events.

Cheshire East

Cheshire & Merseyside Health & Care Partnership

"Be the reason someone receives better care today."

If Cheshire East was a village of just 100 people...

30 Children are overweight or obese by year 6

14 Adults suffer from depression

8 5-16 year olds have a MH disorder

27 Will die from cancer

58 Adults are over-weight or obese

2 Adults under 40 have Type 2 diabetes

57 people are living with a long term condition

12 Will die from heart disease

13 Are smokers

84 Is the average age that women will live to

21 People take less than 30 mins exercise a week

80 Is the average age that men will live to

10 People are over 75

Statistics from PHE are for the Cheshire East Local Authority area, pop: 377,000

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[1] Source: *Cheshire East Borough Profile and Cheshire East Health & Wellbeing Strategy* www.cheshireeast.gov.uk/planning/spatial_planning/cheshire_east_local_plan/local_plan_consultations/place_shaping_consultation/your_place_2011/snapshot_reports.aspx; www.cheshireeast.gov.uk/council_and_democracy/your_council/health_and_wellbeing_board/health_and_wellbeing_board.aspx

Summary of Findings:

What matters most to people in Cheshire East?

- In order to live a healthy life people felt that access to the help and treatment they need when they want it was most important. This was almost twice as important as their second preference of having professionals listen to their concerns.
- In terms of maintaining their health and independence in later life, people surveyed overwhelming felt the most important factor was being able to stay in their own home for as long as it was safe. This was nearly four times more important than their community being able to support them to live their life the way they want.
- When considering managing and using support and treatment, people felt that the right treatment should be a joint decision between them and healthcare professionals and they should be consulted throughout the process. This was nearly three times more important to people than receiving care and support from out of the area if it is not available locally.
- People in Cheshire East told us that being able to talk to their doctor or other health care professional wherever they are was the most 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.

What are the experiences of people with specific conditions?

- People with, or caring for people with autism felt that the time they had to wait to receive their initial assessment, diagnosis or treatment was too long. Waiting times ranged from eight months to three years. Members of our focus group also felt that there was a lack of understanding by front line staff of the autism spectrum. Funding and access to services was a serious issue for the parents of people with autism spectrum conditions
- Respondents with cancer in the main felt that the support they received met their needs. The number of respondents was however very small.
- People with, or people caring for those with, dementia gave mixed responses to the initial support they received; most felt that it either met their needs or somewhat met their needs. Most reported that ongoing care and support was easy to access.
- Heart and lung disease respondents were only a small cohort. They felt that overall initial support was somewhat slow, but four out of five people felt that from diagnosis to treatment the timing was acceptable.
- Of those with other long-term conditions, such as diabetes and arthritis, 11 of the 15 respondents had more than one long term condition. Just over 60% of the respondents felt that the timescale from initial assessment or diagnosis was very good or satisfactory.
- 16 people with a Mental Health condition responded to the survey. 94% of them felt that their overall experience of getting help was either average (6 people), negative (6 people), or very negative (3 people). When asked how easy it was to access ongoing support, 69% felt that it was okay (4 people), difficult (4 people), or very difficult (3 people) to access support.

Survey results

The following sections now break down the results of the 270 responses across Cheshire East to the surveys designed by Healthwatch England. The first sections use the 202 responses to the general 'People's general experiences of health and care services' survey, before breaking down the 68 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.

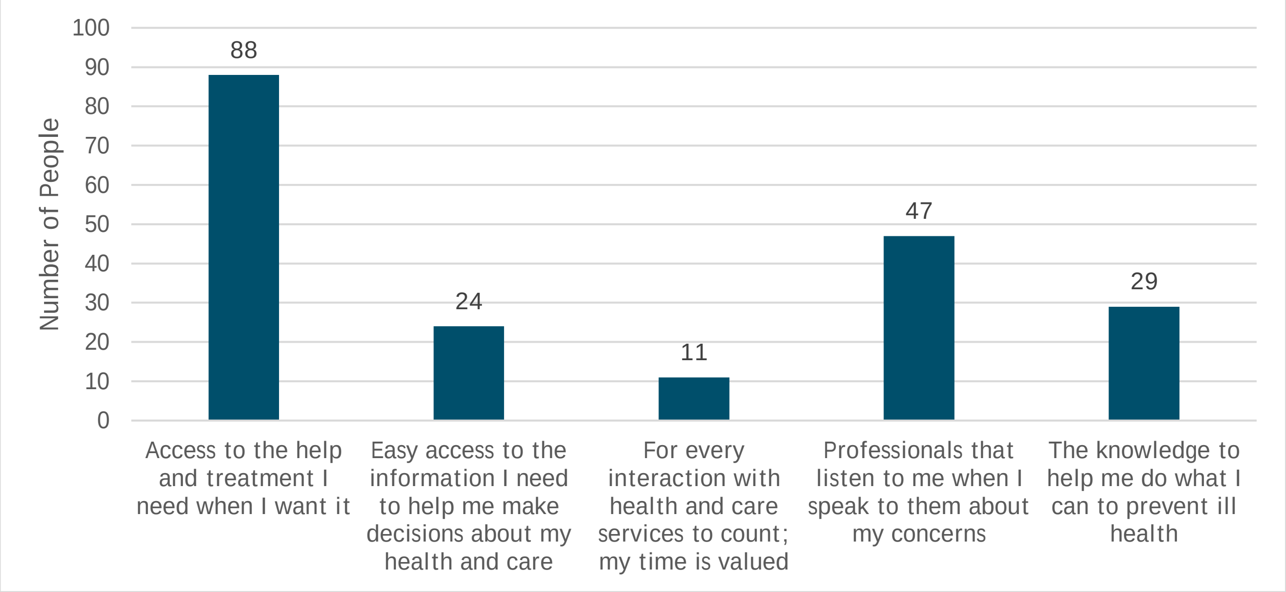
For each of these, people were asked to choose which of a number of options was most important to them. Following this, people were asked to rate each of the options on a scale of 'very important' to 'not important at all'. Therefore, more than one option could be considered 'very important'. Finally, 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, Chart 1 shows that having access to the help and treatment needed when it is wanted was deemed to be most important by people responding to the survey. 199 people responded to this question.

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



However, when asked to rate on a scale of very important to not important at all, all other options were considered either very important or important as the table 1 below shows. Up to 200 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
Access to the help and treatment I need when I want it	175	23	0	1	1
Professionals that listen to me when I speak to them about my concerns	171	25	0	1	0
Easy access to the information I need to help me make decisions about my health and care	141	48	5	1	2
Having the knowledge to help me do what I can to prevent ill health	135	55	5	0	2
For every interaction with health and care services to count; my time is valued	129	54	5	3	2

Help to be healthy

Many people commented on their desire to eat healthily, lose weight and to attend exercise classes with some suggesting these should be made more easily available. People also mentioned stress reduction:

- *“Easier access to support, health walks, support groups, etc. especially in early evening or weekends, variety of times of day/week.”*
- *“Easy access to dietary needs as you get older, easy access to exercise.”*
- *“Access to the things that help lead a healthy life, like exercise and good food is very expensive. Less expensive access to these would benefit all.”*
- *“More healthy options on restaurant menus. Cheaper access to exercise classes.”*
- *“Having dedicated cycle paths to enable me to commute to work safely.”*
- *“Proper recognition and help with the stress and strains of being a full-time carer. It is patronising to say that carers need to have a break and go for a walk or the gym - no use giving this advice without the back-up to follow it through or expecting carers to pay exorbitant costs to get help.”*
- *“For stress levels to be reduced life now seems so fast paced.”*

People commented on the quality of their environment and everyday living, citing air pollution as a common concern:

- *"A healthier environment free from carcinogenic, as found in our water and food."*
- *"Less traffic, very concerned about rising air pollution."*

Access to GP appointments

The accessibility of GP appointments was also important to respondents:

- *"The ability to have access to my GP or health practitioner in a reasonable time. The time spent trying to contact the surgery by telephone at 8am is often very long and having re-dial is a necessity. Then to be told no appointments left and ring at 8am tomorrow a frustration."*
- *"Make it easier to book an appointment with my GP when I need it. Shorter waiting times for operations and a guarantee that they won't be cancelled at the last minute. Better education to patients as to what constitutes as an emergency or routine appointment. Better education of what can be offered by a nurse practitioner so that the GP doesn't have to deal with minor health concerns."*

Person-centred

The ability of professionals to listen to their patients and treat them as individuals was also very important to people:

- *"Somewhere to go for professional advice about health matters which may not be serious, but can be concerning to myself."*
- *"A loving and caring environment. Not computerised 'visit online'."*
- *"Staff who have time to listen - everybody appears to be in a hurry due to pressure of work."*

Self help information

Respondents also told us that information should be more readily accessible regarding any self-help and support services available:

- *"Better awareness of regulated support services available in the area, to avoid having to ask my GP for them first."*
- *"Increase social prescribing to access non statutory services that can help my overall wellbeing."*
- *"For health care professionals to enable access to all health options for patients not just the current options and targets of the NHS."*
- *"Greater provision of preventative medicine and self-management programs."*

Keeping independence and staying healthy in later life

Chart 2 shows that overwhelmingly, when people were asked what was most important to them in respect of keeping independent and staying healthy in later life, they responded that to be able to stay safely in their own home for as long as they could was the most important consideration. 195 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?

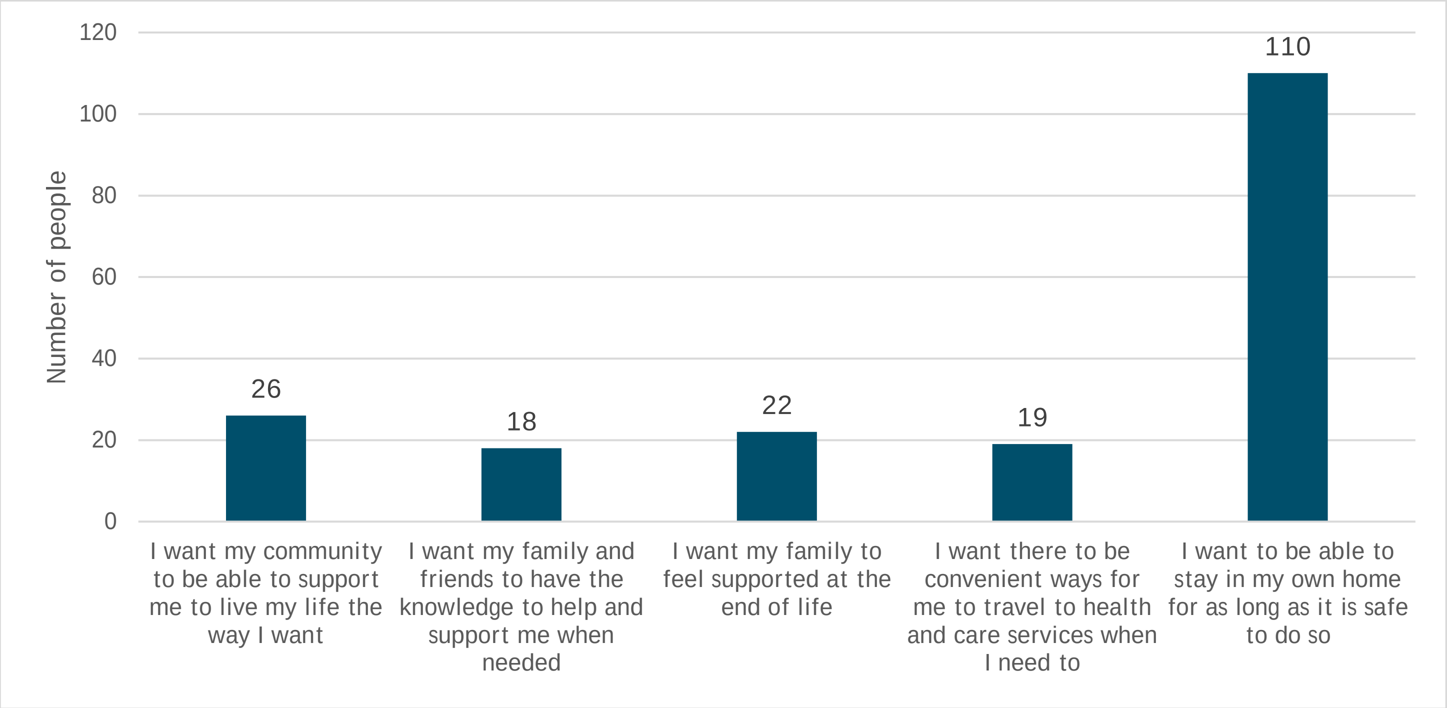


Table 2 shows that other concerns were felt to be either very Important or important, but did not receive such a large response. Up to 196 people responded to this question, but not everyone responded to each option:

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	157	28	8	2	1
I want my community to be able to support me to live my life the way I want	107	62	15	7	2
I want my family and friends to have the knowledge to help and support me when needed	117	67	7	1	0
I want there to be convenient ways for me to travel to health and care services when I need to	148	38	8	1	1
I want my family and me to feel supported at the end of life	157	29	6	2	1

Staying independent

Comments made regarding the desire to keep independence and stay at home included:

- *"Domiciliary care, support at home, personal assistance - affordable and accessible. Adjustments to home."*
- *"To have care and help at home without having to spend life savings. I think being able to stay at home is really important but help needs to be at hand."*
- *"Help to make changes to my home so I can stay in it. Make home help cheaper, it's too expensive and they are only in for two minutes."*

Home visits

It was also felt that both district nursing and home visits by GPs should be more readily available to maintain independence and stay healthy. The need for quality visits was also emphasised:

- *"Domiciliary care must be more careful than adequate and free."*
- *"Extra support at home, independent living skills for those that are less able."*
- *"Health care visits at home."*
- *"If I feel the need for a home visit because I am ill, that someone from my practice does so."*

Public Transport

The question of how to get to medical appointments by public transport when you are no longer able to drive was addressed by many:

- *"Appropriate help is available to stay in my own home and travel around where I live. The bus services are not good and I know of non-drivers who are stranded."*
- *"Transport when I am no longer able to drive to appointments."*
- *"Better public service vehicles, no buses to hospital on Sundays."*
- *"I'm not in need yet in this area but I know transport is a big problem for older people."*

Information on available services

Responses also showed that making information available on care and support services was important to people to assist them in remaining healthy and independent:

- *"Make sure information of available services, support, community resources were shared effectively."*
- *"On going education through life to provide the best opportunity to remain healthy and independent in later life."*
- *"Better understanding of services available, how to access and any costs associated."*

Links between health and care

The continuity of care and communication between health and care services was also considered to be an important factor:

- *"Joined up care between health and social care and voluntary sector. Talking to each other."*
- *"Support services to go to, to prevent having to see GP or hospital."*

Access to GPs

Respondents stated that having easy access to GPs was important to them to help them maintain their health and independence in later life:

- *"A no fuss access to my GP."*

- *“Perhaps having a surgery or other facility available by internet or phone and someone who would send a reply within a specified time e.g. two hours/one day.”*
- *“More access to the doctors instead of waiting for the days for an appointment.”*

Loneliness and isolation

The ability to get out into the community to spend time with other people was also considered to be very important and emphasised strongly:

- *“Share company with like-minded people of a similar age. U3A and similar organisations are very active in my area and provide a very valuable service.”*
- *“More community clubs for the elderly and not run by volunteers to go out and meet other people spend more money on supporting the elderly.”*
- *“More community support for each other.”*
- *“Total connection to all that is available to my family and myself.”*
- *“Better community services that funded by the NHS and are not run by "for profit" companies.”*

Palliative care

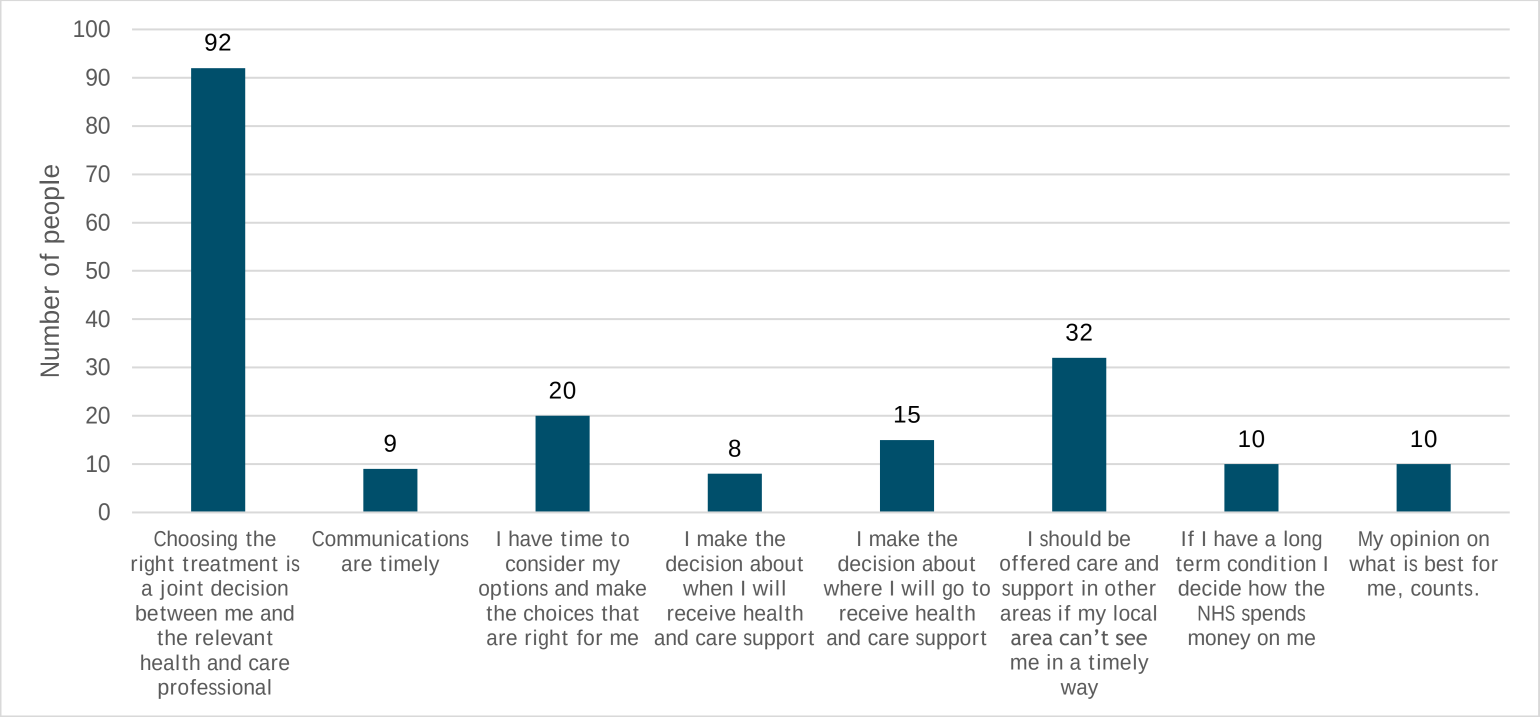
Palliative and End of Life care were considered to be very important and some of the comments we received reflected a desire for more funding to enable more nursing hours:

- *“My recent experience of having a terminally ill husband at home with "end of life" palliative care which amounted to one 20 min visit by a district nurse each week was not impressive.”*
- *“My experience of nursing hours as they need more funding and auditing of the care at end of life. End of life options not varied enough.”*
- *“Palliative care to help me live comfortably when my condition deteriorates.”*

Managing and choosing support and treatment

Chart 3 shows that people we spoke to in Cheshire East 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 in their local area was deemed as the second most important option. 196 people responded to this question.

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



When asked to select how important different factors were on a scale of very important to not important at all, people also deemed making the decision about where they go to receive health and care support and timely communications 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. This is detailed in table 3 below, in order of the options that most people classed as being very important. Up to 199 people responded to this question, but not everyone 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 the relevant health and care professional	133	57	7	1	1
Communications are timely	121	63	9	1	1

I make the decision about where I will go to receive health and care support	112	62	18	3	3
I have time to consider my options and make the choices that are right for me	108	77	8	1	1
I should be offered care and support in other areas if my local area can’t see me in a timely way	97	79	17	1	2
My opinion on what is best for me, counts.	90	86	17	2	0
I make the decision about when I will receive health and care support	80	78	27	7	2
If I have a long term condition I decide how the NHS spends money on me	70	77	43	2	2

Being offered care and support in different areas

People chose to offer comments regarding being offered care and support in other areas if their local area cannot see them in a timely way. People specifically commented on concerns around certain services being offered in some areas but not others. For example:

- *“I don’t care which surgery or hospital I go to, it’s much more important for me to be seen quickly even if it means I have to travel further.”*
- *“Services should be provided locally but without restrictions on being able to get treatment in another areas if desirable. We should be able to choose which NHS Trust we attend for treatment regardless of where we live. If my local NHS hospital is not rated 'outstanding' by the CQC then I want to be treated in a hospital that is. Money should follow me for that treatment. The CCG should not tell me they 'won't pay because they don't have a contract with that Trust'.”*
- *“Closer cooperation [needed] between different Trusts, i.e. no postcode lottery. Some services are provided by West Cheshire, some provided by North Staffs, but Alsager in the middle falls between the two and doesn't have access to this provision.”*

Funding for local services

Furthermore, people told us that they would like to see more services provided locally with good public transport links to make them easy to travel to and from. This was also articulated through support for keeping local community hospitals open and having them hosting more services. This also linked into comments that called for more investment in frontline services. For example:

- *“Keep community hospitals like Congleton War Memorial. I struggle to get to Macclesfield or Crewe.”*
- *“[Would like] more investment in front line services. Happy to see things like fertility being private only.”*

Staff

Along with investment, it was recognised that funding challenges and demand for services was putting the NHS and particularly its staff under strain. We received praise from various people regarding NHS staff. For example:

- *"I think the NHS do a fantastic job, they're under such pressure and strain. Any dealings I've had with them I can only praise."*

Communication

In regard to staff, 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:

- *"Give easier access to appointments and doctors. It isn't always necessary to see a doctor. Sometimes emailing or speaking would be enough."*
- *"[Would like] continuity of any health professionals seen and any info to be shared in simple language as patients don't always think about any questions they may have until later."*
- *"Communication between all Multi-Disciplinary Team members and looked at as a whole person not just a symptom."*
- *"More and better information on all options that are available."*

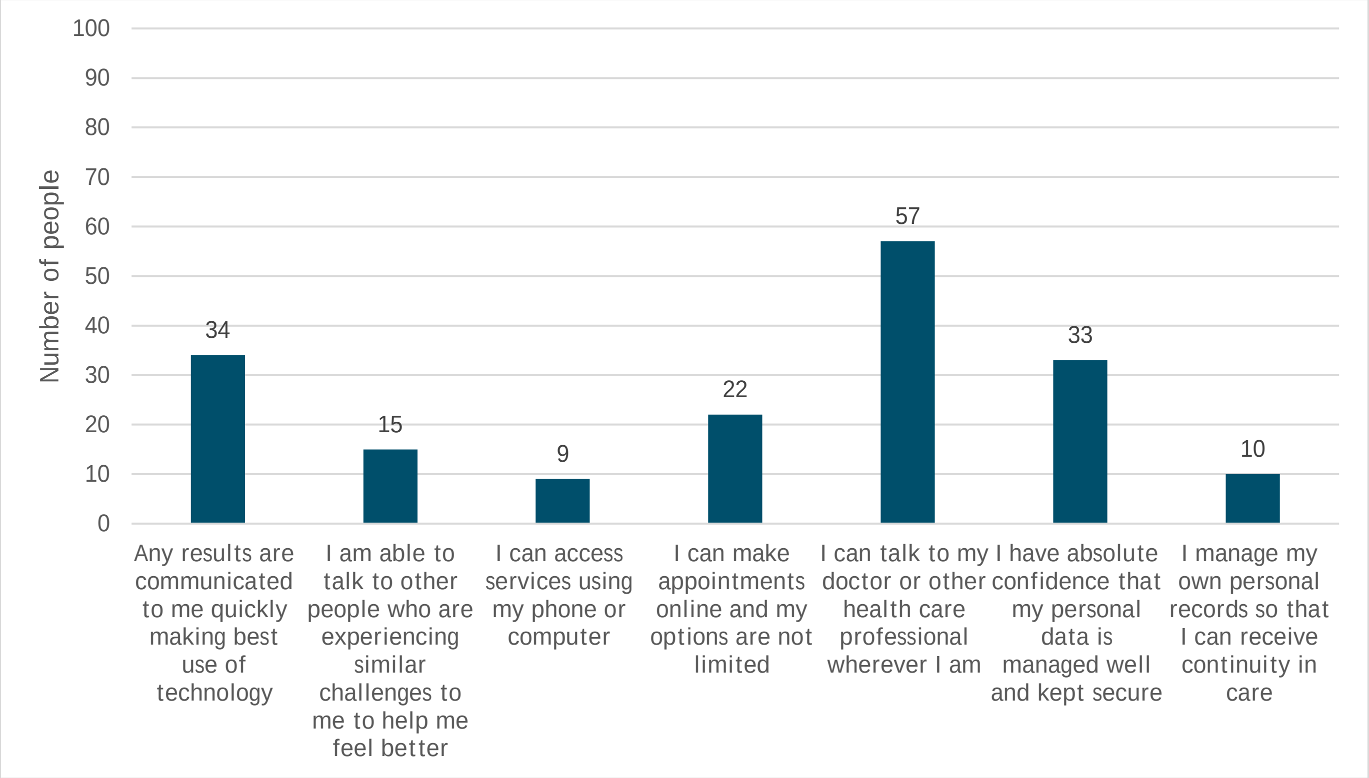
Engaging people in health service delivery

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.

Chart 4 shows that people in Cheshire East told us that being able to talk to their doctor or other health care professional wherever they are was the most 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. 180 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 also deemed accessing services using their phone and computer to be very important. It must be noted that all options offered to people were generally considered to be very important or important. People managing their own personal records so that they can receive continuity in care, and being able to talk to other people who are experiencing similar challenges 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 197 people responded to this question, but 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
I have absolute confidence that my personal data is managed well and kept secure	120	53	23	1	0
Any results are communicated to me quickly making best use of technology	118	53	20	2	4
I can talk to my doctor or other health care professional wherever I am	104	56	30	4	3
I can access services using my phone or computer	103	56	29	4	5
I can make appointments online and my options are not limited	90	51	34	9	8
I manage my own personal records so that I can receive continuity in care	70	71	45	5	5
I am able to talk to other people who are experiencing similar challenges to me to help me feel better	64	75	42	8	6

Use of technology

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 easily able to access records and results, whereas others felt that they would like to see less technology. Comments included:

- *"More online appointments for all services so working people can manage their time off. Work better with choices of various hospitals so if someone works a long way from home they could attend appointments there."*
- *"I think results could be emailed or collected from your GP. I think easy access to records and making appointments is the way forward."*
- *"Better choice of appointments for those that have work commitments. Not everyone has the time at 8am to fight in a queue for an appointment."*
- *"I do not have access to a computer or know how to use one. I have a telephone and postal address."*

Other comments referred to the importance of online support groups enabling them to link with other people living with similar conditions. For example:

- *“Currently, there is a Facebook support group for my condition, which is very helpful when you have something rare. The GPs and Macmillan nurses do not really understand it.”*

Communication

Other comments stressed the importance of speaking to medical professionals, either face-to-face or over the telephone. People told us they wanted to feel listened to and their wishes taken into consideration. For example:

- *“I want to be able to 'speak' to another human be it in person, phone or email with regards appointments and results. I want to be able to speak and see a doctor, not have a telephone consultation or a member of reception staff make decisions as to who I go and see. I think it dangerous for non-medical staff to be making decisions on my health and vital 'clues' to diagnosis are missed when the GP does not see the patient.”*
- *“Listening to what I want and taking my wishes into consideration, not being told what I need. I know me. Talk to me, not about me. Being treated with dignity and respect at all times.”*

We also received comments about inefficiencies in referral processes. For example:

- *“When doctor is seeing a patient and he is writing to his secretary to book a hospital appointment why can’t he simply fill in a standard form that goes off as an email to the hospital immediately? I recently had to wait three weeks for my surgery to type up and send off a simple knee scan letter due to admin backlog. Very inefficient system.”*

What people expect during service change and transformation

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

- *“My concern is living in an area with massive new housing developments - population will almost double - without any addition to services. Surgery is always busy - 4 to 6 week waits for appointments and blood tests. It will only get worse.”*
- *“Leighton Hospital has a serious A&E waiting time crisis. It now covers a much greater area and population and cannot cope. More walk-in centres, GP appointments, out of hours services, nurse appointments in local communities could have a major impact on A&E & hospitals in general.”*

In the future people told us they would like to see more emphasis on patient-centred care, more access to community-based services, and changes in the way health records are managed. For example:

- *“A fundamental transformation in how doctors and healthcare professionals are educated and trained, so that the new emphasis is on partnership of care with patients, and not for patients.”*
- *“Better promotion of services. More access to local community-based services such as nurses.”*
- *“All health records shared on one system.”*

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

As part of our research activity, Healthwatch Cheshire East conducted a focus group with students from South and West Cheshire College's Crewe campus 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 30th April 2019, and was attended by 16 health and social care students.

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, which could indicate that the NHS is struggling to reach young people in communication.

Training and support for NHS staff

The students talked about a lack of staff training and support. It was acknowledged that pressures on NHS services were being caused by insufficient GPs and nurses. They felt that the removal of bursaries for trainee nurses has caused a fall in new recruits to the profession. Many of the students had initially considered this as a career but felt that it was no longer an option as they did not have the financial support or capacity to do so.

Accessibility of services

Accessibility of GP and specialist services in the local community was discussed. Attendees felt that specialist services tended to be grouped together meaning longer waiting lists. It was felt that travelling a long way, difficulties in families visiting, and inadequate transport links added to a poor experience and could put people off accessing treatment.

Lack of mental health support

Student attendees told us that it is very hard to get support for mental health conditions. One person talked about a waiting list to get onto a waiting list. They felt uncomfortable having to do group meetings prior to being able to access a counsellor. Some told us that they were not comfortable with this and by the time patients recognise they need support they were often in crisis.

Inconsistency

People attending the focus group were concerned about not being able to see the same GP. They said that this results in often being forced to repeat why they were attending, GPs taking time to read previous notes form other GPs, and then telling patients their time is up. They felt this approach lacks empathy. There were also perceived inconsistencies in standards of services and treatment even within the same GP Practice or health centre. The example was given that some allowed self-referral for physio where others did not.

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 and people told us that they wanted professionals to "*say it as it is*".

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 68 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	7
Dementia	15
Heart and lung diseases	7
Learning disability	1
Long-term condition e.g. diabetes, arthritis	16
Mental Health	16

Table 6: Who are you responding on behalf of?

	Myself	Someone else
Autism	3	0
Cancer	5	2
Dementia	4	11
Heart and lung diseases	5	2
Learning disability	0	1
Long-term condition e.g. diabetes, arthritis	9	7
Mental Health	8	8

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

	Yes	No
Autism	0	3
Cancer	7	0
Dementia	7	8
Heart and lung diseases	6	1
Learning disability	0	1
Long-term condition e.g. diabetes, arthritis	7	8
Mental Health	7	9

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	5	1	0
Dementia	6	2	6
Heart and lung diseases	3	1	3
Learning disability	0	1	0
Long-term condition e.g. diabetes, arthritis	8	4	4
Mental Health	2	9	5

Autism:

- “Support available for those diagnosed with an eating disorder and autism was lacking.”
- “The only support available was with the third sector, Space4Autism. I don't know what we would have done without their support. The NHS only offer help to those in crisis.”
- “My daughter has autism, ADHD, SPD and anxiety. After diagnosis there was very little help in terms of support and management. This makes everything so much harder. What could the NHS do: They could offer practical support and help after diagnosis. They could reduce waiting lists so diagnosis doesn't take years.”
- “We would like to see more support for adults with autism and mental health issues, particularly eating disorders.”

Dementia:

- “A memory test had to be requested twice, this caused months of delay.”
- “Proper social care for all. Dementia for example is a life changing and terminal illness with no cure but is still treated as a 'social' disease instead of a disease of the brain.”
- “Dementia rehab came to visit and provide some info about support.”
- “My surgery is now making an effort to make appointment's etc. Easy for my husband. They will also do the bloods tests instead of going to the hospital. They are planning to do a dementia care plan.”
- “I am struggling with my diagnosis and there is no professional who I can sit down with to talk about it. I need this.”

Heart and lung diseases:

- “Discharge letters are very slow in coming and sometimes people have to park, incurring parking charges because a patient has to wait for a letter.”
- “Accessing help was very difficult, it took two years. Once accessed the system it was very helpful.”
- “Care is helpful. I understand and accept resource limitations.”
- “Initial diagnosis and care were very quick. Full diagnosis didn't happen until 6 years later. The condition needs constant monitoring 6 months appointments are over 2 years apart.”

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

- “The services that help me realise how conditions affect day to day living. Physio therapists, occupational health and carers hub.”
- “I see a specialist nurse every 3 months. Yes, it is a great support but availability for appointments is difficult.”
- “Provide me with clear information. A designated person who I can contact to sort out prescriptions and information/help.”
- “After M.R.I scan, lumber puncture organised this was done in a short space of time and results came quite quickly.”

Mental Health:

- “My wife was prescribed medication with which she suffered some side effects. Our GP took her off for six weeks to see if anything changed, but when seen again by the psychiatrist she said the GP should never have taken her off the medication and as a result could not be put back on the same drug.”
- “Better mental health services and more resources for preventative services and lower level services such as counselling, CBT [Cognitive Behavioural Therapy] etc, especially coping with stress which I think is a big factor for people over eating, not having the energy to exercise and contributing to other serious illnesses. There is currently a waiting time of up to a year for access to counselling in this area.”
- “Luckily I could afford private healthcare - the wait for mental health treatment was over 12 months and I was off work until I had received the treatment I needed.”
- “CWP [Cheshire and Wirral Partnership] has completely ignored me. I am appalled at the unprofessionalism and expected much better. My GP says they can't do anymore for me... I do feel like giving up completely as I don't 'think I can cope with living like this.”

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	1	0	0	2	0
Cancer	4	3	0	0	0	0
Dementia	4	3	6	1	0	1
Heart and lung diseases	0	3	3	1	0	0
Learning disability	0	0	1	0	0	0
Long-term condition e.g. diabetes, arthritis	6	5	2	2	1	0
Mental Health	0	1	6	6	3	0

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

Condition	Yes	No
Autism	0	3
Cancer	5	2

Dementia	9	6
Heart and lung diseases	6	1
Learning disability	0	1
Long-term condition e.g. diabetes, arthritis	12	4
Mental Health	6	10

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	0	0
Cancer	1	2	1	0	1
Dementia	2	4	2	0	1
Heart and lung diseases	1	4	1	0	0
Learning disability	0	0	0	0	0
Long-term condition e.g. diabetes, arthritis	4	5	0	1	1
Mental Health	0	3	2	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	Slow	Very slow	**Don’t know**	Ok	Fast	Very fast
Autism	0	2	1	0	0	0
Cancer	2	1	0	1	2	2
Dementia	3	0	2	3	6	0
Heart and lung diseases	3	1	0	3	0	0
Learning disability	0	0	1	0	0	0
Long-term condition e.g. diabetes, arthritis	1	3	0	4	3	3
Mental Health	3	6	1	3	1	1

Autism

- *“Eight months”*
- *“We waited three years.”*

Cancer

- *“The waiting time is now 10 months.”*
- *“There was no delay at all from seeing my GP through specialist examination CT scan etc. All very timely.”*

Dementia

- *“About three weeks.”*
- *“The support was offered quite quickly but we did not take up the support for over a year.”*
- *“I initiated referring my husband to a unit which specialises in his dementia, we were seen quickly.”*
- *“It took more than one year between consulting a GP and getting an appointment with the dementia consultant.”*
- *“We waited six months to go to the memory clinic.”*
- *“A memory test had to be requested twice, this caused months of delay.”*

Long term conditions

- *“Diagnosis made that day.”*
- *“12 months to see a Lipoedema nurse. and now for bariatric surgery and counselling for my eating issues it’s also a 12 month wait.”*
- *“It was four weeks after last scan to tell me I had Parkinson's.”*
- *“We found out by accident that he had Parkinson’s by seeing a different doctor but we had to travel to Oldham Hospital to be seen earlier but he also had COPD [Chronic Obstructive Pulmonary Disease] and a pacemaker.”*

Mental Health

- *“Waiting over a year for support.”*
- *“Six months”*
- *“Around 18 months. and I am still waiting to talk to mental health therapy.”*
- *“After calling the GP surgery I had an appointment within a week.”*
- *“I self-referred and waited 2 weeks before I was 'assessed' by phone.”*
- *“It was going to be over 12 months which was ridiculous, so we pursued another avenue and went private.”*
- *“As it was a serious situation it was dealt with quickly. A police officer rang on my mum's behalf and she was seen at their house within days.”*

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

Condition	Slow	Very slow	Ok	Fast	Very fast	**Don’t know**
Autism	0	2	0	0	0	1
Cancer	0	1	2	2	1	0

Dementia	3	0	3	6	0	2
Heart and lung diseases	3	1	3	0	0	0
Learning disability	0	0	0	0	0	1
Long-term condition e.g. diabetes, arthritis	1	3	4	3	3	0
Mental Health	3	6	3	1	1	1

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

Condition	Yes	No
Autism	0	3
Cancer	6	1
Dementia	2	13
Heart and lung diseases	5	2
Learning disability	0	1
Long-term condition e.g. diabetes, arthritis	10	3
Mental Health	10	5

If you accessed support, what aspects worked well?

Cancer

- *"Macmillan Cancer St Luke's Hospice."*

Dementia

- *"Help with knowledge and accessing benefits available and applying for financial and health power of attorney."*
- *"Carer's support groups, especially at Cerebral Function Unit/Salford Royal Hospital."*
- *"A visit from a dementia nurse annually to assess my progress."*
- *"Regular checks (weekly) by district nurse."*
- *"The Alzheimer's Society have been very supportive."*

Heart and lung disease

- *"Seeing a consultant."*
- *"Ongoing support is okay."*
- *"Help given by Age UK in Macclesfield."*

Learning disability

- *"Information from Parkinson's UK and post and local group."*
- *"Multiple Sclerosis nurse regularly also email as needed extra support between appointments."*

- *"Made aware of support by MS nurse who visits Leighton weekly from Stoke-on-Trent hospital."*
- *"Carers coming in to give practical/personal assistance."*

Mental health

- *"Individual therapy, dietetic input."*
- *"My wife was prescribed medication with which she suffered some side effects. Our GP took her off for six weeks to see if anything changed, but when seen again by the psychiatrist she said the GP should never have taken her off the medication and as a result could not be put back on the same drug."*

If you accessed support, what could be improved?

Cancer

- *"Chemotherapy could have been delivered in Leighton not Manchester - less travel, less stressful."*

Dementia

- *"I was satisfied with the support offered."*
- *"Being told what is around. I myself found a dementia group in Stockport, no one suggested it."*
- *"An opportunity at regular checks for both of us to discuss progress of the disease and possible help*
- *"A more in-depth appointment, and the opportunity for my partner to explain how my condition affects my everyday life."*
- *"Respond quicker and we wanted people to tell us what we needed to know. We don't know anything about dementia."*

Long term conditions

- *"Knowledge and attitude of specialist staff."*
- *"Leighton Hospital should extend hours of neurological department."*
- *"Availability of support is limited, and when you need an appointment there is waiting time."*

Mental health

- *"Taking time to listen instead of writing out a prescription within the first few minutes of entering the office."*
- *"More psychiatric reviews, especially after a long 4-year delay and better review/monitoring of drugs prescribed."*
- *"To be matched with a more suitable CBT therapist. For the therapy to be more tailored."*

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

Conditions	Yes	No
Autism	0	3
Cancer	7	0

Dementia	12	3
Heart and lung diseases	7	0
Learning disability	0	1
Long-term condition e.g. diabetes, arthritis	13	2
Mental health	9	6

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

Conditions	Very slow	Slow	OK	Fast	Very fast
Autism	n/a	n/a	n/a	n/a	n/a
Cancer	1	2	0	3	1
Dementia	0	2	5	4	0
Heart and lung diseases	0	3	3	1	0
Long-term condition e.g. diabetes, arthritis	1	3	4	3	2
Mental health	3	2	2	2	0

Please tell us more about the length of time you waited.

Cancer

- *“10 months”*
- *“One week”*
- *“Six months”*
- *“Six months”*

Dementia

- *“After referral by our GP the wait to see the specialist was about six weeks and tests were done very quickly after that.”*

Heart and lung diseases

- *“First appointment was OK, but afterwards I was not informed of the results for four months in which time I could have died. The admin is what lets this service down.”*
- *“Initial letter in August. Appointment to have MRI scan in September. Old age psychiatry in Stockport in October, neuro psychologist in January.”*

Long term conditions

- *“Referred to hospital within two months of diagnosis.”*
- *“12 months wait for bariatric consultant and six months for gastro appointment and I’m meant to be on barrettes monitoring programme.”*
- *“Not too long, my dad went to see a doctor at Jocelyn Solly House.”*
- *“Couple of months but symptoms unusual.”*

- *“Six months”*

Mental health

- *“4/5 months”*
- *“When I complained to our GP about my concerns regarding my wife's mental state, things moved on pretty quickly from then on.”*
- *“Six months”*
- *“Very fast appointment we received.”*
- *“The length of the wait further intensified symptoms.”*
- *“Two weeks after being diagnosed.”*

Table 17: How easy did you find it to access ongoing support after you were diagnosed or assessed?

Conditions	Very easy	Easy	Difficult	OK	Very difficult	Don't know	Not applicable
Autism	0	0	0	0	2	1	0
Cancer	0	1	0	1	0	0	2
Dementia	0	1	0	7	3	1	3
Heart and lung diseases	0	0	3	4	0	0	0
Learning disability	0	0	1	0	0	0	0
Long-term condition e.g. diabetes, arthritis	2	4	1	4	2	1	0
Mental health	2	1	4	4	3	0	1

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

Conditions	Yes	No	Somewhat
Autism	0	3	0
Cancer	3	0	0
Dementia	6	4	3
Heart and lung diseases	3	1	3
Long-term condition e.g. diabetes, arthritis	7	1	7
Mental health	2	8	6

Please explain how the care did or did not meet your expectations and how it could have been improved.

Autism

- *“I expected to be referred to other specialists.”*

- *“The only support available was with the third sector, Space4Autism. I don't know what we would have done without their support. The NHS only offer help to those in crisis.”*

Cancer

- *“All treatment seemed organised.”*
- *“I expected to have surgery or radiotherapy but I am on chemotherapy tablets which is marvellous.”*

Dementia

- *“Would welcome day care availability locally, without having to pay for transport to a centre 13 miles away.”*
- *“I was satisfied with support given.”*

Heart and lung diseases

- *“While in hospital the care had been superb but aspects fall short when it comes to admin translation.”*
- *“Once the system was accessed the help and advice was available and helpful. It was the initial access that was difficult and information is still difficult to access.”*
- *“Distance, 40-mile round trip.”*

Long-term condition

- *“Seen on a regular basis.”*
- *“Long term it become apparent that the knowledge of specialist staff was woefully out of date.”*
- *“M.R.I scan took ages as diagnosis was vague had to have a scan on a car park as a scanner brought in due to large waiting list.”*
- *"Waiting times.”*
- *“Medication changes review needs improving.”*

Mental Health

- *“Told to ring talking therapies, which doesn't work. I was with CMHT for years and it helped but since being signed off in November 2017, I have been left with no support. My mental health is the worst I've ever known. I've become agoraphobic, severe anxiety but totally unsupported and my GP just isn't interested.”*
- *“No support has been offered. Lack of care and empathy, treated like we were animals in a feeding zoo.”*
- *“Tons of booklets/handouts /sheets of information was given but more practical help would have been better. In the early days, money seemed to be the deciding factor, if we have it, we then have to organise it ourselves, no one will recommend or suggest.”*
- *“My operations were quick, but my parents and wife because they are in their 70s and 80s very slow, waiting for replies.”*

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?

Conditions	Yes	No	Somewhat
Autism	0	2	1
Cancer	6	0	1

Dementia	5	7	3
Heart and lung diseases	3	2	2
Learning disability	0	1	0
Long-term condition e.g. diabetes, arthritis	8	6	1
Mental health	4	8	3

Please explain how the care did or did not meet your expectations and how it could have been improved.

Cancer

- *"It made life easy for me to plan each stage - Chemotherapy/Operation/Chemotherapy."*
- *"The only improvement could be, an increase in doctors and consultations as they have to double book. Patients and the wait in clinic can be rather long."*

Dementia

- *"I was satisfied with the time taken."*
- *"We did find that initially care and support was good, but we had to ask for appointments with specialist after a couple of years as we felt a bit forgotten."*
- *"Went online/word of mouth to access various courses on Alzheimer's and support group. GP referred us to a specialist in Macclesfield, who said my husband is lazy and not ill. Second specialist finally agreed he had dementia."*
- *"Phone calls are often difficult - having to leave messages - then not hearing from services."*
- *"The service from my GP and practice is first class."*

Heart and Lung diseases

- *"Discharge letters are very slow in coming and sometimes people have to park, incurring parking charges because a patient has to wait for a letter."*
- *"Care is helpful. I understand and accept resource limitations."*
- *"I was never given a letter confirming diagnosis which meant I couldn't access some services."*
- *"It always seems very difficult to access."*

Long term conditions

- *"It was impossible to get answers to questions from a doctor/consultant, as appointments were not offered."*
- *"Once I got a gastroscopy letter on the day of the procedure and I work full time I can't just drop my job to go. But the nurse gave me a lecture about missing the appointment. I'm sorry but I consider it your issue. If it's that close you should have called me."*
- *"After MRI scan was ordered this was done in a short space of time and results came quite quickly."*
- *"Time waiting needs improving. Meds review needs to be quicker."*
- *"Diagnosis took about eight weeks to get an MRI scan to confirm what was diagnosed in days."*

Mental Health

- *"I haven't been offered any support whatsoever. I've tried talking therapies, useless. For over a year and four referrals from my GP. Not heard a thing and GP not interested. Feel suicidal and have given up as sick of being treated so appallingly."*
- *"Have not yet accessed talking therapy/CBT, still on the waiting list."*
- *"There were a couple of times due to work commitments and illness I was unable to attend a session and trying to contact the right person to inform the clinician and rearrange was difficult. I was told someone would be back in touch and they never did. Even the telephone numbers I was given on the paperwork supplied to me were not correct."*

Time spent travelling to access support and care

Table 20: What is your main means of transport?

Conditions	Another person's car	Bicycle	Bus	Other	Own car	Taxi
Autism	1	0	0	0	2	0
Cancer	0	0	1	0	6	0
Dementia	2	1	1	1	10	0
Heart and lung diseases	0	0	0	0	7	0
Learning disability	0	0	0	0	1	0
Long-term condition e.g. diabetes, arthritis	1	0	0	0	13	1
Mental health	2	0	2	3	8	1

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

Conditions	Less than 30 minutes	30 minutes to 1 hour	1 - 2 hours	Over 2 hours
Autism	0	1	0	2
Cancer	1	2	1	3
Dementia	5	8	0	2
Heart and lung diseases	2	4	1	0
Learning disability	0	0	0	1
Long-term condition e.g. diabetes, arthritis	2	8	4	0
Mental health	4	8	3	0

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

Conditions	Less than 30 minutes	30 minutes to 1 hour	1-2 hours	More than 2 hours
Autism	1	0	2	0
Cancer	0	1	3	2
Dementia	3	7	2	3
Heart and lung diseases	1	5	1	0
Learning disability	0	0	0	1
Long-term condition e.g. diabetes, arthritis	3	4	5	2
Mental health	3	6	5	1

What is most important to you?

Table 23: When first seeking help

Conditions	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	2	1	0
Cancer	1	6	0
Dementia	7	6	1
Heart and lung diseases	2	2	2
Long-term condition e.g. diabetes, arthritis	4	7	1
Mental health	2	10	3

Table 24: When you received a diagnosis and explanation of treatment or support options

Conditions	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	3	0
Cancer	3	4	0
Dementia	5	7	1
Heart and lung diseases	1	2	2
Long-term condition e.g. diabetes, arthritis	6	4	2
Mental health	8	5	2

Table 25: During your initial treatment or support

Conditions	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	2	0
Cancer	2	5	0
Dementia	4	8	1
Heart and lung diseases	2	1	2
Long-term condition e.g. diabetes, arthritis	8	2	2
Mental health	7	7	1

Table 26: During your long-term support

Conditions	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	3	0	0
Cancer	2	4	0

Dementia	4	9	1
Heart and lung diseases	2	1	2
Long-term condition e.g. diabetes, arthritis	7	2	2
Mental health	8	6	1

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?

Conditions	A lot of support	Some support	I don't need support	Don't know
Autism	0	2	0	1
Cancer	4	3	0	0
Dementia	3	10	0	2
Heart and lung diseases	1	5	1	0
Learning disability	0	0	0	1
Long-term condition e.g. diabetes, arthritis	3	7	2	2
Mental health	5	10	0	1

What could the NHS do to help you stay healthy or manage any condition you have?

Autism

- *"Support for autism and eating disorders."*

Cancer

- *"Just give lots of advice and build confidence."*
- *"Regular check-ups."*
- *"The NHS currently gives me a lot of support with ongoing CT scans and chemotherapy tablets."*
- *"Keep the NHS going with some slight improvements. Treat doctors and nurses with more pay and respect."*

Dementia

- *"NHS do provide literature which is very helpful but maybe annual follow up appointment would be helpful. We had to ask for follow up appointments."*
- *"Keep in contact - Make appointments easy to access for dementia patients and carers. No long queuing"*

- *"Regular checks on progress of disease. Advice to wife on handling, to save having to search it all out ourselves. My husband is seen once a year better now it's at home and not in the local hospital."*
- *"Be aware of my Alzheimer's diagnosis and check me over in meaningful way every 6 months."*
- *"I need more time away from the daily drudgery of being nursemaid - he's like a 2-year old and needs constant care. Cannot be let out on his own - Has no sense of direction, road sense etc."*

Heart and lung diseases

- *"Keep funding the respiratory teams."*
- *"Nothing, have been given all the help and support with my condition."*

Long term conditions

- *"Provide up to date and holistic advice."*
- *"Start listening to symptoms better and not assuming the patient is being paranoid"*
- *"Improve communication and streamline processes esp. between GP and hospital and specialist services."*
- *"Admin and customer service are shocking and lets the doctors, consultants and nurses down because they are generally brilliant- across the whole of the NHS. Admin staff can be so rude and dismissive, and disorganised too."*
- *"Just keep doing what you are doing."*
- *"At every large hospital (800 beds) there should be a neurological dept, with specialist staff."*
- *"Stress management support."*

Mental health

- *"I would just like my referrals to stop being ignored. I struggle day to day and I feel very isolated and my anxiety is stopping me from doing anything. I just want some mental health support."*
- *"Long term support and therapy until I feel able to manage my mental health independently"*
- *"Stress, anxiety and mindfulness workshops possibly alternative prescriptions like yoga on prescription"*
- *"Provide more counselling or support groups for people with mental illnesses."*
- *"Keep checking my health and update on ongoing medication they require."*
- *"Provide resources to be able to give the guidance and advice immediately when I am concerned or worried about a condition, then prompt treatment thereafter."*
- *"Surgeons and nurses work there guts out, but support through there hospital slow and hopeless."*

Further comments

Cancer

- *"I had a bad start to my journey from November 2015 to June 2016. OK from July 2016 onwards."*
- *"I am fortunate to live near Macclesfield where doctors from the Christie hospital hold clinics. The treatment I have had has been first class, no complaints at all."*
- *"Nurses work long hours for very little pay, don't get paid over time."*

Dementia

- *“My surgery is now making an effort to make appointments etc. Easy for my husband. They will also do the bloods tests instead of going to the hospital. They are planning to do a dementia care plan.”*
- *“I am struggling with my diagnosis and there is no professional who I can sit down with to talk about it. I need this.”*
- *“Receptionists are usually very helpful.”*
- *“We feel the amount of contact from NHS services has been poor. We are unsure of the future and need more support, advice, information.”*
- *“My general opinion of the NHS is a good one. No complaints.”*

Heart and lung diseases

- *“Please charge drunks for treatment at A&E.”*
- *“National program for example; bowel cancer, aortic aneurysm is to be commended.”*
- *“Initial diagnosis and care were very quick. Full diagnosis didn't happen until six years later. The condition needs constant monitoring six months appointments are over two years apart.”*
- *“Help with cost of residential care as it becomes necessary.”*

Long term conditions

- *“Not always easy to get advice on phone as difficult to get through.”*
- *“My dad was my mum's carer but due to failing health I now care for both of them.”*
- *“Visiting your own local hospital is better for my own health well-being, it cuts down on stress which doesn't help my condition.”*
- *“Overall quite happy.”*

Mental Health

- *“CWP has completely ignored me. I am appalled at the in professionalism and expected much better. My GP says they can't do anymore for me.”*
- *“I have a community psychiatric nurse but they are not very good. Ended up in hospital three times in four weeks.”*
- *“Both my wife and myself spent time in Her Majesty Armed Forces and unless there is physical disability, there is little or no help from any other than the NHS.”*
- *“There are a lot of places to visit to help in recovery and helping with confidence but no door to door transport.”*
- *“I am the carer to my mum who suffers with Agoraphobia, depression, anxiety and social phobia so some of these questions (travel) do not apply as she has been housebound for over 3 years.”*

In focus: what are the main issues for people with autism and carers for people with autism in health and care?

As part of our research activity, Healthwatch Cheshire East conducted focus groups with people with Autism Spectrum Conditions and Parent Carers of people with Autism Spectrum Conditions from Space4Autism in Macclesfield in order to gain the views and experiences from people who can struggle to have their views heard in regard to health and care. These focus groups took place on the evening of 23rd April 2019 and the morning of 24th April 2019, and were attended by 17 individuals in total.

Main issues raised by the people with Autism Spectrum Conditions:

- Knowledge / training around Autistic Spectrum Conditions - many health professionals only have a basic understanding.
- Systems and Processes - many standard health systems and processes are not autism friendly.
- Funding/Access to services - there is general lack of support services and where they do exist, they are underfunded/oversubscribed.
- Engaging with community in developing strategies and designing services - greater use of co-production.
- Knowledge - lack of understanding or blanket misunderstanding of autism spectrum disorders and how the experience of using health services is affected by these condition(s).
- Training - Need for front line delivery staff to undergo training to improve their understanding of autism spectrum conditions and how this affects the care journey for adults with autism spectrum conditions. It appears that how people are dealt with is very inconsistent.

Some interesting comments included:

- *"[We] feel many Health professionals lack knowledge/experience of Autism."*
- *"Ten-minute appointments don't work for someone with autism."*
- *"I find it hard to process the health information I am given - written info is not Autism friendly."*
- *"[I] feel I am shunted into services that are not appropriate, then from one to another. [This] just becomes a 'tick-box' exercise."*

Main issues raised by Parents of People with Autism Spectrum Conditions:

Systems and processes - many of the processes involved in accessing health care are not necessarily tailored for people with Autism Spectrum Conditions and where they do exist are not consistently managed/delivered well.

Funding/Access to services - There is a general lack of services and it appears something of a post code lottery. It would appear funding is the issue and where funding has been raised it is not through either health or social care commissioning but through the hard work of third sector/ charity organisations. There is also a need to support adults with autism spectrum conditions to navigate the care system and their own personal care journeys and to ensure that front line delivery staff in the NHS understand their needs.

Strategy/Service development - The feeling of those living with Autism is that they are not listened to and when it comes down to statutory bodies developing strategies / designing services the idea of "Co-production" is almost non-existent.

Some interesting comments included:

- *"The NHS' [front line delivery staff] understanding [of Autism spectrum conditions] is poor."*
- *"The 111 online service is easier than waiting on the [111] phone [service]."*

healthwatch

NHS Long Term Plan Report

Chapter 3 - Healthwatch Cheshire West

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.[2]

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.

Cheshire West

Cheshire & Merseyside Health & Care Partnership

"Be the reason someone receives better care today"

If Cheshire West was a village of just 100 people...

33 Children are overweight or obese by year 6

16 Adults suffer from depression

9 5-16 year olds have a MH disorder

28 Will die from cancer

59 Adults are over-weight or obese

3 Adults under 40 have Type 2 diabetes

57 people are living with a long term condition

11 Will die from heart disease

20 Are smokers

83 Is the average age that women will live to

19 People take less than 30 mins exercise a week

80 Is the average age that men will live to

8 People are over 75

Statistics from PHE are for the Cheshire West and Chester Local Authority area, pop: 332,000

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[2] 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

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.
- 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.

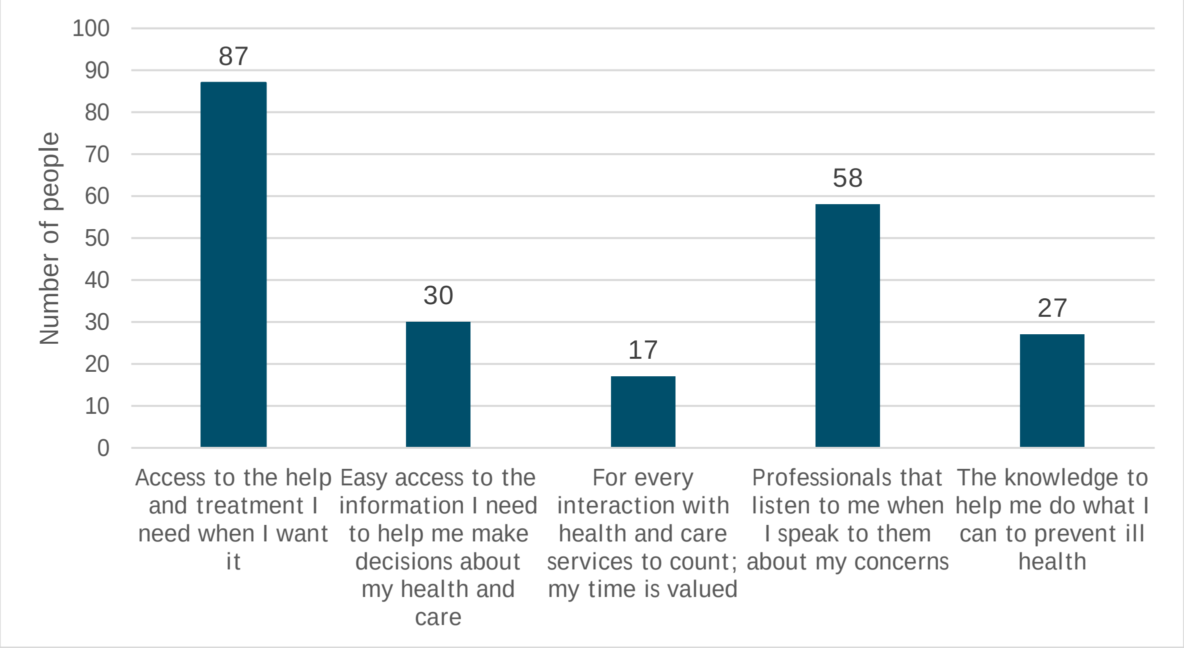
For each of these, people were asked to choose which of a number of options was most important to them. Following this, people were asked to rate each of the options on a scale of 'very important' to 'not important at all'. Therefore, more than one option could be considered 'very important'. Finally, 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 linked 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:

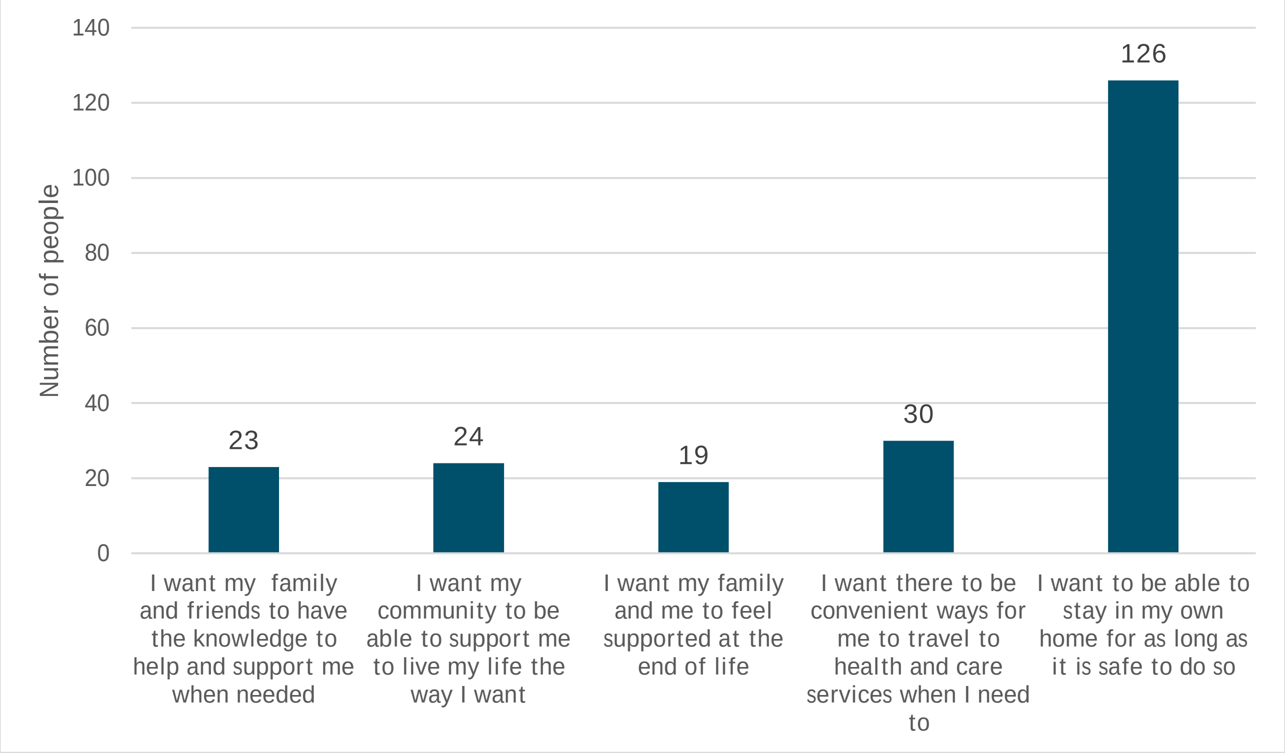
- *“Increase local Doctors appointments times from 10 minutes to 15 minutes or even longer.”*
- *“Longer appointments with the professional, so that more than one condition or problem can be thoroughly dealt with.”*
- *“Extra time allowed at appointments. Just GPs who are so overstretched. Possibly more 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

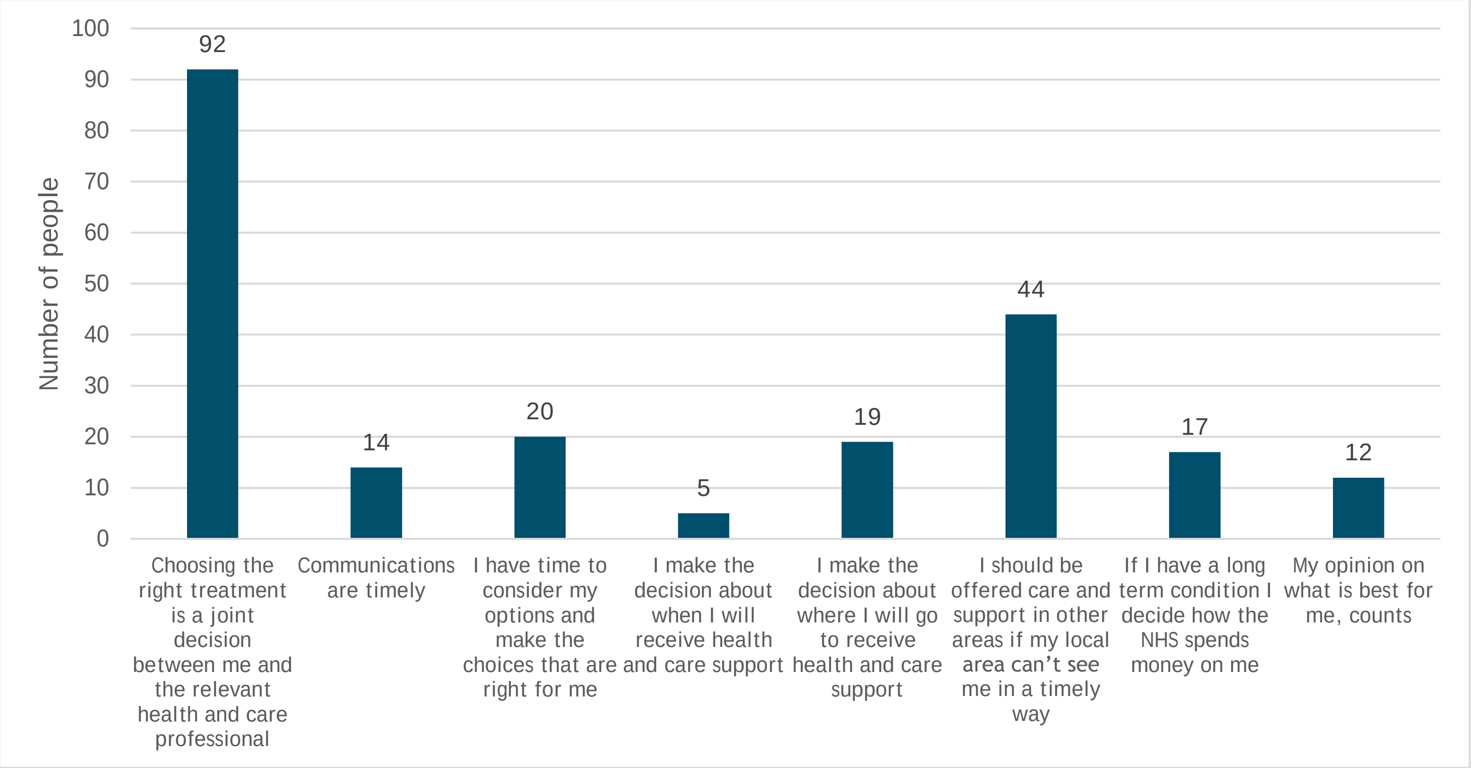
A number of respondents felt that more financial security was the most important element when it came to leading a long and healthy life.

- *“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 the relevant health and care professional	148	65	11	2	1
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."*

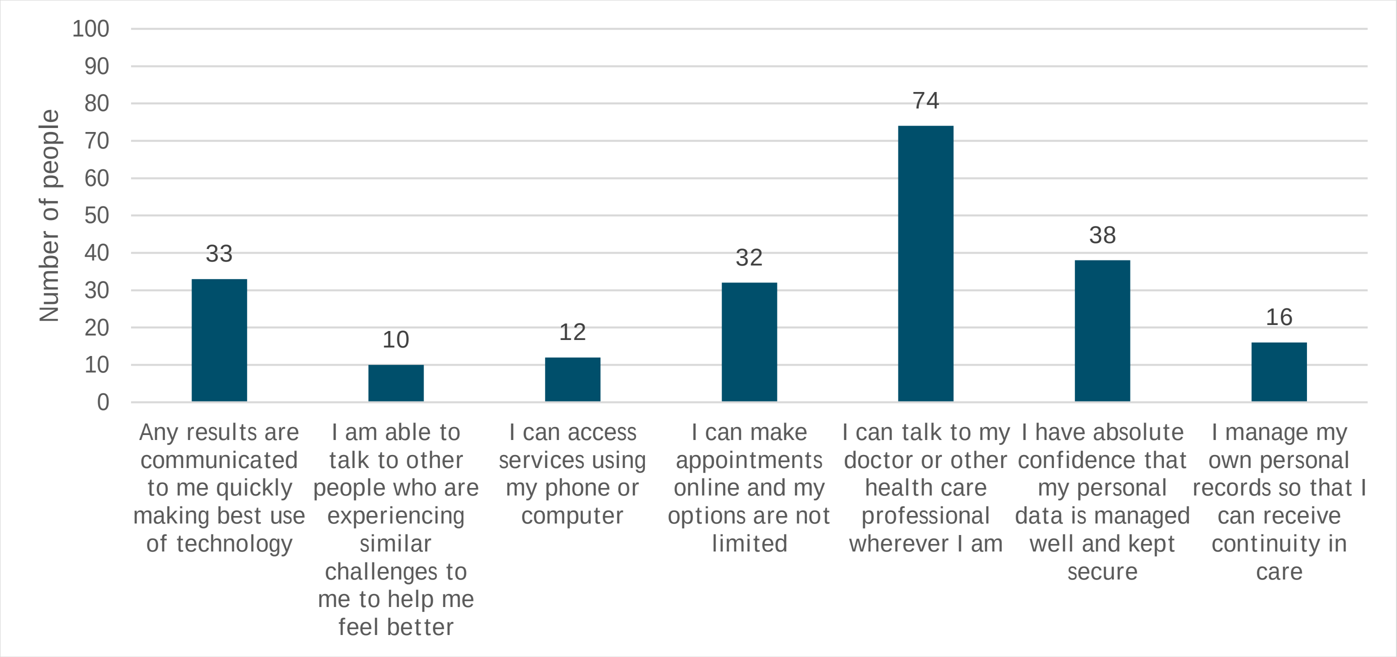
Engaging people in health service delivery

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 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, NHS111 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'."*

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 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.”*

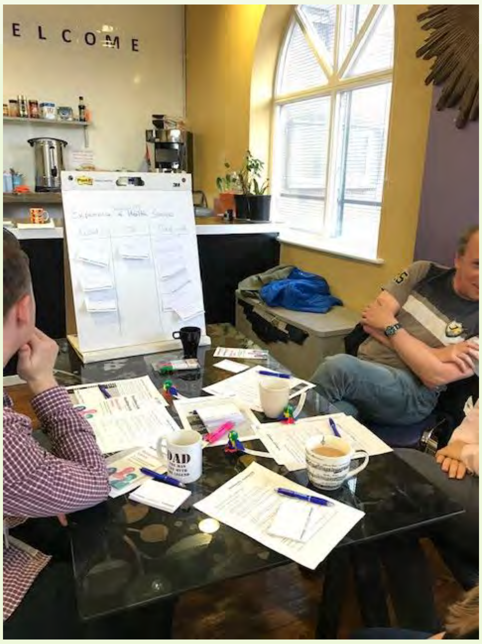
Further comments

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. NHS111 was mentioned by two of the group who felt that they were *"reading from a script",* both mentioned that NHS111 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.

healthwatch

NHS Long Term Plan Report

Chapter 4 - Healthwatch Halton

Halton

The borough of Halton consists of the towns of Runcorn and Widnes and the civil parishes of Hale, Daresbury, Moore, Preston Brook, Halebank and Sandymoor. It covers just over 30 square miles. Over 127,000 people live in Halton. The borough straddles the River Mersey.

The health of people in Halton is generally worse than the national average in England. Halton is one of the 20% most deprived district or unitary authorities in England and about 26% (6,400) of children live in low income families. Life expectancy for both men and women is lower than the national average in England.

Life expectancy is 12.7 years lower for men and 9.3 years lower for women in the most deprived areas of Halton than in the least deprived areas.[3]

In Halton, we received 259 survey responses, consisting of 206 general surveys and 53 specific condition surveys. There were also 32 attendees across two specific focus group events.

Halton

Cheshire & Merseyside Health & Care Partnership

"Be the reason someone receives better care today"

If Halton was a village of just 100 people...

38 Children are overweight or obese by year 6

19 Adults suffer from depression

10 5-16 year olds have a MH disorder

30 Will die from cancer

71 Adults are over-weight or obese

4 Adults under 40 have Type 2 diabetes

59 people are living with a long term condition

13 Will die from heart disease

18 Are smokers

81 Is the average age that women will live to

24 People take less than 30 mins exercise a week

77 Is the average age that men will live to

7 People are over 75

Statistics from PHE are for the Halton Local Authority area, pop: 126,000

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[3] Source: *Public Health England - Local Authority Health Profiles* (https://fingertips.phe.org.uk/profile/health-profiles)

Summary of Findings:

What matters most to people in Halton?

- When people were asked to consider what was most important 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 70% of responses. Respondents primarily focused on factors relating to exercise and diet, as well as information on lifestyle improvements. Easier access to GP appointments, longer appointments and improvements to the GP phone systems were also considered to be important.
- The ability to be able to stay in their own home for as long as it was safe to do so was considered the most important factor in retaining independence as people get older. Home support and community support, assistance from nursing and care staff to stay in their own home, alterations to homes and being in their own home and community were all emerging themes when respondents.
- The most important factor in managing and choosing support and treatment was that choosing the right treatment was a joint decision between the individual and the relevant healthcare professional. Timely communications were also deemed as very important.
- Funding and investment were dominant themes in managing support. Respondents also mentioned information, advice and communication. Many respondents also took the time to praise NHS staff.
- When interacting with the NHS a small majority of respondents felt that being able to talk to their doctor or health professional wherever they are was most important. This was closely followed by respondents having absolute confidence that their personal data is managed well and kept secure.
- People felt that technology and online services should be more user friendly and personal and health information should be shared among all health-based services.
- People with Cancer were largely positive about the care and support they have received, both in speed and quality. They did though believe there needs to be greater capacity in Halton in terms of more GPs and specialist services provided locally rather than having to travel for treatment.
- Respondents with Mental Health conditions found waiting times to access support and the information and support provided to be unsatisfactory.
- Those with Long Term Conditions such as diabetes or arthritis also found waiting times to be slow, but were more positive about the quality of the actual support they received.

Survey results

The following sections now break down the results of the 259 responses across Halton to the surveys designed by Healthwatch England. The first sections use the 206 responses to the general 'People's general experiences of health and care services' survey, before breaking down the 53 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.

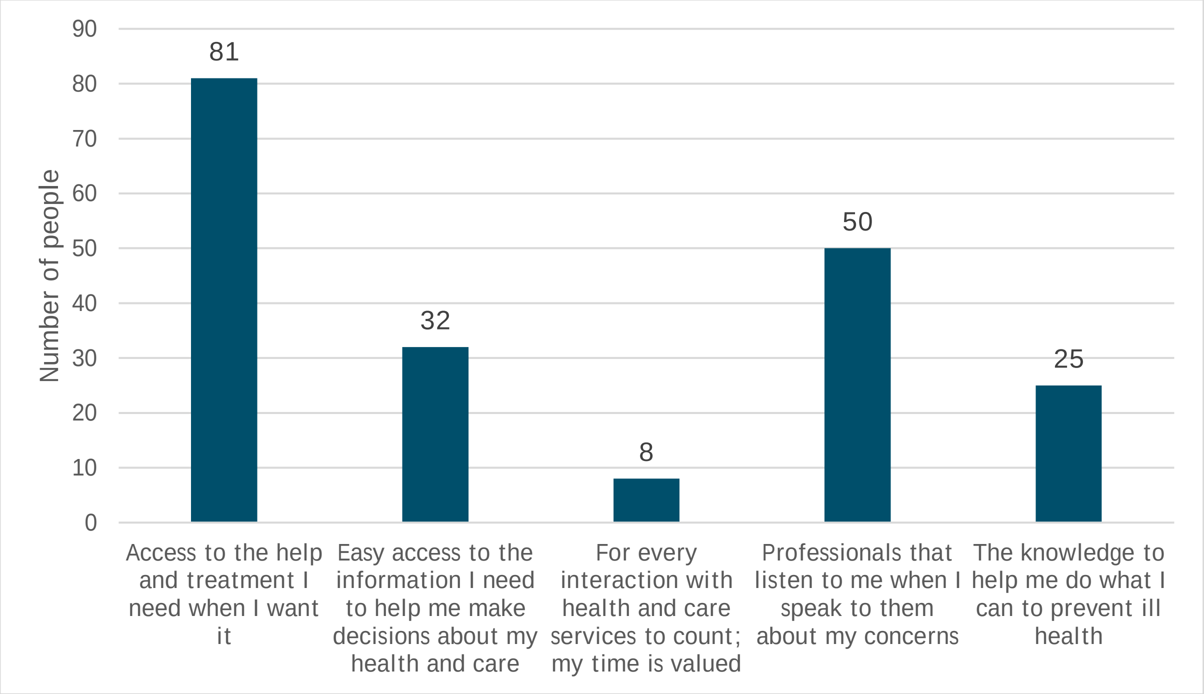
For each of these, people were asked to choose which of a number of options was most important to them. Following this, people were asked to rate each of the options on a scale of 'very important' to 'not important at all'. Therefore, more than one option could be considered 'very important'. Finally, 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, Chart 1 shows that having access to the help and treatment needed when it is wanted was deemed to be most important by people responding to the survey. 196 people responded to this question.

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



However, when asked to rate on a scale of very important to not important at all, all other options were considered either very important or important as the Table 1 below shows. Up to 192 people responded to this question, though 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
Access to the help and treatment I need when I want it	173	15	2	0	0
Professionals that listen to me when I speak to them about my concerns	171	13	3	0	0
Easy access to the information I need to help me make decisions about my health and care	145	35	10	0	0
For every interaction with health and care services to count; my time is valued	144	44	4	0	0
Having the knowledge to help me do what I can to prevent ill health	134	46	9	0	0

We also asked respondents to thing 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:

<u>Help to be healthy</u>

Many people commented on their desire to lose weight and to attend exercise classes, with some suggesting these should be made more easily accessible and cheaper. People also mentioned about transport and community opportunities:

- *"I feel there is limited opportunity to partake in Tai Chi therefore a centre where services such as this, yoga, healthy eating café etc are all provided in a large central location being mindful of public transport."*
- *"Information on lifestyle regarding diet and exercise. Then being able to consult with an expert for appropriate services both for currently healthy people and people with long term conditions."*
- *"Community gym access and free community exercise opportunities."*

Access to GP appointments

The accessibility of GP appointments was also significant to respondents:

- *"More out of hours GPs for working people and regular GP check-ups."*
- *"More time to discuss problems by getting more staff to help people."*
- *"Quicker access if there was an online service."*
- *"There needs to be improvements to the phone systems at GP practices. I have struggled to get appointments to see anyone at my practice recently. I had a painful heel, following a hip operation. Ringing for an appointment only to have a recorded message say 'you are number five in the queue' is not progress."*
- *"I'm sure the GP surgeries should definitely be local rather than moving them to bigger practices, making them larger but further away from people."*
- *"My local council stadium gym to be open more than it is, council cuts have led to restricted opening times, it is a deprived area and needs support from NHS/council to keep it going."*

Person-centred

The ability of professionals to listen to their patients and treat them as individuals was also very important to people:

- *"Joined-up treatments - being treated as a whole person, you are always treated as though you only have one thing wrong with you."*
- *"Developing social care systems which encourage independence for as long as possible but if illness does begin, to inhibit independence a system which is able to provide the right support in a timely manner at little or no cost."*
- *"Maybe an NHS voucher to buy things, support you and community. Especially if suggested by a physiotherapist/health nurse or even doctors when talking about health and lifestyle. It would probably impact the nation let alone the borough alone. I know there's Halton leisure card but not everyone is able to get one, only particular circumstances and working isn't one."*
- *"Mental health support for families living with autism."*

Health Education for self help

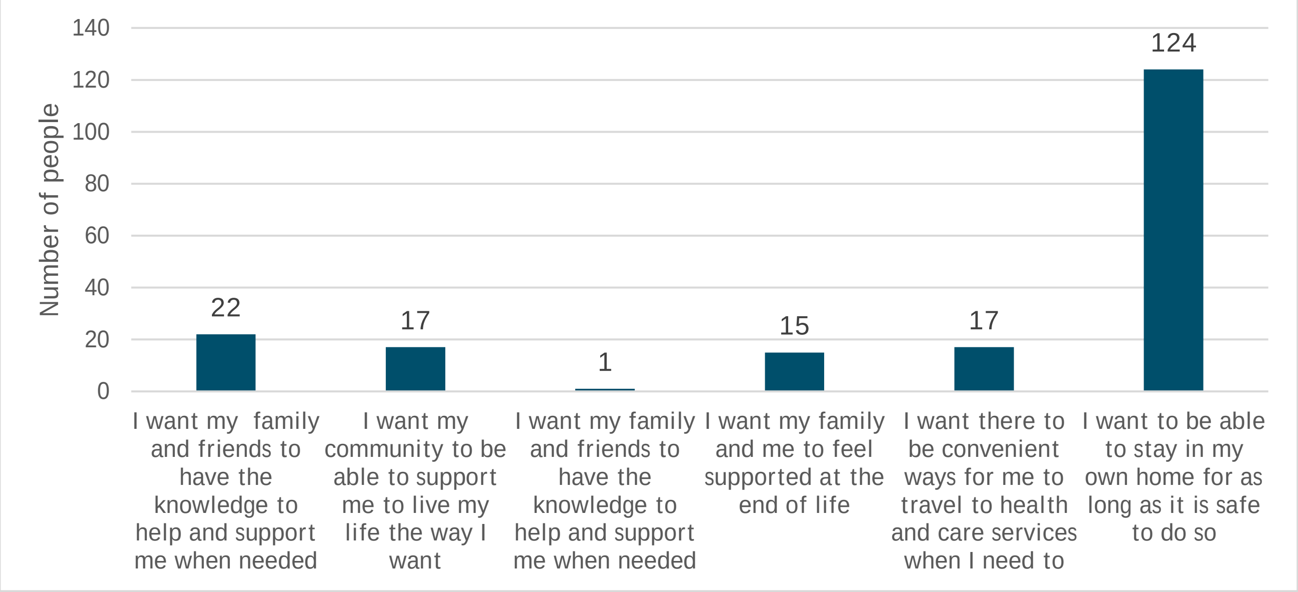
Respondents also told us that information should be more readily accessible regarding any self-help and educational health information with support services available and earlier interventions for people:

- *"I want appropriately trained health professionals to support me to manage my health, staff with experience in delivering care."*
- *"Health Education is vital through our life, from school to care home. Everybody should understand what is needed for our health and wellbeing, especially at a young age."*
- *"Being able to get early intervention/advice for any health issues, e.g. GP appointment or access to other healthcare professionals."*

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). 196 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 was rated as the most important, all of the other statements identified were also rated as very important or important. In particular having a community who are able to support them to live their life the way they want to was deemed as very important, second to being able to stay in their own home for as long as possible. Up to 196 people responded to this question, though 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	172	20	3	0	1
I want my community to be able to support me to live my life the way I want	159	31	5	0	0
I want there to be convenient ways for me to travel to health and care services when I need to	127	60	8	1	0
I want my family and me to feel supported at the end of life	109	65	19	1	0

I want my family and friends to have the knowledge, to help and support me when needed	104	50	4	1	0

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:

- *“Better availability of things to allow independent living. Alterations to home etc.”*
- *“Being in my own home and community.”*
- *“Assistance from nursing/care staff in my own home.”*
- *“Access to ground floor housing.”*
- *“To be confident in knowing that if I wished to stay at home, I would receive a constant and appropriate level of care.”*
- *“This would include the provision of a free 'Life Line' service.”*
- *“If I'm staying at home in my own house, not creating any bed blocking scenario, I am therefore saving the NHS money.”*
- *“If I am of such an old age that I require 'Life Line', why don't I receive it freely through the NHS?”*
- *“Staying at home is my choice, but I bet it is one which the NHS wished most elderly people would select.”*

Financial Support/Funding

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

- *“Clarity of funding systems for care.”*
- *“I will probably be able fund routine help at home but many people will find the funding available is insufficient to provide adequate home care.*
- *“To have cheaper home care help.”*
- *“Fully funded care services.”*

Prevention

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

- *“Staying active.”*
- *“That I don't get dementia of any type.”*
- *“Work sheets sent out when people get older to help with diet and keeping fit.”*
- *“Change in lifestyle.”*
- *“Staying fit and connected with community.”*

Community Support

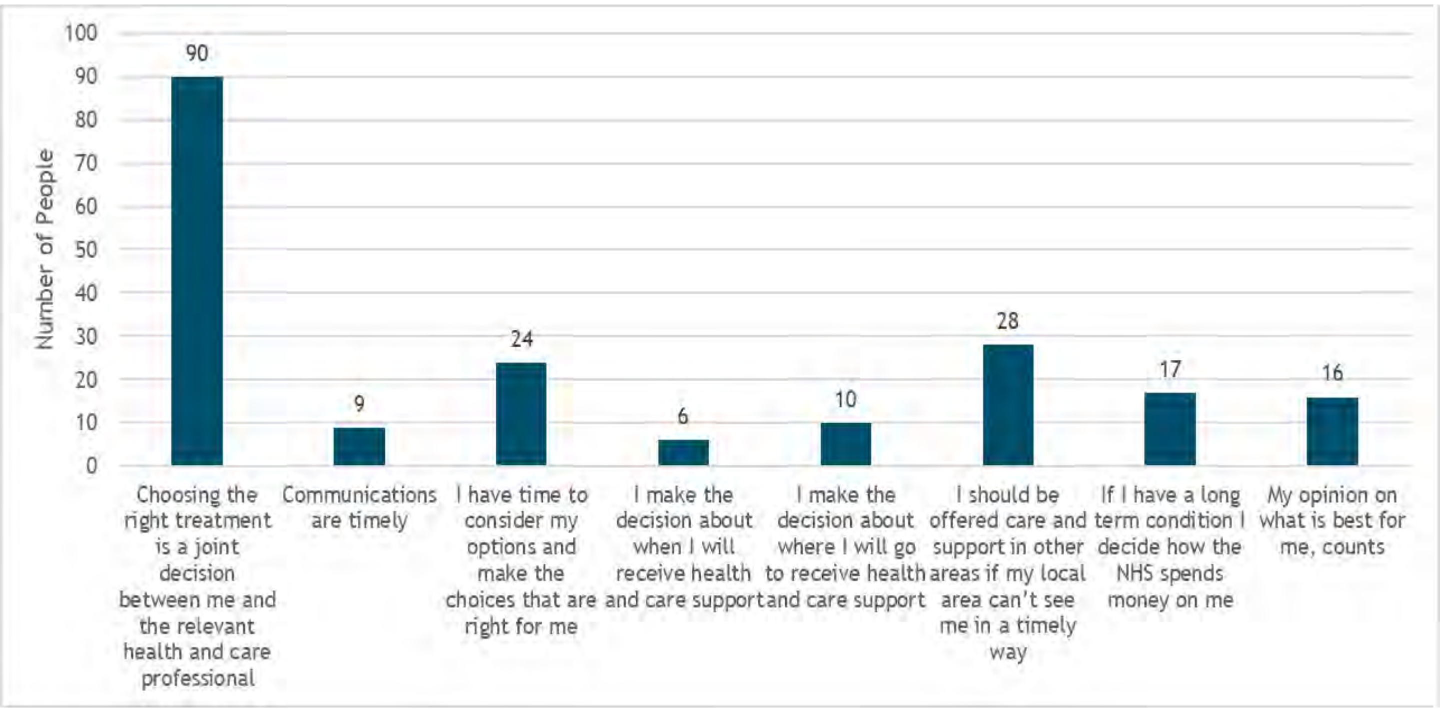
A number of respondents commented on the need for community support to enable them to stay healthy as they get older:

- *"Access to social activities that keep me involved in the community and ensure that I am in touch with people regularly."*
- *"Improved community care services."*
- *"Increase community support service."*
- *"Frailty is a really important consideration for the aging population and is the key factor for falls. Routine assessment and access to strength and balance series should be put into place."*
- *"To have access to exercise and wellbeing sessions for the retired."*

Managing and choosing support and treatment

Chart 3 shows that people we spoke to in Halton 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 in their local area was deemed as the second most important option. 200 people responded to this question.

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



When asked to select how important different factors were on a scale of very important to not important at all, people also deemed making the decision about where they go to receive health and care support and timely communications 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. This is detailed in table 3 below, in order of the options that most people classed as being very important. 201 people responded to this question, though not everyone 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
Communications are timely	128	55	13	0	0
My opinion on what is best for me, counts.	107	66	18	5	1
I have time to consider my options and make the choices that are right for me	106	79	13	0	1
I should be offered care and support in other areas if my local area can't see me in a timely way	104	75	18	4	0
I make the decision about where I will go to receive health and care support	102	76	19	3	1
I make the decision about when I will receive health and care support	88	69	35	4	2
If I have a long-term condition, I decide how the NHS spends money on me	69	68	47	8	1
Choosing the right treatment is a joint decision between me and the relevant healthcare professional	69	68	47	8	1

We also asked respondents to tell us one more thing that would help them to manage and choose how the NHS supports them. Answers have been collated and categorised under emerging themes.

Funding for local services

Respondents told us that they would like to see more budget shares between the NHS and local authorities. Others mentioned about more funding going into extra staff and effective online services. This also linked into comments that called for better treatment planning and public treatment spending. For example:

- *"Sharing of budgets between the NHS and local authorities for care at home or in respite or in hospital when recovering from an operation or illness should make better use of resources. The Government has reduced local authority grants more than those of the NHS. Poorer councils cannot raise enough from Council Tax to adequately fund social care."*
- *"Extra funding prioritised for more staff available for drop in services and online systems."*
- *"If I am told that nothing can be done for a life-threatening condition, then the NHS should fund an alternative treatment (I paid £4900 for a therapy which resolved a problem the NHS couldn't fix. It worked but I'm now impoverished)."*

Staff

Along with investment, it was recognised that funding challenges and demand for services was putting the NHS and particularly its staff under strain, which affected the staff service with patients. We received praise from various people regarding NHS staff, while others were asking for more staff consistency and staff training. For example:

- *"They always give time at the end for me to ask questions and ask me if I'm happy with the advice they have given me."*
- *"At the moment, if I have a District Nurse appointment visit twice a week, I could see at least six different people over the month. These District Nurses 'travel-in' from other areas in order to provide cover."*
- *"Many more trained staff to be able to reduce waiting times appointments and delays in receiving treatment. Better and quicker one to one contact."*
- *"That I feel listened to when seeing consultants who I haven't seen before, I've suffered with long term health condition and subsequent injuries - my latest consultant made me feel not listened to and kind of fobbed me off."*
- *"Consistency of nursing/doctors. By this I mean having the same District Nurse visiting me for my treatment each week. Having the same nurse/doctor* would provide *compassion and a better all-round relationship feeling, with better health care service."*

Appointments, Communication and Signposting

In regard to staff, a common theme people highlighted was the need for better communication both within the NHS and when talking to patients and signposting them. People told us that they would like their GP to have more time available to them in order to speak to their patient, so they are not categorised into a one size fits all. 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:

- *"Having more time in conversation with GP or relevant health care professional."*
- *"Managing appointments and care with online services."*
- *"Carers need to be fully included and considered in all discussions, decisions and actions associated with NHS support."*
- *"Clear letters, information leaflets and written communication of appointment outcomes."*
- *"Be able to choose where to have treatment or surgery even if this means travelling to another specialist centre in another region or country within the UK."*
- *"I would like if someone would explain test results to me and where to go from there. I don't think they should only call if there is a problem with the results. Should discuss them with you."*
- *"For GPs to let patients know about healthcare choices available not to just refer to the nearest hospital patient choice."*
- *"More information in paper format are much preferable to everything being online."*

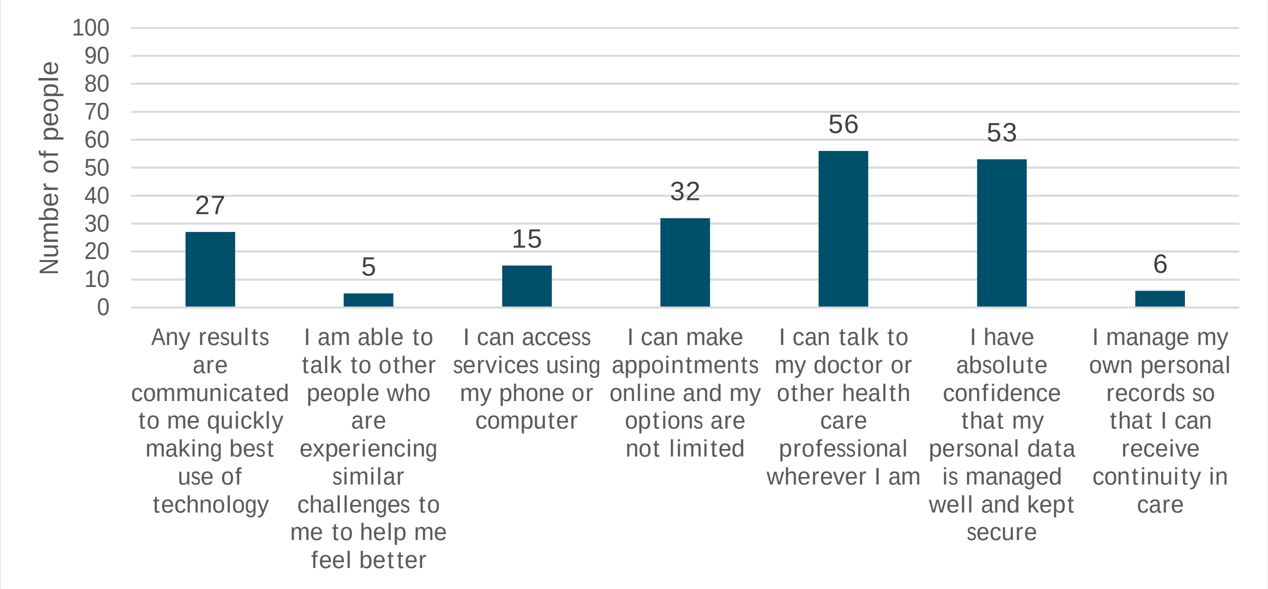
Engaging people in health service delivery

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.

People in Halton told us that being able to talk to their doctor or other health professional and having absolute confidence that their personal data is managed well and kept secure, were both deemed as the most important when interacting with the NHS (see Chart 4 below). 194 people responded to this question.

Chart 4: What is most important to you 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 (Table 4), people said that the most highly rated factor was having confidence that their personal data is managed well and secure, followed by results being communicated quickly making the best use of technology. However, all factors were deemed to respondents as being important or very important. Up to 201 people responded to this question, though not all responded to each option.

Table 4: 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 have absolute confidence that my personal data is managed well and kept secure	138	27	28	0	2
Any results are communicated to me quickly making best use of technology	133	45	16	4	1

I can make appointments online and my options are not limited	115	51	21	8	5
I can talk to my doctor or other health care professional wherever I am	111	73	13	3	1
I can access services using my phone or computer	107	56	30	4	1
I manage my own personal records so that I can receive continuity in care	90	59	38	6	8
I am able to talk to other people who are experiencing similar challenges to me to help me feel better	69	64	54	7	6

Respondents were then asked to think about one more thing that needs to change to help them to successfully manage health and care. These answers have been categorised under emerging themes.

Technology

A number of people talked about not only the continued use of technology for a more accessible service, but also an awareness that not everybody is able to use technology:

- *"[I wish] that the online access service was more user friendly."*
- *"Personal records/health information should be a shared to all health-based services that you are accessing."*
- *"Being able to access more services online."*
- *"I am dyslexic so could not manage my own records there would be too much to read or use a computer."*
- *"To have a health care app with interactive advice."*
- *"I feel for the older generation(s) who did not experience computers. If the NHS went totally down the road of using technology to deliver to a patient's home desk, where does that leave those who do not use the technology? It is the way ahead for the future, but for now it should be a gentle introduction."*

Communication

Communication was also an emerging theme amongst respondents and in particular, how they are communicated to:

- *"Better communication. Keep website up to date. Consistency in care and services from all staff."*
- *"Contact details are easy to find."*
- *"Ensure all communication platforms have ease of use and are not overly wordy or complicated."*
- *"Support I can phone for info and advice between appointments."*
- *"More human contact."*
- *"To improve the ability for healthcare professionals to communicate important messages in a timely and clear way. It often feels like messages are rushed or just not given because of pressures on individuals time."*

GP Appointments

GP appointments were also mentioned by respondents, and for a number of reasons, including accessibility, i.e. ease of making an appointment, to quality of appointment; including how much time people get to spend with their GP:

- *"Timely access to appointments."*
- *"Access to my GP. This front-line service is extremely important to me. He knows me well and also my family and circumstances within this family which may help at some time with the decisions made about my health and wellbeing."*
- *"GPs are afforded time to deal with their patients."*
- *"Understanding that I never ask for an appointment for something trivial. It's a big effort... making an appointment when you are exhausted and/or in pain... and no I can't phone at 8.30am if I've been up all night unable to sleep..."*
- *"Follow up appointments with written information so I can fully take it in and understand."*
- *"Better access to doctors' appointments to suit me. My doctors currently offer over the phone hoping to save appointments which puts me off."*
- *"Length of appointment with medical practitioner is appropriate to the needs of the patient, giving time for questions, worries or concerns and being able to receive information, without feeling time-bound."*

Information provision

A number of people mentioned the importance of information and training:

- *"I would like to see clear instructions and education and training in the various online and appointment systems. These should be appropriate to the people involved, as not all people have a phone/computer or are IT literate."*
- *"Knowledge of available services and groups."*
- *"Health education sessions."*
- *"Quality treatment and more information given."*

What people expect during service change and transformation

A number of people feel frustrated at the system but also reflect upon funding and ongoing issues facing the NHS:

- *"I would like to see GP Practices providing short training courses on how to use Patient Access, appointment systems and care navigation and other services provided at the practices."*
- *"Stop the insidious privatisation of services and invest more to keep the NHS safe."*
- *"The decision on the best way forward with my health and wellbeing is a discussion between myself and the health care professional and it is a joint decision and an informed choice."*
- *"Transport is an issue for me, getting to the Royal Liverpool is hard for me."*
- *"There is an assumption that the family will be involved. In my case, apart from my wife, I have no blood relative within 200 miles and do not want to bother them except when it is necessary."*
- *"Medical professionals 'not listening' is really bad. That's how I ended up in hospital."*
- *"Time-wasting: I work from home and have a heavy workload. I also have to get a lift as I'm often too ill to drive."*
- *"I know the NHS is underfunded and understaffed so I feel bad about commenting on the amount of time spent waiting to see a specialist I have an appointment with."*

- *"Last week I had two appointments; one early afternoon, one late afternoon but at different hospitals… After nearly two hours I had to leave without being seen in order to get to the next appointment."*

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 53 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	4
Cancer	16
Dementia	4
Heart and lung diseases	9
Learning disability	0
Long-term condition e.g. diabetes, arthritis	11
Mental Health	9

Table 6: Who are you responding on behalf of?

Condition	Myself	Someone else
Autism	1	3
Cancer	14	2
Dementia	0	4
Heart and lung diseases	5	4
Learning disability	n/a	n/a
Long-term condition e.g. diabetes, arthritis	11	0
Mental Health	5	4

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

Condition	Yes	No
Autism	2	2

Cancer	6	9
Dementia	1	3
Heart and lung diseases	5	4
Learning disability	n/a	n/a
Long-term condition e.g. diabetes, arthritis	4	7
Mental Health	3	5

Your 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	4	0
Cancer	11	0	4
Dementia	0	2	2
Heart and lung diseases	4	3	2
Learning disability	n/a	n/a	n/a
Long-term condition e.g. diabetes, arthritis	6	2	3
Mental Health	2	4	3

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	4	0
Cancer	9	4	2	1	0	0
Dementia	0	0	3	1	0	0
Heart and lung diseases	2	2	2	1	2	0
Long-term condition e.g. diabetes, arthritis	3	4	2	1	1	0
Mental Health	0	2	3	1	2	1

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

Condition	Yes	No
Autism	2	2
Cancer	9	7
Dementia	2	1
Heart and lung diseases	6	3
Long-term condition e.g. diabetes, arthritis	9	2
Mental Health	3	6

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
Autism	0	1	1	0
Cancer	1	4	1	0
Dementia	0	2	0	0
Heart and lung diseases	0	1	5	0
Long-term condition e.g. diabetes, arthritis	0	6	1	2
Mental Health	0	2	1	0

The health and care support you 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	4	0	0	0	0	0
Cancer	0	1	3	8	4	0
Dementia	0	3	1	0	0	0
Heart and lung diseases	3	3	1	2	0	0

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

Autism:

- *"It took 18 months to be referred by a school professional who had no awareness training and disputed my concerns. I visited GP surgery eight times. After GP sent a letter to wood view direct, it then took 12 months until family feedback. And even then, we were given a diagnosis of Social Communication Disorder. We have since had no contact or referred to support for any condition."*
- *"12 months- and case notes were ' lost' and still waiting for diagnosis."*
- *"Over 13 months and still waiting."*

Cancer:

- *"Immediate Help."*
- *"I was completely satisfied."*
- *"Took a long time between scans prior to formal diagnosis."*
- *"Once symptoms became more obvious. Each stage was 2-3 weeks max."*
- *"I was diagnosed in January, finished my treatment in August."*
- *"Within NICE guidelines."*

Dementia:

- *"Two months."*
- *"I think about six months might have been longer."*

Heart and Lung diseases:

- *"It involved a telephone consultation, which may have been more efficient had it been face-to-face?"*
- *"More than the waiting time is the lack from consultants who only look at symptoms only in their field of expertise. All doctors undertake the same training and deals with the human body so why can they not look outside the box and recognise that if a patient tells them they are having appointments in different clinics all symptoms could be linked."*
- *"From registering with urgent care, describing symptoms, immediately being seen, then transferred to hospital coronary care unit."*
- *"Although the patient is supposed to be beginning their discharge plan more or less as soon as a proper diagnosis is given this woefully falls below expectation. Even when an initial Social Services Plan was supposed to be in place and meeting needs, prior to hospital admission and the diagnosis of two further life changing conditions, Mum is still waiting for a comprehensive holistic approach to her long-term management and care plan."*
- *"It takes a month to get an appointment with the doctors (GP)."*

Long-term conditions:

- *"I was seen straight away."*
- *"Six months."*
- *"Waited two years for operation."*
- *"Can't remember exact timescale but it took longer than first stated. It took several phone calls - which was stressful - before I received basic feedback. This left me in limbo."*

- *"Waited 12 weeks for balance class and 12 months for Laser Eye Surgery."*

Mental Health:

- *"I waited three months for my mental health assessment, and then waited another two months to get my log in details to start my online CBT (Cognitive Behavioural Therapy). I've now been waiting two weeks so far for an appointment to start my new therapy."*
- *"In the early days it literally took years to get the help required. Because my son was refusing to accept his illness, despite obvious and apparent symptoms and the danger to himself, he was allowed to refuse treatment and disengage with services. It seems that individual freedoms are being used by the NHS staff as excuses not to make interventions and this means that they wait for serious/acute events to occur before taking needed actions."*
- *"Diagnosis quick, aftercare poor and length of wait unacceptable- particularly for a child."*
- *"I had to pay a local charity to get one to one counselling."*
- *"We are still waiting after two and a half years."*

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	4	0	0	0	0	0
Cancer	0	1	3	8	3	0
Dementia	0	3	1	0	0	0
Heart and lung diseases	0	5	1	2	1	0
Long-term condition e.g. diabetes, arthritis	4	3	0	2	0	1
Mental Health	3	3	1	2	0	0

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

Condition	Yes	No
Autism	0	4
Cancer	8	7
Dementia	4	0
Heart and lung diseases	6	3
Long-term condition e.g. diabetes, arthritis	2	8
Mental Health	2	7

If you accessed support, what aspects worked well?

Cancer:

- *“I was referred to a number of professionals who were all excellent.”*
- *“Had calls immediately from my specialist nurse.”*
- *“Macmillan cancer support.”*
- *“Widnes and Runcorn Cancer Support."*
- *“Clatterbridge Centre.”*

Dementia:

- *“For my late husband him being taken out for a few hours.”*
- *“Age UK Mid-Mersey have been brilliant.”*
- *“I was given an Alzheimer’s leaflet but I didn't phone them for ages.”*

Heart and lung diseases:

- *“Diagnosis delivered once blood results returned then next stage of treatment explained.”*
- *"I think a leaflet given to the patient on a ward when the health conditions are still being monitored and as yet not being fully medicated or controlled is clearly not something any patient would feel met any needs.*
- *“The fact that this was when the patient was clearly very unwell, very confused and totally overwhelmed at the time."*

Long term conditions:

- *“Initially Physio and Radiotherapy.”*
- *“Laser treatment on right eye OK, unsuccessful on left."*

Mental Health:

- *"Pre-arranged regular appointments with my GP.”*
- *“Having a regular therapist checking in online with me every week"*
- *“The support I now get is medication and I also have a care worker who comes and visits me once a week.”*

If you accessed support, what could be improved?

Autism:

- *“It’s clear the health service can’t cope and depends on carers and in particular family to ease the NHS pressures, transferring this responsibility to carers needs more thought, checks on capability and generally the carers health and ability to support for example, if they are working, can they get time off from work for hospital visits, etc.”*

Cancer:

- *“I felt overwhelmed by it all maybe having someone to speak to during whole process.”*
- *“Bridging the gap between therapies (i.e. therapists continuing to see patients until patients have their new therapists not just until they are put on the waiting list for new therapy).”*
- *“My additional condition is arthritis. Everyone is different with this complaint. Diet was not discussed?”*

Long term conditions:

- *"Liaising with the primary care team to be aware of where the patient is at in regards to their physical condition, the current understanding of the illness and the current mental state of the patient. Perhaps this is the time to gently broach the discussion with a further couple of planned visits to ensure full understanding, medication awareness and guidance and an emergency plan of worsening symptoms."*

Mental Health:

- *"Support services should be available from the outset."*
- *"More holistic support required: e.g. massage, Reiki, reflexology, oncology."*
- *"Getting a quicker diagnosis."*

Table 15: Were you referred to a specialist?

Condition	Yes	No
Autism	0	4
Cancer	15	0
Dementia	3	0
Heart and lung diseases	8	1
Long-term condition e.g. diabetes, arthritis	7	4
Mental Health	5	4

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	0	0	0	0	0	0
Cancer	1	0	4	7	3	0
Dementia	0	2	1	0	0	0
Heart and lung diseases	0	3	2	1	1	0
Long-term condition e.g. diabetes, arthritis	2	1	2	0	2	0
Mental Health	2	1	1	1	0	0

Cancer:

- *"Two weeks"*

Dementia:

- *"Dementia treatment is still slow compared to other illness."*
- *"Two months."*
- *"We only waited a few weeks."*

Heart and lung diseases:

- *"Waited five months for follow up appointment."*
- *"24 hours before being transferred to have stents fitted."*
- *"still not clear who the patient will see, when this will happen and what the care plan will be."*
- *"it's always about a month waiting times."*

Long term conditions:

- *"They came as soon as I came out of hospital (carers)."*
- *"Several weeks for hip knee replacement."*
- *"Waiting time just makes a person very anxious."*

Mental Health:

- *"My care had been transferred between teams and if I had not proactively contacted them, I would have waited even longer as my details hadn't been passed over."*
- *"I am waiting to see a back specialist to help me it needs to be quicker."*
- *"In reality services waited for acute situations to develop before responding."*
- *"I got an appointment to see a psychiatrist and that was pretty quick and I have seen him many times since."*

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

Conditions	Difficult	Don't know	Easy	Not applicable	OK	Very difficult	Very easy
Autism	1	0	0	0	0	3	0
Cancer	4	1	3	2	2	0	4
Dementia	1	1	0	0	2	0	0
Heart and lung diseases	0	0	1	2	3	2	1
Long-term condition e.g. diabetes, arthritis	1	2	3	1	2	0	2
Mental health	1	0	1	1	2	4	0

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

Conditions	No	Somewhat	Yes
Autism	4	0	0

Cancer	4	4	7
Dementia	2	2	0
Heart and lung diseases	3	3	3
Long-term condition e.g. diabetes, arthritis	3	2	6
Mental health	3	3	2

Autism:

- *"Children are not given support soon enough."*
- *"I would expect a child of three to be offered support than being told we'll reassess in six months if nursery/ healthcare professionals re refer and fill in these forms."*

Cancer:

- *"The care for my cancer diagnosis met all my expectations, I just felt overwhelmed with it all."*
- *"More information truth and care."*
- *"Need more support after diagnosis."*
- *"Symptoms were showing in June however was not taken seriously until September. Once it was diagnosed all scans/consultants' reviews were very quick."*
- *"Was never given a care plan, not signposted to support services."*

Dementia:

- *"The system is stretched to the point of breaking. Social workers are massively overloaded and can't get support to those who need it. Far too much paper pushing and form filling resulting in less one-to-one support."*

Heart and lung diseases:

- *"Again, once diagnosed with a number of minor health issues when more life changing conditions appear, there is no joined up collection of staff and services to meet individual needs."*
- *"Primary Care didn't act quickly enough, blue lighted to hospital."*
- *"Excellent care - no change needed."*
- *"Not personalised, not done in a timely fashion, uncoordinated with a constant feeling of being passed around like a parcel without the chance of ever getting a prize."*

Long term conditions:

- *"The consultant did not give me enough information or answer my questions. I was told to see my GP regarding the medication I was to take."*
- *"No aftercare provided."*

Mental Health:

- *"I was given medication which is useful. I was given access to CBT but had to wait approximately 18 months for this. The initial services such as IAPT would look at my diagnosis (bipolar) and decide I needed more specialist services - if I could have used their lower level ones it might have prevented a lapse into severe depression."*

- *"Acute wards are basically prisons where the focus is on security, stupefying medication and containment and little or no attempt is made to provide therapy or rehabilitation."*
- *"Services providers use low paid, poorly trained, unqualified, unmotivated, none dedicated staff resulting in high turnover, low motivation and hence lack of continuity of care."*
- *"Offered very little help and no information for my anxiety. I expected to be put on a list for one to one therapy. Not a mental health ward but to improve wellbeing and prevent the need for that."*

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?

Conditions	No	Somewhat	Yes
Autism	3	0	1
Cancer	4	7	4
Dementia	2	2	0
Heart and lung diseases	5	2	2
Long-term condition e.g. diabetes, arthritis	6	0	5
Mental health	6	2	1

Autism:

- *"Letters not received; appointments changed without notice."*
- *"No communication between professionals."*
- *"All reports have to be repeatedly requested. One report took two months to type."*
- *"Early detection and quick diagnosis care and support is crucial to ensuring the best outcomes for autistic spectrum conditions."*

Cancer:

- *"I think someone explaining everything the outcomes as I was shocked from the diagnosis."*
- *"When diagnosis you don't know how long you have left my husband lasted 12 months."*
- *"No problems, I was satisfied."*
- *"Better notification of test results."*

Dementia:

- *"Staffing shortages in social care and lack of awareness of what dementia is in some areas of the health service."*
- *"I was shocked that my husband had dementia and could not take the information in."*
- *"I think the doctors need to talk to each other."*

Heart and lung diseases:

- *"An ongoing written record that the patient has because departments don not communicate."*
- *"Instead of the obvious symptom or condition, it was lost in the transfer to other staff who only zoned in on their one spoke of the wheel."*

- *“Tracking the patient’s journey, future care plan and life that should be lived with support and information that will enable them to self-care as much as possible.”*
- *“Although we all appreciate that the staff are under a lot of pressure, with limited funds and time, with an overwhelming number of initiatives with new policies and procedures, they are still a very small part off a patient’s journey. This patient will then be passed on and in most cases forgotten."*

Long term condition:

- *“I was just told I had my condition and given tablets.”*
- *“At times I felt rushed and on a conveyor belt.”*
- *“Did not meet expectations.”*

Mental health:

- *“I found that the psychiatric services did not always coordinate appointments with the quantity of medication prescribed. This meant I would often have to spend a long time on the telephone with the team and/or the hospital pharmacy. This was extremely difficult for me when unwell and caused stress.”*
- *“One example (there are many) - Despite multiple pleas to services over many weeks to intervene based on carer's observations of deteriorating health a serious incident occurred, driven by psychosis, causing massive life changing injuries to the service user. The carer observations and pleas were essentially ignored.”*
- *“Counselling non-existent support or communication.”*
- *“Things were very slow at the start and it took me to reach crisis point before they helped more with the therapy and family work I am doing.”*

Table 20: What is your main means of transport?

Conditions	Another person's car	Bus	Own car	Taxi
Autism	0	1	3	0
Cancer	1	1	14	0
Dementia	0	0	3	1
Heart and lung diseases	4	0	4	1
Long-term condition e.g. diabetes, arthritis	4	2	3	2
Mental health	2	3	3	0

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

Conditions	1 - 2 hours	30 minutes to 1 hour	Less than 30 minutes	Over 2 hours
Autism	0	2	1	1
Cancer	4	7	2	2

Dementia	0	1	1	2
Heart and lung diseases	1	2	4	1
Long-term condition e.g. diabetes, arthritis	2	6	2	1
Mental health	4	4	0	0

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

Conditions	1-2 hours	30 minutes to 1 hour	Less than 30 minutes	More than 2 hours
Autism	0	2	1	1
Cancer	3	8	1	4
Dementia	1	0	1	2
Heart and lung diseases	1	5	2	1
Long-term condition e.g. diabetes, arthritis	3	4	3	1
Mental health	5	2	0	2

What is most important to you:

Table 23: When first seeking help?

Conditions	**Don't mind**	Seeing a health professional, you normally see but you may have to wait	Seeing any medically appropriate health professional who is free immediately
Autism	0	0	3
Cancer	1	6	6
Dementia			3
Heart and lung diseases	2	2	4
Long-term condition e.g. diabetes, arthritis	0	6	5
Mental health	2	2	5

Table 24: When you received a diagnosis and explanation of treatment or support options

Conditions	**Don't** mind	Seeing a health professional, you normally see but you may have to wait	Seeing any medically appropriate health professional who is free immediately
Autism	0	0	3
Cancer	0	6	7
Dementia	0	0	3
Heart and lung diseases	4	1	4
Long-term condition e.g. diabetes, arthritis	0	5	6
Mental health	1	7	1

Table 25: During your initial treatment or support

Conditions	**Don't** mind	Seeing a health professional, you normally see but you may have to wait	Seeing any medically appropriate health professional who is free immediately
Autism	0	1	2
Cancer	0	7	6
Dementia	0	0	3
Heart and lung diseases	4	2	3
Long-term condition e.g. diabetes, arthritis	0	4	6
Mental health	0	4	5

Table 26: During your long-term support

Conditions	**Don't** mind	Seeing a health professional, you normally see but you may have to wait	Seeing any medically appropriate health professional who is free immediately
Autism	0	2	1
Cancer	0	4	9

Dementia	0	0	3
Heart and lung diseases	5	3	1
Long-term condition e.g. diabetes, arthritis	0	5	4
Mental health	0	6	3

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

Conditions	A lot of support	Don't know	I don't need support	Some support
Autism	0	0	0	4
Cancer	4	1	1	10
Dementia	2	0	0	2
Heart and lung diseases	2	2	0	5
Long-term condition e.g. diabetes, arthritis	4	0	1	6
Mental health	3	1	0	5

What could the NHS do to help you stay healthy or manage any condition you have?

Autism:

- *“Access to specialist teams.”*
- *“Care coordinator for all health needs - to signpost and make sure appropriate support given for autism.”*

Cancer:

- *“Regular health checks and keeping in touch.”*
- *“Offer more wellbeing services for working people over 50.”*
- *“Not had to use any services as yet. But hope transport is available when I need it and a care package is put in place. Have worries about having to travel far for treatment when unable to drive.”*
- *“Better access to dietician, physio and Occupational Therapist.”*

Dementia:

- *“NHS is slow to respond in many areas it appears outdated in many aspects of its service. Management and continuous improvement need to improve considerably if it is to keep pace or exceed the private sector. The reluctance to accept change in any form I find staggering.”*
- *“Explain what to expect or what could happen more information without jargon.”*

Heart and lung diseases:

- *"Continue to offer local support and advice within the community."*
- *"Have contact with patients regularly before they have a health crisis. Group sessions with certain conditions so peer support or ongoing services that could help patients increase their confidence and knowledge to self-care."*
- *"Have information and referrals to places that the patient can get accurate information and expertise from patients with the same condition. Patient are well placed to share personal experiences, levels of support available and a feeling part of a community. A professional coordinator available for expert advice of needed referrals."*
- *"Give the patients access to the tools and skills to be able to self-manage conditions and how to prevent their health declines. We would all like to be as well and healthy as possible, being a valuable member of our community and feeling that a quality organisation will provide excellent care in a timely way when needed."*
- *"Be quicker with appointments and get all your ailments sorted quicker."*

Long term conditions:

- *"Tell me the clear, concise and full details of my condition at all times."*
- *"Set up patient reviews regularly as a person needs them."*

Mental Health:

- *"The physical health checks done in my local area are helpful. I would say better communication between the consultants and GP would be useful. One of my medications requires regular blood tests and I have to remind my GP when they are due. Other people may not be able to do this."*
- *"More wellbeing activities (maybe focused at younger age groups, most the groups I'm aware of are for lonely older people not anxious or depressed younger people)."*
- *"NHS essentially ignores the side effects of the medications it prescribes to treat mental health conditions. This leads to those prescribed with conditions such as schizophrenia living shorter and much less productive lives. There is no such thing as 'holistic' and patient centred care in the NHS from a mental health service user perspective.*
- *"The fact that physical disability and life-threatening conditions can result from its prescribed treatments (e.g. through induced obesity and self-harm) is something that the NHS needs to (a) acknowledge (b) plan for and (c) act on to provide lifelong interventions that will hopefully ensure that the life expectancy gap is closed."*

<u>Further comments:</u>

Autism:

- *"Halton needs a clinical team who specifically deal with neurodevelopmental disorder/autism/heavy metal poisoning in a purpose-built clinic which is accessible to everyone, regardless or diagnosis. Oxygen therapy, chelation therapy, complementary therapies, salt water therapy, and all other known interventions."*

Cancer:

- *"Help cancer sufferers who want to work to get back into work, if unable to do their previous employment role."*

Dementia:

- *"£20 billion spent wisely will improve things significantly, however my confidence in this happening is low given previous behaviours. We need more frontline staff and less* *administration and quangos. Recruitment from the private sector of this who have a track record of successfully managing change would be very beneficial."*

Heart and lung diseases:

- *"We are lucky to have what we have and I appreciate it. I feel that some medical professionals make the patient feel that their agenda is about what they need to show they have done and this is the most important thing - almost a tick box exercise. Often my dad was spoken over, interrupted, shushed up so they could get to the point and get onto the next person which I understand is pressures of the job but now my dad has gone, we are left with a feeling that sometimes he was patronised, not listened to and felt like cattle. This is not true of all - many were warm, considerate and respectful."*

In focus: what is important to people with Cancer about health and care services?

As part of our research activity, Healthwatch Halton conducted two focus groups with a Cancer Support Group and people diagnosed with cancer and their families. Cancer was chosen as a focus due to cancer rates in Halton being higher than the national average. The focus groups were held at Runcorn Cricket Club and Widnes and Runcorn Cancer Support Centre on 7th and 8th May 2019. 32 people were in attendance across the two events. Below are the main themes people told us about at these events:

Good levels of care

Staff from Clatterbridge Hospital visit patients at home every three weeks and have done for five years. This saves so many long trips.

St. Helens Hospital give excellent '*A1*' care. Funding should be used to make sure this level of care can continue under growing pressures. *"I think the funding should go to ensure the excellent standards and cancer care I have received continues, such as the support nurses, fast track and home visits."*

Diagnosis Time

What works: Being seen within the NICE Guidelines time frame. Though NICE recommendation is two weeks, a few members were seen within 10 days or earlier and this was view felt to be extremely positive and reassuring.

Role of Hospices

Hospices should play a bigger role in care. Halton Haven and Marie Curie are a better environment providing 'kinder' care than hospitals. *"Halton Haven is very important in our area. They give outstanding end of life care and should be used more in care and treatment."*

Primary Care

People find it hard to access primary care, so cannot get into secondary care. They find booking a GP appointment too hard. The group shared their experiences of very inconsistent GP services. Some people had no problem booking an appointment and others spoke of three-week waits and not being able to get an appointment even when their GP Practice has asked them to attend. *"I was called for an appointment by a letter and phone call from the surgery. Went to the Reception on three occasions and no appointment available."*

We were told that reviews for medication are inconsistent. Some patients are called in annually for medication checks, whilst some are never reviewed. Some people explained that medicine had been stopped without talking to them.

When prescriptions are changed people explained that they are still sent the old medicine by the pharmacy. One lady explained she had a large bag full of Warfarin that she no longer takes, even though she had crossed it off the list at Asda Runcorn's Pharmacy. It then took several attempts to get the new medicine. In the end one box of the drug was found in Widnes for all of Halton.

What works:

- *"Having a proactive GP who will chase up referrals and results on your behalf."*
- *"When the GP is informed of my cancer diagnosis, they prioritise the availability of an appointment, I am then seen straight away for a GP appointment."*
- *"Having a separate area in the GP waiting area, this is particularly valuable when having treatment which lowers the immune system (can only use if available)."*

What needs to change:

- Some people experienced difficulty with accessing a GP appointment prior to diagnosis and it was felt that prompt access to GP appointments are crucial as this is how you access secondary care.

Greater capacity

People told us they want a seven-day service. They feel that consultants should work weekends and bank holidays as nurses do. Patients described being in hospital during weekends or public holidays and just waiting for care as no senior staff are available.

We were told that more care staff or community nurses are needed. It was felt that hospitals and GP Practices should not expect or presume that people's children will care for them. Many children live elsewhere, work a lot or have health conditions of their own but are relied on to care for people. People also mentioned that some sheltered housing locally has been turned to retirement living with less staff and support available, at a higher cost.

There was the opinion that more GPs are needed in Halton as they are a gateway to all services. It was also said that more support nurses are needed. Not a lot of people get these nurses and they are described as a 'life line' for advice and support.

Targets and time limited appointments should be stopped in the view of attendees. Patients want all their conditions and problems to be discussed and taken into account at appointments rather than being told they can only say one thing and must leave in eight minutes.

Consistency

It was felt that GP Quality and Outcome Framework (QoF) targets should be scrapped. Patients feel they are called in for checks, such as blood pressure or cholesterol, that they don't want or need so GPs can meet their targets and get financial rewards. 'Tick box exercise' checks are described as 'unhelpful'. It is believed that they don't work as illness levels and hospital admissions have increased since these checks have come in. *"GP QoF targets are a disgrace and should be scrapped. They are not useful and are just a tick box exercise."*

Choice

The groups would like a choice over who provides care, and information such as which providers are Centres of Excellence and which are the best consultants to inform this decision. They said that they would travel for more specialist treatment if needed. Timing of appointments is important if travelling is required, and shuttle bus services were suggested.

Information and communication

The groups all felt that people are responsible for their own health and more education is needed. People would like more information and for it to be explained in person, although it was acknowledged that a pamphlet with basic information to read at home would be useful.

It was told that some consultants invite people to call their secretary with any questions, whilst others do not offer this. Some consultants send a copy of appointment records to the patient and their GP but again, some do not. Members of the groups found it very important to have these notes and always asked for them, explaining they are the only person who holds all their records from different services.

Other members of the groups did not want to be sent these records and were happy if they had trust in their consultant. The groups believed that choice is important. Everyone should be offered their own records and record sharing should be consistent.

What Works:

- The group felt staff were very pleasant and supportive without being patronising or pitying.

What Needs to change:

- When discussing communication, it was stated *“Some aspects were very clinical and direct”.*
- Some members of the group had been given written information such as the Macmillan service. All members of the group agreed that a standardised written care plan is required including information about who to contact if they have concerns and local support groups.
- During the appointment there is a lot to take in and having the information in writing following the appointment is valuable.
- Rolling information screens could be used in hospitals and GP practices to inform people of local cancer support services.
- Providing information and support about availability of services if there is more than one hospital that provides the particular treatment is required.
- *“I wasn’t aware I had a choice of where I could receive my treatment I was told I had to go to a certain hospital but would of preferred another that do offer the same treatment - the choice would of helped me feel more in control as the one thing cancer does is make you feel not in control”.*

The groups said it was important to be able to feedback to Healthwatch as we are independent and give them a voice.

Investigations and Medication During Treatment

What Works:

- Finding the right pain relief and medication to manage the condition and associated symptoms. Radiotherapy was valued as it was “*painless*”.

What Needs to Change:

- Although the group thought that they were seen quickly they felt the wait between having tests and receiving their results is lengthy (to do with consultant availability rather than not having the information). The group suggested using a nurse led service would be appropriate to reduce waiting times.

Specialist Cancer Nurse

What Works:

- A named specialist nurse to provide emotional and practical support and consistency throughout the ever-changing stages of the cancer journey.

What Needs to Change:

- The consistent provision of a single point of contact to provide support throughout the journey, emotion, practical and signposting.
- A drop-in service provided by either Macmillan or Widnes and Runcorn Cancer Support to be based in the outpatient clinic when there is a Consultant clinic running to provide further support following the appointment, the group felt this was particularly important at the time of diagnosis and discussing changes and prognosis.

Transport/location of hospital

What needs to change:

As the closest specialist cancer centre isn't very local, when the ambulance picks up for the daily trip during radiotherapy the journey is extremely long as it picks several people up and if you're the first person on or last to be picked up it prolongs the journey after an already exhausting day.

A member of the focus group is at the beginning of their cancer journey following a recent diagnosis and stated the following:

- *"[I] Have worries about having to travel for treatment when [I'm] unable to drive."*

As the local hospital does not offer many services and patients are having to travel a long way for treatment when already very unwell it was suggested that satellite centres are created. With the idea that consultants can come from the specialist regional centres to the local hospitals. Suggested by the group was a regular visit from Clatterbridge Hospital to see patients at Halton Hospital which would be helpful to reduce travel time and enable family members who were local to attend for a short while to visit. *"A local hospital/centre to offer treatment, to save travel (time)."*

An individual who has a Cancer diagnosis had an operation at 8.00am and was sent home at 4.00 with a drain. During the week they had to attend the specialist hospital three times due to issues with the drain and changing the dressings. This resulted in an expensive, lengthy taxi journey. If a district or community nurse could have done this it would have saved the time and money attending the hospital and had an overall positive impact on mental wellbeing.

Integrative/multi-disciplinary working

What Works:

Peer support was valued highly by the groups, access to non-medical support such as counselling and holistic therapies, particularly in a non-medical setting which mattered greatly to the group.

It was felt this should be expanded and all services; NHS, Social Care and Voluntary services should work more collaboratively. Integrated support services to include medical practitioners, dietician, physiotherapy, alternative therapies, emotional and mental health support, employment and financial support services.

What Needs to Change:

A person told us: "*Hospital Trusts have different IT systems and I'm treated at different hospitals as I have different types of cancer. One Trust is unable to have complete access to my medical records as another Trust uses a different IT system*". This shows there is a requirement for uniformity amongst the trusts to enable them to share medical records easily to benefit both patients and staff.

This was corroborated by other members of the group who felt that having to explain their whole history to each professional and at each appointment is unnecessary; they felt that if there was a IT system set up with a front page bullet pointing where they are at regards diagnosis and treatment it was prevent the need to provide a detailed history at each appointment with different professionals.

Post-Discharge

What Needs to Change:

It was discussed about there being no support following discharge once treatment has finished - "*when cancer, treatments and appointments have been your life for over a year it's a huge adjustment to then move on*." A contact to continue to provide ongoing support for a time specific period following discharge would be helpful according to some members of the focus group.

healthwatch

NHS Long Term Plan Report

Chapter 5 - Healthwatch Knowsley

what would you do?

It's your NHS. Have your say.

Knowsley

Knowsley's 2017 population was estimated to be 148,560. Almost a fifth of the borough's population (18.8%) are aged 0-14 years. 11.9% are young adults (aged 15-24). Almost a fifth (19.3%) are aged 25-39. People aged 40-59 make up the largest single age group (26.7% of the population). Over a fifth of the population (23%) are aged 60 or over, of which 15.4% are aged 60-74 and 7.8% are aged 75 or over.

Knowsley is the second most deprived local authority in the country and Kirkby is the most deprived of the four locality areas within Knowsley. Levels of deprivation in Kirkby are over double that of England. Overall life expectancy in the Borough currently stands at almost 77 years for males and just over 80 years for females.[4]

In Knowsley we received 255 survey responses, consisting of 102 general surveys and 153 specific condition surveys. There were also 94 attendees across four specific focus group events.

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[4] Source: http://knowsleyknowledge.org.uk

Summary of Findings:

What matters most to people in Knowsley?

- Having access to the help and treatment needed when it is wanted was the most important factor people told us was needed in living a healthy life. For example, people said they wanted more support with healthy eating and exercise, as well as better access to services such as GP appointments. Having health professionals that listen was also considered very important.
- To help keep independence and stay healthy whilst getting older, people indicated that being able to stay in their own home for as long as possible was most important to them. Greater access to, awareness of, and investment in services was also mentioned, as well as initiatives to tackle social isolation.
- Choosing the right treatment being a joint decision between the person and the relevant health and care professional is most important to people in Knowsley in managing and choosing support and treatment. Better communication, information, advice and guidance, as well as services being available locally, were themes of comments we received.
- People in Knowsley told us that having absolute confidence that personal data is managed well and kept secure was considered very important, as well as a desire to talk to a doctor or other healthcare professional wherever people may be. Responses regarding online technology were mixed between those who wanted to see more of its use and those who did not. People also wanted reduced waiting times and tailored support for long-term health conditions.
- Those with heart and lung conditions and other long-term conditions such as diabetes or arthritis were largely positive about the initial support they received relating to their condition and said that it met their needs.
- People with multiple conditions found that this made no difference to their ability to access support.
- Accessing ongoing support was largely seen to be difficult, but people were generally satisfied when they did access it. People generally told us that they would be willing to travel up to one hour for diagnosis, assessment, treatment or support.
- Most people who responded with Cancer or Mental Health problems said that seeing any medically appropriate health professional who is free immediately was more important than waiting to see someone they normally see even if there is a wait initially when first seeking treatment, but for long-term support seeing someone they normally see became more important. For other long-term conditions and for those with heart and lung conditions, seeing someone they normally see tended to be most important throughout.

Survey results

The following sections now break down the results of the 255 responses across Knowsley to the surveys designed by Healthwatch England. The first sections use the 102 responses to the general 'People's general experiences of health and care services' survey, before breaking down the 153 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.

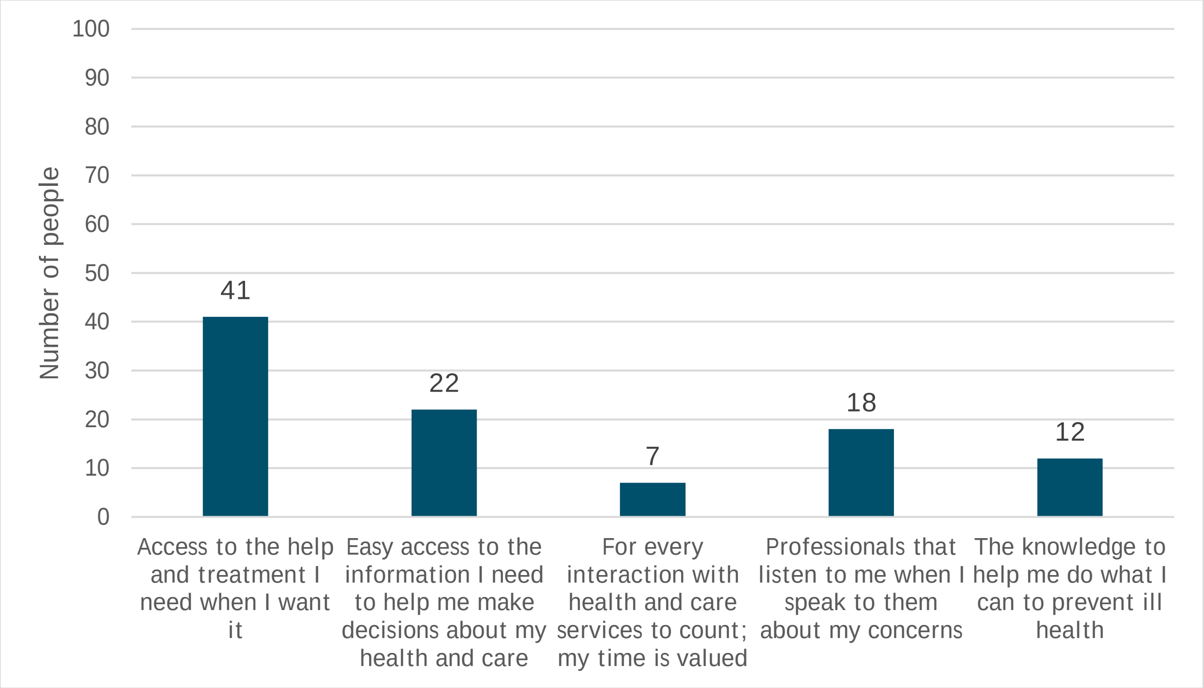
For each of these, people were asked to choose which of a number of options was most important to them. Following this, people were asked to rate each of the options on a scale of 'very important' to 'not important at all'. Therefore, more than one option could be considered 'very important'. Finally, 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). 100 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 also very important. It is also important to note that all five statements were predominantly deemed as very important or important, as the table below shows. Up to 99 people responded to this question, though not all 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
Access to the help and treatment I need when I want it	88	9	0	0	0
Professionals that listen to me when I speak to them about my concerns	86	12	1	0	0
Having the knowledge to help me do what I can to prevent ill health	75	20	3	0	0
Easy access to the information I need to help me make decisions about my health and care	74	21	3	0	0
For every interaction with health and care services to count; my time is valued	74	21	3	0	0

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:

Healthy eating/exercise

Many people commented on the impact of poor diet on health, particularly the importance of improving nutritional knowledge and enabling people to make healthier eating choices. Increasing access to exercise (particularly financial enablement) and the importance of a social element present in physical activities was mentioned *“Education is a huge part of health ... it is one of the most important factors in equipping people to be able to manage their own lives and conditions.”*

- *“Eat healthy and do exercise.”*
- *“Lower price of fruit and healthy snacks.”*
- *“Access to healthy cooking course, health walks, more outdoor activities.”*
- *“Educate young people on how to stay healthy and keep fit.”*
- *“To make sure that doctors tell you to eat the certain diet you need.”*

Access to services

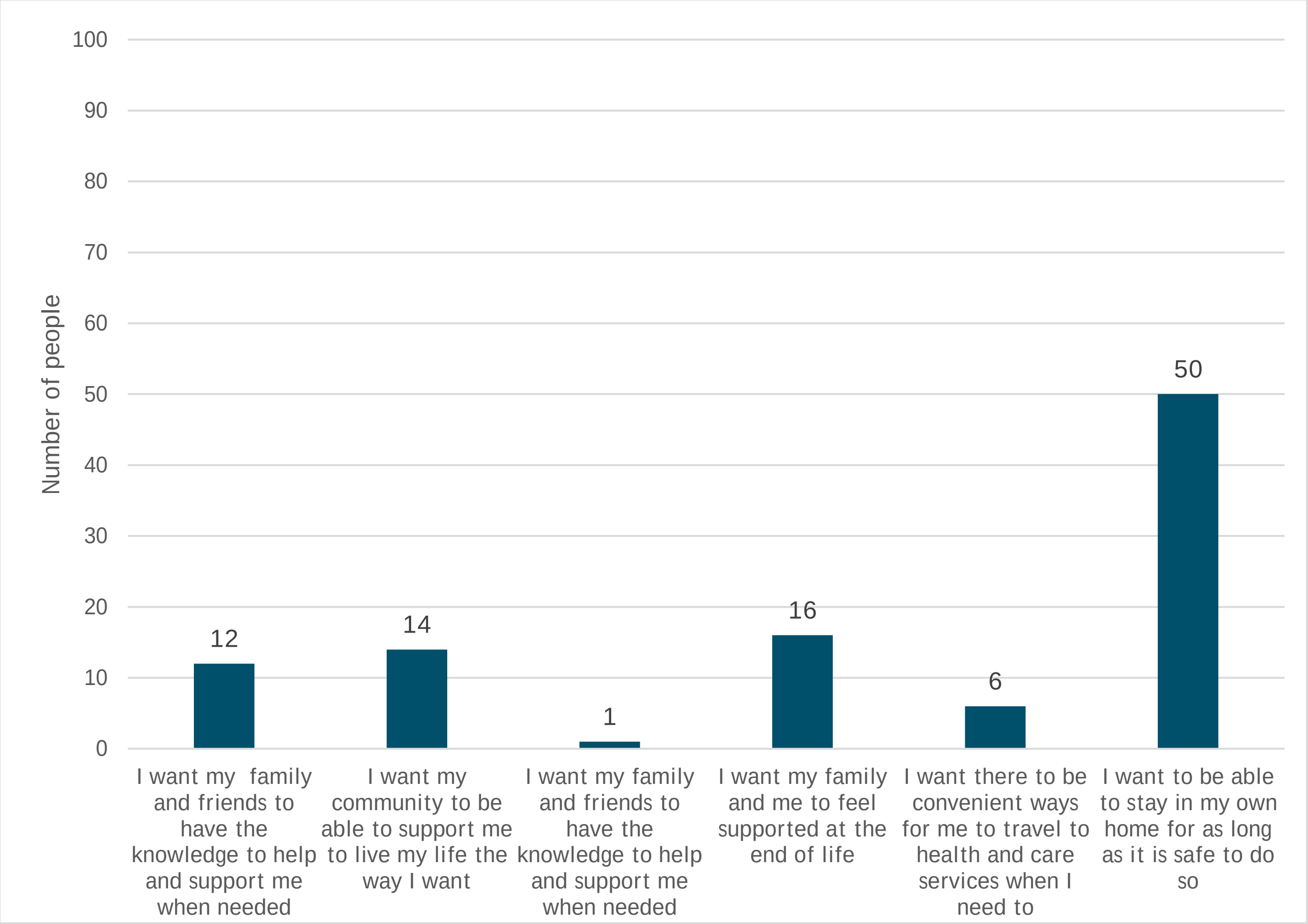
Increased availability of GP appointments and a wider range of appointment times was prevalent here, alongside a desire for more regular check-ups (i.e. monthly/yearly health 'MOTs' to improve prevention.

- *"GP surgery to open more throughout the day."*
- *"Prompt and easy access to a GP."*
- *"A yearly/every couple of years, standard check-up."*
- *"[Services] seeing you in less time. Offer leaflets for better health tips."*
- *"Acceptable wait times for GP and A&E services."*

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). 99 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 100 people responded to this question, though not all 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	83	9	8	0	0
I want my family and me to feel supported at the end of life	78	18	3	0	0
I want there to be convenient ways for me to travel to health and care services when I need to	72	19	7	2	0
I want my community to be able to support me to live my life the way I want	66	23	8	2	0
I want my family and friends to have the knowledge, to help and support me when needed	66	25	6	2	0

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 question so answers were collated into themes and summarised below:

Awareness of services

One of the most prevalent themes with regards to what people feel would help them to live independently was related to people's awareness of available services:

- *"Knowing there is help out there when needed."*
- *"Having up to date health information."*
- *"Better communication around prevention services."*
- *"Provide people with reliable and consistent information."*
- *"Better services and support for mental health."*
- *"Access to exercise for all family."*
- *"Give better choices including holistic therapy approaches."*
- *"Access to exercise for all family."*
- *"Exercise, healthy diet, staying aware of your mental and physical conditions."*
- *"By providing people with information about commissioned services and focus on their own strengths and assets."*
- *"Much better communications regarding availability of services etc."*

Access to services

Related to the above theme, a number of respondents linked this with ease of access to services:

- *"Getting help from all the services that are out there for you."*
- *"Access to info and opportunities to live a healthier lifestyle, nutrition, activity."*
- *"Contact with other people is important, sometimes you need to speak to people who aren't in your family or who aren't that close to you, this is tricky if you're housebound, how about 'mobile support groups' or organised 'E support groups' that 'meet' online at set times/webinars/WhatsApp support groups"*
- *"Having annual health checks with reasonable access to appointments."*
- *"Older people need the availability of regular monitoring of their health."*
- *"Shops, transport services and primary health care all nearby."*
- *"More local interest groups."*
- *"Better services and support for mental health."*

Social isolation

Some respondents expressed a desire to feel more connected to their community and the people in it. There was also a need to receive more support to enable this to happen.

- *"Someone to talk to."*
- *"Some support within the community would be a start."*
- *"To be able to get out more. Before I got my wheelchair, I was really depressed."*

Investment in services

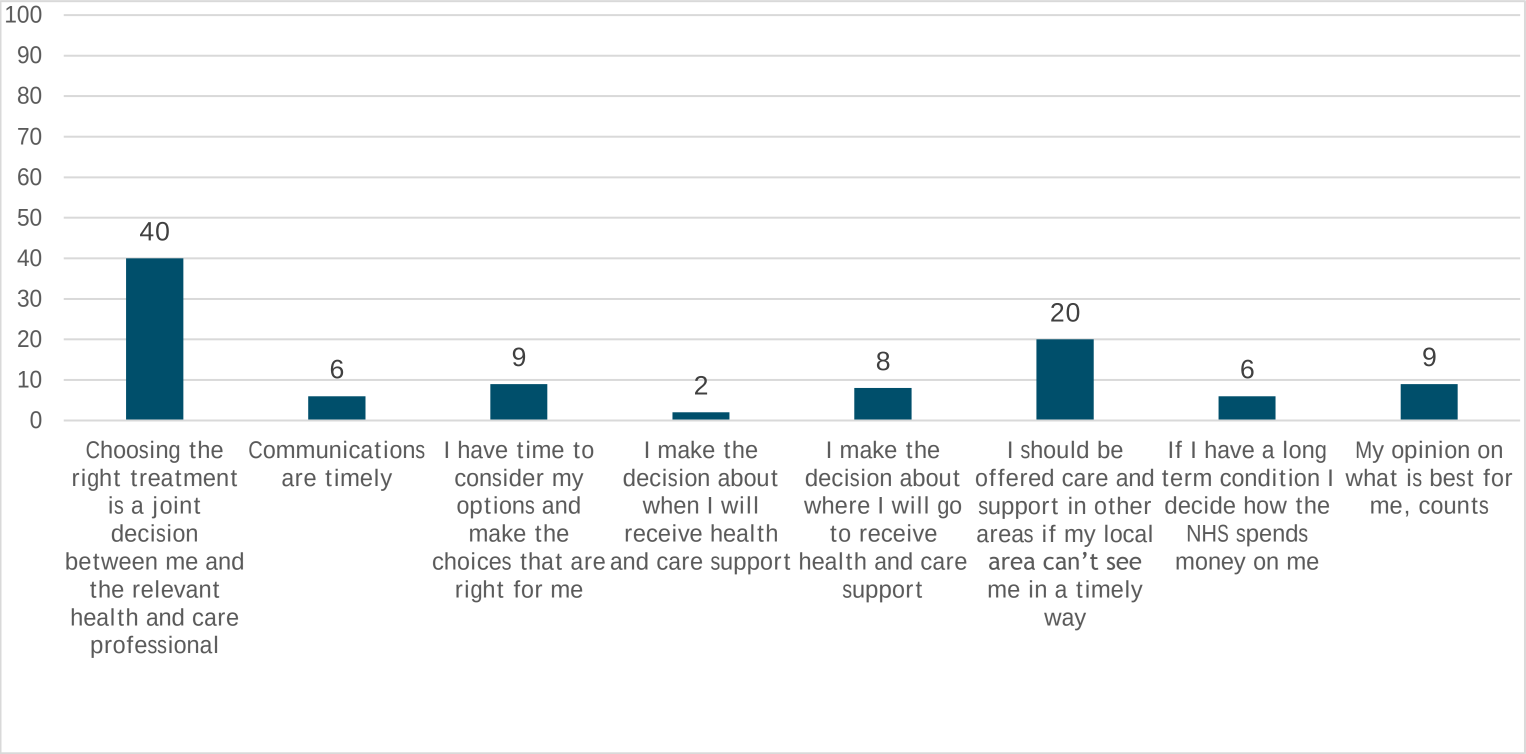
A number of respondents expressed a desire for increased investment to boost the range, availability and capacity of services. Some also expressed concerns regarding the effects of underinvestment.

- *"More investment on the front line i.e. the care workers etc."*
- *"Support from councils as well as NHS. I am aware of council's finances but perhaps government should give more to local councils specifically for this."*
- *"Older people need the availability of regular monitoring of their health. This is often the first service to go when money is tight."*
- *"The local authority act like debt collectors in terms of paying for the care costs and it is a minefield for the relatives to understand. Patients and their families are deliberately kept in the dark regarding options and that with some conditions, the NHS is responsible for care costs."*
- *"The availability of non-profit making care homes is slim and the very worst of patients are given second rate provision. A complete state funded system needs to be instigated even if it means income tax is increased. This should be available regardless of income as it is grossly unfair that patients who have worked hard to provide for their children are penalised when it comes to healthcare in old age."*
- *"The right amount of help of nurses or doctors. To eat right and make sure I don't take the wrong medication."*

Managing and choosing support and treatment

Chart 3 shows that people we spoke to in Knowsley 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. 100 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 deemed choosing the right treatment as a joint decision between themselves and a relevant health and care professional as the most important factor when managing and choosing the support they need, followed by a desire to be offered care and support in other areas if unable to be seen in their local area in a timely way. Up to 100 people responded to this question, though not all people 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 the relevant health and care professional	65	28	6	1	0
Communications are timely	60	34	4	1	0
I should be offered care and support in other areas if my local area can't see me in a timely way	55	37	5	2	1

My opinion on what is best for me, counts	53	36	9	2	0
I have time to consider my options and make the choices that are right for me	50	41	6	0	0
I make the decision about where I will go to receive health and care support	49	34	51	1	0
If I have a long term condition I decide how the NHS spends money on me	38	34	18	4	4
I make the decision about when I will receive health and care support	37	42	20	0	0

Communication, information, advice and guidance

A common theme stemming from people’s comments was the need to be given more information, advice and guidance. People wanted to gain knowledge about what services are available and where, and the options available to them for care, discussing these in light of their needs with their GP, in particular. There was also a feeling that more information should be provided in a clear and straight-forward “no-nonsense” manner. Comments included:

- *“Individuals do not always know what is best and I think NHS professionals should advise and offer guidance as required.”*
- *“Make services more known to people. There is plenty of help out there, people just need to know about them.”*
- *“Listen to your requests and answer all questions honestly and offer support needed where possible.”*
- *“Giving recommendations on the best support for them.”*
- *“Communication is the key between me and the health care professional and I feel they do not tell you about options for treatment itself or the place it can take place.”*
- *“Clear no-nonsense information about conditions.”*
- *“A more comprehensive knowledge of what options are available and chance to discuss the pros and cons.”*

Funding for, and availability of services locally

Furthermore, people told us that they would like to be able to access GP services in a more timely manner, with options to see a GP when it is convenient for them or to see one that might not necessarily be their own, if the option is made available. For example:

- *“The ability to get a reasonably soon doctor's appointment.”*
- *“To be able to get an appointment when you need one.”*
- *“If your personal GP wasn't available, another one should be able to be accessed.”*
- *“Refer you to other GP practices if my local one has no availability.”*
- *“Acceptable wait times for GP and A and E services.”*

- *"Enough time in appointments to be able to talk through concerns and any issues that I may need to address no matter how big or small."*
- *"Clearer access points that are responsive."*
- *"Different clinics near me."*
- *"A more efficient way to get seen quicker."*
- *"More timely/earlier access to services such as cataract surgery which would make independent living easier."*
- *"Getting GP appointments when I need them, especially for routine /non-emergency treatment, I shouldn't have to take up an emergency appointment for that, I should be able to plan in advance."*

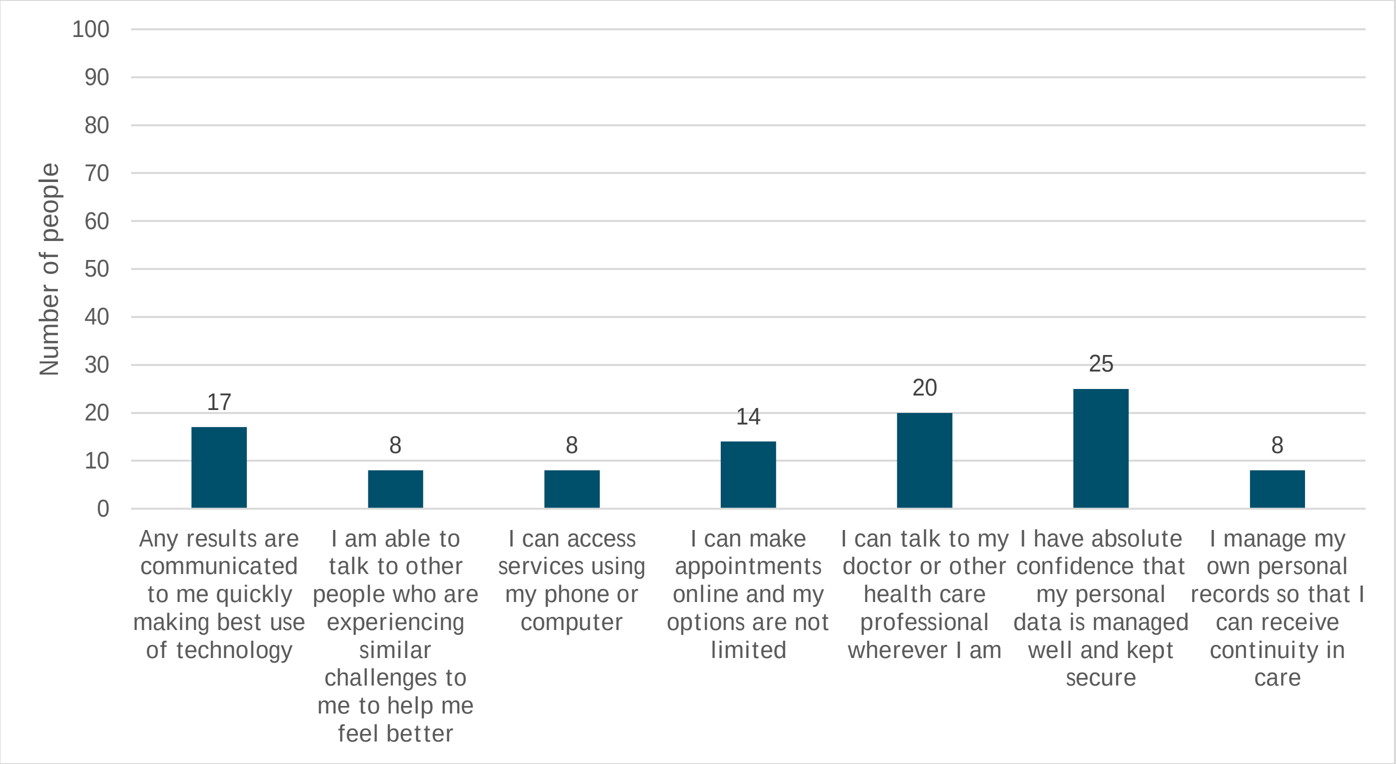
Engaging people in health service delivery

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 Knowsley told us that having absolute confidence that personal data is managed well and kept secure was considered most important by people who answered the survey, this was followed closely by a desire to talk to a doctor or other healthcare professional wherever people may be. Also considered important was the need to make the best use of technology whether for communicating results quickly or to make appointments online with options not being limited by this service. 100 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 having absolute confidence that their personal data is managed well and kept secure was very important as well as making good use of technology to access and book services and receive test results. 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 100 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
I have absolute confidence that my personal data is managed well and kept secure	72	23	5	0	0
Any results are communicated to me quickly making best use of technology	65	28	7	0	0
I can access services using my phone or computer	61	23	12	3	1
I can talk to my doctor or other health care professional wherever I am	51	34	11	1	1
I can make appointments online and my options are not limited	49	25	17	6	2
I manage my own personal records so that I can receive continuity in care	38	36	24	2	0
I am able to talk to other people who are experiencing similar challenges to me to help me feel better	37	34	19	7	3

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:

- *“Options in communication, not everyone is comfortable with today's technology.”*
- *“Elderly cannot access technology easily. There needs to be consideration of alternatives for older people.”*
- *"Technology should be utilised further, I should be able to make my own health appointments with all health services including hospitals (assuming I have a doctor's referral).”*
- *“I would like to see test results online including health tests so I can see improvements over time following routine health checks, e.g. weight, cholesterol levels, blood pressure, blood results that will give me an indication and motivation overtime whether I am improving my health or it is deteriorating. An 'App' for this would be very useful."*
- *“Already described above, embrace the digital age especially for appointments, and lots more mental health investments and general empowerment for people to take charge of their own health.”*
- *“Allow patients to manage their appointments directly with healthcare providers. The current system of letters and phone calls is inefficient and expensive.”*
- *“Recognition that online apps aren't always good for medications not able to be on repeat - holistic choices to be made available in GP surgeries too. The recognition of carers and being able to prevent crisis or overwhelm.”*
- *Whilst I appreciate that there is a move to using technology, many people still prefer to use the telephone and I feel this is being phased out in every area of life. It is especially important for older people or those suffering with mental health and learning difficulties that telephone systems are still maintained as part of accessing care and treatment. Also, good old letters work well for the same vulnerable groups.”*

Tailored support and involvement for people with long term conditions

People told us that, in particular cases, there is a need for in depth consideration around what works best for them. This included elements of healthcare from consultation to treatment and general involvement and communication with services. Comments included:

- *“Better communication between patients and health services around multiple and long term conditions.”*
- *“People with long term conditions having a clearer way to influence services.”*
- *“Clear options - discussed slowly at my own pace and clarifying my understanding.”*
- *“Give you the time and care to help with tailored solutions.”*
- *“Giving recommendations on the best support for me.”*
- *“To be able to know that someone can understand and address my particular situation.”*
- *“Seeing how your body reacts to different things and treatments.”*

Waiting times and access to appointments

Responses regarding the booking of health and care appointments arose frequently, where some people told us that they would like to see faster referrals and quicker access to their GP. Respondents also mentioned the possible ramifications of such a delay. Comments included:

- *“Acceptable wait times for GP and A&E services.”*
- *“Availability of appointments.”*
- *“More time with professionals.”*
- *“I would like making appointments with my GP to be an easier process. Due to how difficult it is I often delay accessing GP care.”*
- *“More GPs.”*
- *“Ability to access GP appointments without having to wait over a month to see someone.”*

- *“The availability of GP appointments at the time of being symptomatic. More often than not, a clinical concern cannot be reviewed by the GP doctor any sooner than in 7 days’ time (one might be dead by then!)”*

Further Comments

- *“Elderly health care is fragmented when someone has a number of health issues. Most important issue is to get support/treatment that considers the whole person when you need it. Too often medication is prescribed that conflicts with other medication. There's a wastage of medication.”*
- *“I want to be in control of my own health issues for as long as is possible. Honesty and being given choices about treatments available and being in control are very important to me. If this is not possible, it should be allowed to give a named member of the family choices over my treatment.”*
- *“Want to see a doctor without a nurse over the phone telling me to go the local Walk-in Centre as she is just as good as my doctor? A doctor is a doctor, a nurse is a nurse.”*
- *“I have experienced poor mental health for over two decades, I am highly medicated, isolated, do not have a care plan. I feel neglected and rejected by services.”*
- *“I think more emphasis should be on early diagnosis. This is GP level and consultant level. don't dismiss elderly persons’ concerns. My mum's cancer was not spotted by a consultant eye doctor. She was told the severe pain in her eye was because she was old, so she needs to wear her glasses all the time. It was actually secondary cancer in her eye.”*
- *“GPs need to offer a walk-in basis so people can get access to help and support as opposed to waiting over a week for an appointment.”*
- *"All NHS estates need to provide free parking for staff and patients.”*
- *“Letters and faxes are old fashioned. The NHS needs to adapt to new technology and enter the 21st century."*
- *“More holistic choices in health care and CBD oil to be given on prescription.”*
- *"For blind and visually impaired in hospital - you are sometimes brought food or medication and they leave it on the table and do not tell you.”*
- *“I think the NHS is doing very well and nurses are under so much stress.”*
- *“I need information in a format I can access as a blind person.”*
- *“Professionals who do not address me by name, I do not know they are talking to me - should be visual awareness training.”*
- *“Community groups in the local area i.e. gardening, should be able to support people with visual impairments."*
- *“We need to get considerably better at getting to grips with smoking on site. Despite the site apparently being Non-smoking, we continually walk past smokers immediately outside the doorway. This sometimes drifts into clinics/wards. Need some national support/back up on this, please.”*
- *“No more outsourcing of NHS services to private health providers, bring all outsourced services back into public ownership as contracts expire.”*

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

As part of our research activity, Healthwatch Knowsley conducted a focus group with members of the general public in order to gain specific insight into the views of people accessing services. This focus group took place on 30th April 2019, and was attended by 16 people. Below is a summary of the themes and issues they raised:

What is good about health and care services?

Online Access

A member of the focus group stated that he believed the electronic system for his appointment booking and online prescriptions worked extremely well for him. He added that it allows him to easily book appointments at his GP without the hassle of having to ring up at 8:00am.

"The practice provides an online service which I have used. I sent in a form to my GP and he came back to me with a response in 2 hours. I wish this service was available months ago but happy we have it now."

Responsiveness of Services

A focus group member gave a patient experience story from a patient at the Prescot Primary Care Centre.

- *"I noticed being short of breath and feeling nauseous whilst walking and visited my GP who took my blood pressure and temperature. The GP then rushed me to hospital and within an hour had two stents fitted."*

The focus group member was extremely pleased with how fast the practice and hospital had acted in saving her life.

- *"I have had two knee replacements at Whiston Hospital and it was excellent. The shuttle between the two hospitals is excellent also. There should be a shuttle service between other hospital sites such as Aintree, the Royal Liverpool and Broadgreen."*
- *"Aintree Hospital is great. I had problems eating and found out I had cancer. The GP referred me; I was seen by the hospital within three days of being seen by the GP. I was also diagnosed as diabetic so had to be treated for both. Doctors and Nurses are fantastic. I am in Aintree again soon to decide how to treat the cancer to get rid of it. They put a camera down and found the cancer last time and took samples. I find the hospital brilliant. The food is bang on, what I can eat of it."*

Services in the Community

- *"The Ear, Nose and Throat services provided at the Towerhill Walk-in Centre is really good, it is closer to home and much better than travelling to a Hospital."*
- *"The local Walk-in Centre is fab and really helpful - followed us up afterwards also. My GP again, really helpful and understanding."*
- *"St Chad's Walk-in Centre is where I attend for my bloods to be taken. I never have to wait very long. The staff are always lovely."*
- *"I visited the Walk-in Centre in Knowsley with my daughter who lives away. The service we received was first class. She lives in London and you have to wait ages to be seen. At Halewood we were seen really quickly."*
- *"The hospital is brilliant. Two hip replacements and joint in left foot. Very caring staff and specialist who treated me. My hips and foot have lasted 7 and 14 years."*

Seven Day Working

"I attended Aintree Hospital six weeks ago for a colonoscopy on a Sunday afternoon. It was good because family could come with me without taking time off work and it was quite empty. The only negative was that there was no one around to ask any questions."

Screening Services

- *"The staff on the mobile unit were all very friendly. In the past the person actually doing the screening has made me feel ill at ease as they just physically manipulated me without any conversation. On my last visit, the radiographer was very friendly and chatted to me putting me totally at ease."*

The group acknowledged that there are a number of NHS services within Knowsley and the surrounding Cheshire and Merseyside area that are recognised as being centres of excellence. Services such as: St Pauls Eye Unit, Liverpool Heart and Chest Hospital, The Walton Centre, Alder Hey Children's Hospital and the Liverpool Women's Hospital and that Trusts such at St Helens and Knowsley Hospitals Trust has a current CQC rating of Outstanding.

What was ok and would have been easy to improve?

Communication

A member informed the group that there is no communication between receptionists and doctors at his local GP surgery. He added that his GP had told him that he needs to be referred to hospital as his ears need cleaning. The receptionist had referred him to get a syringe which his GP had advised that he didn't need. The member told the receptionist that the GP had said he can't have a syringe and instead needed his ears fully cleaned. However, the receptionist said that she can't refer him to get his ears cleaned as the GP had not informed her of the referral.

Another member added that GPs will not discuss his medical details with his wife, even though she is his primary carer. He said this makes it difficult as he struggles to understand all that is being told to him by his doctor. The member added that the system is no longer personalised, and strong relationships between patients and health professional are diminishing.

A member noted that some staff within GP practices have attitude problems. Most of the problems that occur between a GP and patients are attitude problems and not training problems.

What didn't work well?

Barriers to access (online routes)

A member noted that the change to repeat online prescriptions is not good as it makes it too difficult to access. The member noted that to order your online prescriptions, you now need to download an app. The member added that this limits the number of people who are able to order their prescriptions online as a lot of people are not IT literate.

A member noted that his online prescriptions would never be completed on time for when he wanted to pick them up. He added that it was easier to physically give the chemist the prescription as it would be completed within 20 minutes of handing in the information.

- *"On the 18th March I rang my surgery to ask if I could speak to a doctor or could I have a home visit as I felt really ill. I have severe asthma. I was told I had to fill a form out online, I tried to explain I couldn't understand the form, I had a headache and felt unwell, the form states if you need help filling it in ring the surgery. I received no help at all from the surgery. I rang 111 for advice, after hearing my symptoms they sent an ambulance. I* *was admitted to Whiston Hospital where I found out I had a temperature of 104. I had flu and a chest infection."*

- "I rang the surgery again the other morning to ask to see a doctor, I explained I was still feeling unwell, I tried to fill the form in online but I was told to seek urgent medical advice. She told me I would need to go to A&E I explained I didn't think I was ill enough to attend the hospital but could I please just see a doctor. I was told not without filling the online form in. She suggested I try to fill it in in a different way, basically lie and say I am breathless when resting. I put the phone down as I didn't feel I was getting the help I needed."

Hospital prescriptions

The group noted that it is sometimes difficult to obtain prescriptions from hospital pharmacies and the prescription has been given after the pharmacy closes. This results in the patient having to return on a different day. The prescription cannot be used at the local pharmacies - only the hospital ones.

- *"You spend hours waiting in hospital for prescriptions - should be able to get it in the community."*
- *"I had an appointment at Whiston Hospital and was issued with a prescription. I tried to pick up the prescription but Whiston Hospital told me that they couldn't do it for me and that they would send the prescription to St Helens Hospital and asked if I could pick it up there instead. I then travelled to St Helens hospital for my prescription and was informed that it would be a six hour wait until it was ready to be collected. I couldn't wait that long as I had other commitments and subsequently failed to receive my prescription. I now have to wait for the prescription to be sent to my GP, which could take up to four or five weeks."*

Information about diagnosis

Another member stated that doctors only tend to give patients basic information about their illness and don't go into any great detail about their diagnosis. The member added that it would be beneficial if the doctors took more time to explain all of the information to the patient in order to help coping with their illness easier.

Patient choices ignored

- *"My experience was around being misdiagnosed with a problem with my foot. When finally, I was referred to therapy at Aintree Hospital I asked if this could be done in my local Walk-in Centre in St Chads but I was advised they would have to start the referral pathway again to access the service there - closer to my home?"*

A member informed the group that she has had two cortisone injections in her knees which have worked extremely well for her. She visited her GP in order to be given a new set of cortisone injections but the GP was unwilling to give her any as he thought that she needed a knee replacement. The member noted that she felt 'too old' to have a severe operation such as a knee replacement and felt as though the decision should be hers in how her knee should be treated.

Another member added to the last point and informed the focus group that they have been refused a knee replacement as they are 'too young'. The member added that health professionals are refusing to give operations and treatment if the patient is not incapacitated. They suggested that the GPs need to know that quality of life is still being affected.

Waiting times/access

The group highlighted the long waiting times to access services for allergies, dermatology and speech and language therapy.

- *"The long wait for blood results can be worrying."*

The group said the GP should give results to patients when they are received as there may be questions you need answers on.

The group stated that the main problem with GP services is the process in which you can get an appointment. The focus group believed that there should be a fairer way than ringing up at 8:00am and waiting in a queue.

- *"Trying to make an appointment for my son was an ordeal - when I tried to ring I waited 20 minutes to be put through and they told me to go online and use the e-consult system. I was in work, no internet access and said I don't want to use online and they were adamant I use online access. He was in a lot of pain but they only advised attend A&E if that is the case. I tried online, took me ages - trying to do this in work, pages of questions, more in-depth questions that I couldn't answer. My son tried to do it and it kept taking us back to homepage. Absolute nightmare. We very rarely use the doctors. My daughter has diabetes - what if I had to do that for her? My mum is over 70 she wouldn't be able to use this system - it's not fit for purpose. I felt so frustrated."*
- *"It is impossible to get an appointment and it is difficult to get an appointment for young children. There are different doctors and nurses all the time so there is no doctor - patient relationship (to confide in etc.) There are also no late appointments for people who work."*
- *"You can't always get an appointment when you want one, there is a couple of weeks wait. The doctors are good, it is always different ones but I don't mind."*
- *"I attend the Audiology Clinic at Broadgreen Hospital site - I can't understand why you cannot just pick up the Hearing Aid batteries anywhere rather than travelling - why can't they be collected at the walk-in centres? Even then they only give out eight at a time - I think they are trying to make me buy them elsewhere. It's not always about the distance to travel but about how easy the route is on public transport."*

Dignity and respect

A member informed the focus group that during 'quiet time' in the Liverpool Royal Hospital, nurses leave the patients whilst they are eating. The member noted that there are people who struggle to feed themselves who are getting left alone and subsequently failing to eat sufficient food. The member added that another patient was unable to have a shower for weeks as there was no functional bed lift to help the patient out of bed. The member noted that this could be due to lack of funding and staff shortages, but stated that there are basics around dignity and respect that should be adhered to.

Staff and continuity

The group all agreed that the first point of contact that they would all like to have would be with the GP or nurse practitioner.

Whichever practitioner patients access they should be central to the decision making - joint decisions are really important. Very often you feel as though you are a burden on you own practice.

- *"GP continuity is so important - I have seen 7 or 8 different GPs at my practice."*
- *"For long term conditions it helps seeing the same GP."*

- *"It is important for me to see the same GP - so I am happy to wait to get an appointment. Confidence and trust are key."*
- *"Practice Nurse - I am comfortable with seeing the Nurses as they know their limits and can be highly skilled."*

Community based services

It would be good to see more low-level treatments provided through the GP Practices.

Appropriate specialist at an appropriate time

- *"For me I had attended the GP with headaches which the GP was observing but it was an eye test which picked up something more sinister and ensured I was referred to St Pauls Eye Unit it was cataracts and I ended up blind - I would have wanted to have seen an eye specialist sooner as it may have prevented my eye sight loss."*

Location

A member informed the focus group that he had been to see his GP over a problem with his throat. He noted that his GP is a qualified ear, nose and throat specialist, but is not commissioned to deliver healthcare on these aspects. As a result, the member had to then be referred to Broadgreen Hospital. The member stated that this is a waste of resources and time, not only for himself, but also for the staff at Broadgreen Hospital.

- *"I don't mind travelling to see the right specialist but public transport can be so difficult - I ended up opting to use a taxi £25 each way is not affordable. I would try and access Patient Transport Services but I want to be independent. The services are excellent when you get there."*
- *"It doesn't matter where I pick to access a service - when the appointment letter lands it is always for another Trust."*
- *"You only have a choice if the options are communicated clearly - very often you attend where you are told to."*
- *"A lot has changed and the choice of services closer to home has really improved - we can get x-rays done in our Walk-in Centre now."*
- *"It still seems that Trusts compete against one another rather than prioritising what is best for patients."*
- *"I am happy to go where they can access my records."*
- *"Cost is a big factor in where I chose to attend."*

Access to information

A member of the focus group wanted to know if the money being invested by the government into the NHS would be distributed evenly between the boroughs or whether it would be split percentagewise.

- *"Information formats are so important - I request for my information to be emailed through to me as I have a package which reads the text." (I have a visual impairment)*
- *"The more information the better - I would prefer to be told that a clinic is running late and the reason why. My consultant regularly ran late but stayed to give the time needed to patients and complete his list. I have waited on occasion for a long time but I understand the need to prioritise people's needs."*

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

As part of our research activity, Healthwatch Knowsley conducted a focus group with older people in order to gain specific insight into the views of people accessing services. This focus group took place on 5th April 2019, and was attended by 13 people. Below is a summary of the themes and issues they raised:

- Communication
- Inconsistency - the same experience is not always delivered by different services in the same location, or by the same service offered at different locations
- Many NHS services are not as person-centred as they believe they are. There are many examples where the interaction with patients (such as booking of appointments, attending an appointment, having a consultation etc) requires the patient to comply with the established system in that department. Frustratingly, these are not always the same from service to service, requiring patients to be extremely adaptable as they access different parts of the NHS, and leading to confusion.

What is good about health and care services?

- Quick appointments (after being referred by GP)
- Good examples of choice being offered
- There should be comfort that an ambulance or medical referral will direct us to the right place
- Rheumatology is an "*excellent service*".

A member discussed her regular appointments at the rheumatology centre in Whiston Hospital. The member said the service is excellent and she has been given a direct line to the rheumatology nurses if she has any queries that need answering. She also highlighted that she has been given more control over her medication as she can choose when it is delivered as she has limited accessibility to the centre.

Follow-up treatment at Nutgrove Walk-in Centre after surgery was described as "*excellent*". Another member discussed Nutgrove Villa Surgery. The member informed the focus group that they had recently had a spine operation and their spine was in need of a new dressing. The member attended Nutgrove Villa and was seen to straight away. The member informed the group that the surgery also do home visits for people who are unable to make it to the practice.

The development of walk-in centres in Knowsley is generally seen as positive and they offer a good option to people.

Wards 1a and 1b [at Whiston] are used for GP referred admissions and bypasses the usual A&E waiting which helps at times.

Choice

A member told the group that they had an ankle fusion a few years ago but now one of the screws was coming loose and was about to break the skin. The member went to their GP to get referred and was given the choice between attending St Helens Hospital or the Spire Liverpool Hospital. The member was pleased with this as it meant that they were able to pick a service provider that best suited them and an appointment was booked for the next two weeks. The member was pleased with the quickness of getting the appointment and was very pleased with their doctor as he was very efficient.

Importance of continuity of care

One of the focus group attendees stated that continuity of care is the most important factor for them. The attendee informed the group that she had continuity of care from her dentist, whom she saw every month for eight months whilst waiting for an appointment at the dental hospital. The attendee stated that this was extremely helpful to her as she built up a strong relationship with a dentist who she trusted and who knew her dental history.

What was ok and would have been easy to improve?

Choice

A member of the focus group relayed a patient story about a friend who has a heart problem and has had to travel to her hospital appointments. The patient is unable to drive, which makes it very difficult to attend appointments. It was added that patients are not always given options of where they want to attend their appointments. Clarity needs to be provided about what choices are available.

A member of the group furthered this point by informing the focus group that he had been issued an appointment in a hospital that is further away than his local hospital, whilst a friend who has a similar condition, has been given an appointment in the hospital closer to home. Again, it is important to understand why some people in the same community are being sent to different hospitals. A member of the group advised that a GP had sent him to a specific hospital because they **"***had friends there who will see to him quicker***".**

Communication

A member informed the group of a fall that she had recently. The member stated that she had a fall and banged her head quite badly. An ambulance was called and arrived very quickly. The member said that the ambulance service was very effective and quickly referred her to A&E at Whiston Hospital in case there was a bleed on the brain. Once in A&E, the member and her sister were left alone for hours. Food and beverages were not offered to her sister for hours as she was not a patient at the hospital. The member added that nobody came into the room to tell her that she had been discharged from the Hospital. Instead, a message came up on the screen above her head informing her that she had in fact been discharged. The member was disappointed in the lack of communication between her and the doctors but was very complimentary of the ambulance service and their quick response.

What didn't work well?

Sometimes an otherwise good experience of diagnosis or treatment can be undermined by frustrations in the accompanying services, for example blood tests, scans and pharmacy.

The Hospital pharmacy can close preventing people going home, or requiring them to return next day for hospital prescriptions.

A member informed the group that they were referred to Whiston Hospital because of leg pain. The member added that they were extremely happy on the first day as they were seen for a scan within ten minutes of arriving for their appointment. In addition to this, the member added that they were receiving frequent updates from nurses informing him exactly where he was in the process. The member was asked to return the next day for blood tests and was disappointed at the fact that he was left in a waiting room for four hours to receive the tests. The member was eventually seen and was diagnosed with deep vein thrombosis. The member received an injection and was given a prescription at 7:00pm. This was bad as the pharmacy counter in Whiston Hospital closes at 6:00pm. The member had to return the next day to the hospital in order to access his prescription.

With the move towards seven-day working and extended hours, it was felt that support services should be working in a similar manner.

Nursing staff shortages

- *"The consultants are excellent. The nurses pick things up on the changeover but sometimes it can take time to sort things out. The more staff the better as some of the staff are excellent. The hospital can be very good but it is mostly okay. You can buzz and wait up to an hour and a half across a lot of the wards as generally the staff are really busy and stretched to the maximum."*

Misdirected via NHS111

A member told the group about his wife's eye appointment at Aintree Hospital. The member called NHS111 after his wife had complained about bright flashes and a pain in her eye. NHS111 advised that the member took his wife to Hospital in order to have a check-up. The appointment was booked for 9:15pm which meant that the waiting time whilst in the hospital was relatively small. Once in the appointment however, the doctor apologised to the member and his wife and informed them that they would have to visit the Royal Hospital eye specialist walk-in centre as there was nobody present at Aintree Hospital that could diagnose the source of the eye pain. The doctor further apologised as they had out of date equipment which meant they were unable to provide a diagnosis on the eye. The member was left frustrated as they felt as though they had been signposted by NHS111 to somewhere that could not help them.

The group responded to this situation advising that they had had very mixed experiences of NHS NHS111 advice.

Long waits when attending a hospital

A member had a split tongue and attended the Walk-in Centre. The triage at the practice informed the member that there was nothing that they could do as it was late at night and nobody was in the Centre that could help at that stage. The member then went to hospital at midnight and had a four hour wait to be seen by the first available nurse - his tongue continued to bleed. The nurse then tested the member's blood pressure and wanted to take blood tests. The member informed the group that he thought this was unnecessary as it was only a split tongue and the issues was that it would not stop bleeding. The member added that he informed the receptionist that he does not need these types of tests; however, he was met with rudeness from the receptionist. The member then had to wait until 4:30am to be seen by a doctor who could help with his tongue. The member was extremely unhappy with the waiting times and the lack of communication not just between the hospital and the patient but also between the doctors and nurses.

Waiting times and access - Primary Care

A member of the group stated that she had been waiting for a week to get an appointment after finding a lump. She was happy with the service she received and was given the all clear. However, the member was unhappy at the length of time she had to wait for an appointment with her GP, especially when it concerned something as serious as finding a lump.

An attendee informed the focus group that they had recently called their GP at 8:15am for an appointment. The attendee stated that they personally had made 51 calls to the practice without getting through. The attendee also noted that a friend had been trying to call the practice for an appointment and subsequently had to make 101 failed calls to the practice as the lines were too busy.

Communication

During treatment at A&E, a decision was apparently made that a patient was ok to be discharged, but this was not communicated to the patient or their family who remained in the cubicle for some time and could have left freeing up space for another patient.

It was reflected that sometimes the medical staff do not deal adequately with people's questions and concerns. For example, 'why are you undertaking an investigation or suggesting a treatment which does not immediately appear relevant to the condition/injury I'm presenting with?'

The levels of knowledge about services varies between patients. An example of this is that one participant was aware St. Pauls Eye Hospital had out of hours appointments - other people could not possibly know this.

Who to see

- *"Continuity is important. An ongoing problem with my mouth has been helped by always seeing the same dentist who is aware of and understands my condition."*
- *"Our GP is a teaching practice which means little continuity [of who you see]."*
- *"Experience of obtaining results of tests etc. via GPs varies from practice to practice (speed and level of pro-activeness). Also, inconsistencies around who gives you the outcome of your investigation/test - the consultant or your GP?"*

Location

It was said that Centres of Excellence are fine if you can get there. In the main people organise lifts and family members support people. It is the people who are isolated and without support that need to be helped.

The group expressed confusion around whether there are choices for where treatments take place. This extended into uncertainty around which places provide specialisms, and therefore why a referral is to a certain hospital/location rather than a more familiar one or location.

Information

- *"We should seek to make more information [about common long-term conditions] available in schools as part of the curriculum."*
- *"I was given lots of pro-active information from the hospital about blood-thinning medication immediately having been prescribed it - good experience."*

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 153 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	15
Dementia	6
Heart and lung diseases	40
Learning disability	4
Long-term condition e.g. diabetes, arthritis	74
Mental Health	11

Table 6: Who are you responding on behalf of?

Condition	Myself	Someone else
Autism	0	3
Cancer	12	3
Dementia	4	2
Heart and lung diseases	37	2
Learning disability	4	0
Long-term condition e.g. diabetes, arthritis	68	5
Mental Health	9	2

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

Condition	Yes	No
Autism	3	0

Cancer	8	7
Dementia	4	2
Heart and lung diseases	32	8
Learning disability	4	0
Long-term condition e.g. diabetes, arthritis	53	20
Mental Health	6	5

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	Not applicable
Autism	1	2	0	0
Cancer	11	1	3	0
Dementia	3	1	1	1
Heart and lung diseases	31	4	5	0
Learning disability	1	1	2	0
Long-term condition e.g. diabetes, arthritis	55	8	10	1
Mental Health	6	3	2	0

Autism:

- *“We were not signposted to support services. Assessments were not undertaken due to funding issues. Families are left without support.”*
- *“Could have been sooner.”*

Heart and lung diseases:

- *“The GP could have given advice on how to make my problem better.”*
- *“An earlier diagnosis would have been beneficial. I was treated for a heart attack, arrived by ambulance at 10:40am and got diagnosed at 4:30pm.”*
- *“Had to wait 15 months for heart surgery”.*
- *“Could have found my problem sooner. My DNA had to be sent to Newcastle for the results to be correct.”*
- *“There was a lack of communication between hospital departments which resulted in long term inconvenience.”*

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

- *“Referrals to specialists were approved and appointments carried out within timescale.”*
- *“More personal approach.”*
- *“Difficulty getting GP initially.”*

- *"I can't fault the treatment I received."*
- *"The GP could have sent me to the hospital for diagnostics and given advice for therapy."*
- *"The GP has prescribed tablets which were good at first but now no longer work."*
- *"It is very difficult to get an appointment at your local GP as all appointments have gone when you ring in the morning."*
- *"I was advised by my doctor to take statins because of my age. Other than this I take calcium for my bones. My doctor is looking after me well and I feel lucky to be in good health."*
- *"X-rays and physio could have been provided earlier in the problem being diagnosed."*
- *"Earlier appointment once referred to the consultant."*
- *"I would not fault the help that I received."*
- *"I applied for a lift assisted device for a bungalow. But was told I was not suitable as I was not in receipt of any social services help."*
- *"I have been offered no support just pain relief."*

Mental Health:

- *"Daughters first episode with psychosis she was not offered any ongoing support, and has still not been able to access ongoing support. Everything happens in a knee jerk response such as leave well alone until she reaches crisis point yet again."*
- *"Follow up appointments to monitor condition. Difficult getting a doctor appointment."*
- *"On discharge, the nurses gave me information about Imagine support and Headway (support for people with brain injuries). Without those contacts and information, I would not have been able to access the support I needed."*
- *"I was feeling upset and anxious and having a panic attack."*
- *"It is clear that there is the need for the staff to have an understanding of mental health issues."*
- *"I am a qualified mental health nurse and, in my role, I have to be able to look after patients with physical needs as I believe in holistic care."*
- *"It took a very long time to diagnose my conditions."*

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

Condition	Very Positive	Positive	Average	Negative	Very Negative	Don't know
Autism	1	1	0	0	1	0
Cancer	7	4	3	1	0	0
Dementia	1	2	1	2	0	0
Heart and lung diseases	18	14	7	1	0	0
Learning disability	1	1	1	1	0	0
Long-term condition e.g. diabetes, arthritis	19	28	17	6	0	3
Mental Health	2	1	3	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	7	8
Dementia	3	3
Heart and lung diseases	34	6
Learning disability	4	0
Long-term condition e.g. diabetes, arthritis	52	22
Mental Health	6	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	1	0	1	0	0
Cancer	4	2	1	0	0
Dementia	0	2	0	1	0
Heart and lung diseases	12	16	5	1	0
Learning disability	1	0	3	0	0
Long-term condition e.g. diabetes, arthritis	10	25	13	3	1
Mental Health	1	3	2	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:

- *"We are actually still waiting. It's been three years and we have another 6 months to wait, at the least, for a first appointment."*

Heart and lung diseases:

- *"I waited two weeks."*
- *"It was sorted within a couple of weeks."*

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

- *"Waited over a year for an operation."*

Mental Health:

- *"After five years of suffering my daughter still has not had a proper diagnosis, as every time she eventually gets an appointment at mental health she is seen by a different consultant or senior nurse and the reports that they do are not consistent."*
- *"Given that I was feeling vulnerable and not put in a private room it was too long (about 15/20 minutes)."*
- *"I had to wait a long time because they just had a break through on my blood condition as soon as I explained my symptoms to my GP."*

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	0	1	0	0	0	2
Cancer	0	8	1	1	4	1
Dementia	0	2	2	2	0	0
Heart and lung diseases	1	14	11	6	6	2
Learning disability	0	1	2	1	0	0
Long-term condition e.g. diabetes, arthritis	2	19	33	10	7	3
Mental health	1	2	3	0	1	3

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

Condition	Yes	No
Autism	1	2
Cancer	3	12
Dementia	2	4
Heart and lung diseases	13	25
Learning disability	2	2
Long-term condition e.g. diabetes, arthritis	29	42
Mental health	4	5

What could be improved about health and care support?

Autism:

- *“Given printout information of tablets.”*

Heart and lung diseases:

- *“Better communication between healthcare groups.”*
- *“The person who tells you what the condition is so you know exactly what you are dealing with.”*
- *“I had to wait for over three months with a tube in me before I could have my operation.”*
- *“Waiting times at hospital for blood tests could have been shorter.”*
- *“More physio.”*
- *“Improve checking system more often.”*

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

- *“Was offered physio but it was useless.”*
- *“The support could be more accessible locally so I don't have to travel as far to my appointments.”*
- *“More information given.”*
- *“Actual knowledge of correct measurement of supports.”*
- *“The support didn't work for my healing process.”*
- *“More information from clinics and specialists.”*
- *“Having things explained better.”*
- *“I went out of district so nursing staff weren't allowed to support.”*
- *“Waiting times for appointments.”*
- *“Extended support of activity for life.”*

Mental Health:

- *"Mental Health sufferers need long term regular one to one support to enable them to have longer recovery times. Instead of having to start afresh each time they have a relapse of their Mental Health and then having to wait three to six months to get an appointment.”*

- *“Waiting times for appointments just causes more anxiety and stress."*

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

Condition	Yes	No
Autism	1	2
Cancer	15	0
Dementia	3	3
Heart and lung diseases	35	4
Learning disability	4	0
Long-term condition e.g. diabetes, arthritis	57	17
Mental health	7	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	0	0	0	1	0	0
Cancer	0	1	3	8	3	0
Dementia	0	1	0	2	0	0
Heart and lung diseases	2	5	11	10	6	1
Learning disability	1	0	1	2	0	0
Long-term condition e.g. diabetes, arthritis	2	9	21	16	5	3
Mental health	1	2	3	1	0	0

Heart and lung diseases:

- *“One month.”*
- *“Two hours.”*
- *“Three weeks.”*
- *“Over one year.”*
- *“Months.”*
- *“Four days.”*
- *“A few months.”*
- *“Six weeks.”*
- *“Two months.”*
- *“Three months.”*

- *“One month.”*
- *“Two weeks.”*
- *“Only took a few hours.”*
- *“Four weeks.”*

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

- *“It depends on the speciality. Orthopaedics can take longer than upper limb.”*
- *“Two weeks.”*
- *“Three months.”*
- *“Months.”*
- *“Four weeks.”*
- *“1-2 months.”*
- *“Months.”*
- *“One month.”*
- *“Months.”*
- *“Three weeks.”*
- *“Four weeks.”*
- *“18 months for a knee replacement.”*
- *“Three months.”*
- *“Six months.”*
- *“Two weeks.”*
- *“Couple of days.”*
- *“A few months.”*
- *“Not long at all.”*

Mental Health:

- *“I think it was about six weeks.”*
- *“A few weeks.”*
- *“Still waiting, six years later.”*

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	1	0	0	2	0	0
Cancer	3	3	2	4	0	2	1
Dementia	2	1	0	1	1	1	0
Heart and lung diseases	8	8	4	13	1	1	4
Learning disability	0	0	2	2	0	0	0
Long-term condition e.g. diabetes, arthritis	7	9	6	28	3	9	11
Mental health	0	0	1	5	3	0	1

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

Condition	Yes	No	Somewhat
Autism	2	0	0
Cancer	7	1	7
Dementia	3	2	0
Heart and lung diseases	27	5	4
Learning disability	1	1	2
Long-term condition e.g. diabetes, arthritis	42	10	14
Mental health	3	3	3

Why, and what could be done to improve?

Autism:

- *“It could have happened quicker. The waiting was frustrating.”*

Heart and lung diseases:

- *“Be accessible by phone.”*
- *“Better information sharing between healthcare groups.”*
- *“No information on long term care.”*
- *“My doctor didn't know what was wrong with me. I was sent to specialist and they still didn't know what was wrong with me.”*
- *“Different doctors telling me different things.”*
- *“Not to be left in agony for months with several wasted days with unnecessary hospital appointments.”*
- *“Keep issuing sufficient prescriptions.”*
- *“Too stereotyped with the care. Not everybody reacts the same way.”*
- *“More screening after certain ages.”*
- *“Care was very good, met my expectations.”*

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

- *“Ask patient and agree a solution if possible.”*
- *“They needed to talk more and explain things to me.”*
- *“For injections to be continued every so often. I am allergic to so many side effects from tablets.”*
- *“Understanding exactly what was required.”*
- *“Need to prioritise specialist visits.”*
- *“More regular check-ups.”*
- *“More help with travel to appointments.”*
- *“Offer longer home care support after surgeries.”*
- *“Transport could be offered when attending appointments.”*
- *“Trying to get to see the same doctor that found your diagnosis.”*
- *“Time taken to see specialist could have been shorter.”*

- *“Listening to needs and getting medication right.”*
- *“I had a life changing condition and was given very little advice about it. I also had to wait 11 months for a review appointment with a consultant.”*
- *“Problems getting appointments at doctors’ surgery.”*
- *“Explaining as soon as went to support.”*
- *“All being in the same district.”*
- *“Provision of the support given would be better if provided nearer to our home and not limited to just a few visits then being discharged to manage alone.”*

Mental Health:

- *“Needed 1:1 support such as weekly support visits to check on wellbeing.”*
- *“Quicker and more coordinated.”*
- *“Follow up appointments and support groups.”*
- *“The consultant helped with the shock of having surgery.”*
- *“Still awaiting my appointment six years later.”*

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	1	2	0
Cancer	9	2	4
Dementia	2	3	0
Heart and lung diseases	25	6	5
Learning disability	2	2	0
Long-term condition e.g. diabetes, arthritis	47	12	8
Mental health	2	5	3

Autism:

- *“I contacted the early help team, social services and MASH [Multi Agency Safeguarding Hub] myself but was not able to access any help until the family completely broke down two years later.”*

Heart and lung diseases:

- *“Needed more advice.”*
- *“Any shortfall was due to me not expecting the information that I was given at the time.”*
- *“Getting to see the right people for help.”*
- *“By seeing one doctor as every time I went, I had to explain the same thing over and over again.”*
- *“No communication between departments in hospitals.”*
- *“Still waiting for an appointment.”*
- *“Stop putting operations off for several months.”*
- *“More consultation in the beginning.”*

- *"Follow up appointment was given as seven months and should have been four months. I had to ring to get four-month appointment to get further ECG."*
- *"I live on my own and I felt alone throughout the support. I did not have anything explained to me, but I didn't ask either."*

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

- *"More information needed in writing posted to the house."*
- *"Needed to have someone to talk to."*
- *"Not to be told I could not have injections because the NHS was no longer paying for them."*
- *"Never seen the same doctor twice."*
- *"Given extra physio."*
- *"It could have been explained better."*
- *"More information from the specialist."*
- *"Listening particularly when there are health issues."*
- *"Access to medical staff to give advice and not having lengthy gaps between appointments."*
- *"Getting the right information straight away. Didn't hear news as it went along."*
- *"Have had good care but not the assurance of continuity of care from GP. Important to see the same person during flare ups of condition."*
- *"Could offer specialist transport to appointments."*
- *"More follow up appointments."*
- *"I was not told of the various equipment you can get at home to help."*

Mental Health:

- *"Seeing a different professional at each appointment doesn't help at all as you have to go through your situation each time and it's exhausting."*
- *"More explanations needed."*
- *"Help and support to deal with condition."*
- *"Walk in was diabolical."*
- *"6 years is a long time for an appointment."*

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	2	0	1	0	0	0	2
Cancer	7	7	0	0	1	0	7
Dementia	2	2	1	0	0	0	2
Heart and lung diseases	8	10	16	0	6	0	8
Learning disability	2	0	1	0	0	1	2

Long-term condition e.g. diabetes, arthritis	24	13	22	3	11	1	24
Mental health	1	2	4	1	1	1	1

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	1	1
Cancer	4	9	0	2
Dementia	0	4	1	0
Heart and lung diseases	10	19	5	5
Learning disability	1	2	0	1
Long-term condition e.g. diabetes, arthritis	24	36	7	7
Mental health	2	5	1	1

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	1	1	1
Cancer	2	7	4	2
Dementia	0	4	0	1
Heart and lung diseases	6	18	8	7
Learning disability	1	1	1	1
Long-term condition e.g. diabetes, arthritis	15	36	12	11
Mental health	1	5	0	2

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	1	1	1
Cancer	3	11	1
Dementia	1	3	1
Heart and lung diseases	25	12	2
Learning disability	3	1	0
Long-term condition e.g. diabetes, arthritis	45	21	7
Mental health	3	6	1

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	1	0	2
Cancer	4	11	0
Dementia	2	2	1
Heart and lung diseases	22	12	4
Learning disability	1	2	1
Long-term condition e.g. diabetes, arthritis	39	28	7
Mental health	4	5	1

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	1	1	1
Cancer	2	13	0
Dementia	1	3	1
Heart and lung diseases	23	14	1
Learning disability	2	2	0
Long-term condition e.g. diabetes, arthritis	37	27	9
Mental health	5	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	2
Cancer	7	8	0
Dementia	3	1	1
Heart and lung diseases	23	14	3
Learning disability	1	2	1
Long-term condition e.g. diabetes, arthritis	34	31	8
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	0	0	3	0
Cancer	3	2	10	0
Dementia	1	0	5	0
Heart and lung diseases	6	7	26	1
Learning disability	1	0	3	0
Long-term condition e.g. diabetes, arthritis	14	9	48	3
Mental health	1	1	6	0

Autism:

- *"Easily accessible support services 24/7."*
- *"Get the diagnosis sooner and the follow up sessions sooner."*
- *"Healthy living advice and groups available."*
- *"Listen to what I am saying and not be dismissive."*

Cancer:

- *"Easier GP appointments with the same GP."*
- *"Offer regular monitoring and make contact with the patient if necessary over the phone."*
- *"Have community groups to keep fit."*
- *"Employ more staff to advise healthy options."*
- *"Dietary information to control certain conditions."*
- *"Communicate better."*

Dementia:

- *"More information."*
- *"More advice on the condition."*
- *"Have an advice department on premises for patients who need more information."*

Heart and Lung Diseases:

- *"Encourage me to have regular check-ups at my surgery."*
- *"Listen to what I am saying and not be dismissive."*
- *"Getting an appointment within a week and not waiting 3 weeks. Being sent off to the drop-in centre because they can't cope in the surgery is not very good."*
- *"Learn more about my condition as no one seems to know how to deal with me unless I go to Stockport or Newcastle."*
- *"Put you in touch with people with the same problem."*
- *"Regular check-ups."*
- *"More frequent check-ups."*

- *“Publish any information that applies to the general management of my condition.”*
- *“Keep promised appointments instead of cancelling them all the time.”*
- *“Regular health checks to monitor the way the condition is progressing.”*
- *“To be there to give advice when needed.”*
- *“Regular check-ups at the GP for hospital reviews.”*
- *“Provide the information of local support groups.”*
- *“To signpost to support groups in the area.”*
- *“Place the care that I need all in the same place.”*
- *“Keep me informed of any new treatment or exercise that would help me.”*
- *“I enjoy my independence, support when needed to enable this is important to me.”*
- *“Encourage as much normality for ordinary life activities.”*
- *“Look at diet and exercise.”*

Learning Disability:

- *“To have qualified staff running our mental health service.”*

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

- *“Regular visits to the hospital.”*
- *“More staff and shorter waiting times.”*
- *“Have someone to talk to rather than just be handed a leaflet.”*
- *“Regular appointments to check my condition.”*
- *“Regular medicine reviews.”*
- *“Make sure my prescriptions are repeated.”*
- *“Treat me like an adult and explain so that I can understand. If I had the information I could do more to help myself.”*
- *“Give more information about treatment and drugs.”*
- *“More regular check-ups.”*
- *“Offer transport to appointments when help is needed.”*
- *“Keep me informed of all the information I need.”*
- *“Offer literature and advice on keeping healthy.”*
- *“Issue more same day appointments. GPs are too often running out of appointments for the same day resulting in a lengthy wait for an appointment.”*
- *“Provide advice on exercise and healthy living.”*
- *“Visit occasionally and see if the treatment is still suitable.”*
- *“Provide information about how best to manage the condition and sustain at current level for as long as possible.”*
- *“When I need help, I would appreciate KMBC helping me to stay in my own home and provide me with support.”*
- *“Regular contact with the same doctor during each visit.”*
- *“Issue dietary information.”*
- *“Getting the things that you need for quality of life. For example, a ramp for the house if you are in a wheelchair.”*
- *“Give more information on self-management and social prescribing.”*
- *“Ways we can get support in the community.”*
- *“Holistic therapies, particularly to manage pain.”*
- *“Offer more support in the future, when I need it.”*
- *“Keep fit classes.”*
- *“Regular checks on medication and blood tests, podiatry and visits to practice nurse.”*
- *“More information to understand the conditions.”*

- *“More staff to support.”*
- *“Employ enough staff to cope with demand.”*
- *“Provide care locally. Advice and information about life style choices and encourage community to support one another to help those in need.”*
- *“Not have to be between the GP and hospital to get prescription requirements.”*
- *“The NHS send several messages on how to keep healthy. It is then up to the individual to do these.”*
- *“Provide better communication for people to get information.”*
- *“It is up to yourself to stay healthy mainly.”*
- *“Simply to explain all avenues of treatment as the condition continues to progress.”*
- *“Keep a close eye on me.”*

Mental Health:

- *“By regular check-ups on health and wellbeing.”*
- *“Some conditions need more explanations and information.”*
- *“Doctors to keep an eye on your conditions.”*
- *“Staging involved with Imagine Support and my voluntary sector activities is a life line for me. I fight daily against thoughts and suicide so it is so important for me.”*
- *“Have staff who can provide reassurance and knowledge of mental health issues.”*
- *“Listen without thinking they know best.”*

Further comments

Autism:

- *“It took a private service to start the ball rolling. Everyone who needed a copy of the report got one. The NHS has now taken on the situation and are really helpful.”*

Cancer:

- *“I have had three lots of cancer throughout my life time. I am very grateful to the NHS staff who have dealt with me.”*

Heart and Lung Diseases:

- *“Visit my doctor regularly to make sure I have no medical problems.”*
- *“Younger people's needs to be more focused on as they are not getting the right representation.”*
- *“Can't get appointments and if you have more than one thing wrong with you and you make a double appointment you are only in the same time as you would be with a single appointment.”*
- *“Results take far too long to return to you.”*
- *“Regular check-ups for the over 75s”*
- *“I was sent to the dental hospital and was told I have a severe dental problem. I had two follow up appointments but after that, nothing. My situation has got a lot worse and nobody gives me support or asks about my condition.”*
- *“Hospitals are great for heart attack conditions. However, are awful for urinary problems. Any equipment needed for home takes forever to arrive and is usually too late.”*
- *“End up seeing too many doctors at too many different locations. Every doctor has different opinions on the same case.”*
- *“To get advice from the doctor by phone when I am worried.”*

- *"When an item is left off a monthly prescription, the patient should be told why."*
- *"I had a heart attack in November 2018 and the ambulance arrived within minutes. I was taken to the Royal Hospital in Liverpool and the care could not have been better. I saw the consultant straight away and was diagnosed effectively. I stayed 3 days in the hospital and the care was excellent."*
- *"It is extremely hard to be able to see a consultant for things like physiotherapy."*
- *"It is Important that prescriptions are received on time and patients are not left having to wait a week for prescriptions to get from doctor to chemist."*
- *"With my eyes - The advice was wrong and quite often the appointments were cancelled across a few months. The Royal Hospital referred me to local support, Bradbury Fields and they are fantastic."*
- *"Community support could be encouraged to assist."*
- *"More GPs are needed so appointments are quicker."*
- *"More follow up appointments to check health conditions."*

Learning Disability:

- *"There needs to be more help for when my joints need rubbing, due to my arthritis."*

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

- *"This questionnaire does not cover all the long-term conditions that I have which don't get support or medication."*
- *"The doctor is helpful but not always available. Home visits are needed at regular times. Phone calls from nurses."*
- *"I feel as though my condition is ignored a lot. I am just told to keep taking the tablets."*
- *"Need more publicity from Primary Care about what they do and what they are able to attend for."*
- *"Overall the NHS is very good. Always room for improvement."*
- *"The phone consultations are good and I feel more comfortable asking more questions this way."*
- *"When you go to the doctor, they don't back check on your records for what treatment you have had."*
- *"I feel we are very lucky to have our NHS."*
- *"It takes too long to see a health professional."*
- *"I have received excellent attention from private visits to consultants for a skin condition and an eye condition."*
- *"Frequent contact check-ups to see how you are."*
- *"There needs to be more advertising about the aftercare scheme. There also needs to be more advertisements about schemes such as the dial and ride scheme for people with disabilities who struggle to get to appointments by themselves."*
- *"Diabetes can be controlled, checks on general health."*
- *"More money should be given to communities to provide services for health and social care really near to our homes. Family doctors who can know the circumstances of people's lives in the situations they are in."*
- *"Having recently received surgery, I must commend the NHS for all my treatment and support."*
- *"The diagnosis I received was for Osteoarthritis of the knee but after years of complaining of elbow and hand problems I have not been referred for any specialist investigation as yet."*

Mental Health:

- *"Need to involve family and take more notice of family concerns."*
- *"It is so difficult to get GP appointments. I needed aids for my mum but found it difficult to get them. I ended up having to buy them myself."*
- *"It would be better if Lancashire had the contract with Whiston rather than having to travel to the Royal or Aintree."*
- *"Yes - Whiston hospital to introduce the sexual orientation monitoring standard."*
- *"Be more understanding - listen to people with long-term conditions."*

In focus: what are the main issues for people with mental health conditions and carers for people with mental health conditions in health and care?

As part of our research activity, Healthwatch Knowsley conducted a focus group with people with Mental Health conditions and carers of people with Mental Health conditions to gain insight into the experiences of service users. These focus groups took place on the evening of 5th April 2019, and was attended by 12 individuals.

The main issues discussed were:

- Access to GPs appointments to discuss Mental Health concerns as a first point of contact - barriers to accessing support.
- Timely Access to Specialist Support following GP signposting/referral. Specifically, IAPT/CAMHs and access into the services. What happens next if talking therapies do not work for individuals - where are they signposted if it is not working?
- Prevention activities and support in the community through the voluntary sector and community support groups and the impact of Local Authority funding cuts on the community offer.
- Information resources available to community members regarding how to access support to prevent a mental health crisis or to understand what is happening to a person you care for.
- Crisis provision - The group referenced being involved in conversations long term about crisis café or identified safe spaces in the community model but this has not been acted on.
- Importance of building a relationship with mental health practitioners and being able to trust staff.

What is good about health and care services?

The theme of building relationships with staff members was a really important conversation regarding mental health services for Knowsley residents. This featured within what was good about services accessed to show how this really makes the difference for people.

- *"The Pathways advisor went out of her way to help me and that had such a positive impact on my mental health."*
- *"Talking therapies are extremely important for the good health of the patient - for some people this works well."*
- *"Life saving, without (Mental Health Inpatient Unit named) I would have ended my life. They are caring compassionate amazing people and I can't thank them enough for the help and support."*

- *"Lovely staff and good food all helped my recovery when on (Mental Health Inpatient Unit named)."*

Services that are patient focused and responsive to the differing needs of people was a key theme and individual members of staff really make the difference to a positive experience of care.

What was ok and would have been easy to improve?

The group discussed NHS staff leaving posts and the gaps in service this causes and how this can be really distressing for patients. It was discussed that handovers could be improved to ensure that continuity is maintained for the patient and carer.

People also talked at length around what managerial staff think vs community wants and needs. It was highlighted that what communities want may not be possible but this needs to be communicated clearly as to why the services cannot be developed in line with community views.

It was felt that the way in which GPs interact with carers could also be improved. A significant amount of work has been undertaken locally to raise the profile of carers and how they should be listened to and recognised as part of the solution. More can always be done to ensure that people with a mental health illness and their carers feel safe to talk and feel listened to.

There seems to be a concern that GP's awareness of specific conditions such as Autism and Asperger's could be improved. If this is an area that the GP is not comfortable with then quicker referrals should be made through to appropriate services to help people access support or provide a further diagnosis.

The patient wants to feel listened to at each contact with NHS staff members.

- *"Communication skills, listening and people doing what they say they will do make such a difference to me - feeling forgotten is difficult to cope with when you are unwell."*
- *"There is a need for more sympathetic GPs who give more time to patients to talk about their concerns regarding mental health. The 10-minute rule in which GPs give a short amount of time to patients simply doesn't work and if GPs can't provide the time then others should do."*

The group discussed that there is often a common misdiagnosis from the GP and specialists which results in the doctor not looking further than depression. Depression may be the result of an underlying medical problem that doctors are failing to identify. The impact of pain management or dealing with life crisis points such as bereavement/relationship break downs may require additional support other than anti-depressants.

The levels of information available about the types of support people can access is really important. It is important that this is accessible in key places in the community also. Not everyone is online.

- *"The group stated that word of mouth is really important for patients to know what support is good and beneficial for them to access. Utilising the local community is so important."*

It was discussed that not everyone has access to online resources and it is still important to utilise the local community to inform what people can access. It was felt that local communities and voluntary sector organisations are crucial to helping people access the support they need. More promotion is also needed in the work place around what support can be accessed.

Staff members not listening to the thoughts of service users and carers is felt to be an area that can be easily improved on. Initiatives within the NHS such as 'my name is' have had a big impact on practice. 'Here (hear) to listen' may also readdress the balance.

What didn't work well?

The group continually reminded that you cannot overemphasize how important relationships are in supporting people. Comments captured included:

- *"The doctor didn't know me and was quick to judge. I was diagnosed with bipolar at 29; the doctor said that I was 'emotionally unstable' and that I don't 'fit the bill'."*
- *"The CPN didn't get where I was coming from - please listen to me and take the time to understand."*
- *"I have OCD and the CPN misunderstood my condition - I felt as though it was a waste of time and went back to see the GP."*
- *"A person may not have a mental health qualification but are supportive - that is so important. Some staff just do not give a toss."*

Access to timely medication reviews was an area that didn't work well for members of the focus group.

- *"Patients often get given a review date but tend to not get reviewed by the doctors as a result of last minute cancellations, among other factors."*

It was suggested that there should be guidance published over the period of time - six months or so - to see if the treatment is improving someone's mood and more timely reviews undertaken to help people receive the correct levels of medication. Concern was also raised over the lack of information available linked to how medication is affected by alcohol use and how this is communicated to patients.

This was supported by underlying concerns that reviews of medication are never on time and only take place when requested by the patient. For vulnerable people such as those with a mental health condition this can prove to be a barrier to receiving the right level of care linked to medication.

The group agreed that there should be a care plan developed around a person's mental health which details review dates and can be used in both secondary and primary care. Having the systems in place to share this information is really important.

Which person to see

The group stated that in many practices, the receptionist decides how severe the patient cases are. The receptionist has to decide who should be seen urgently and who should not. However, they do believe that it would be better for a doctor or a trained nurse would be better suited in deciding which case is more severe/urgent.

"Continuity of care is extremely important - so the same person whether it be a GP or mental health professional is key. It is better to see the same doctor as they know the patient's history and the familiar face could help the patient feel more comfortable about talking more openly about their problems."

It was stated that:

- *"The GPs sometimes throw medication at you - increase then decrease, then a 4-6 week wait to understand what is going on and with medication tweaks means that it is six months gone and you don't have a clue what is going on - maybe it is better to see mental health professionals sooner to try and access specialist support and consistency sooner?"*
- *"We want to see the right person quicker. My son was on anti-depressants for years but the real issue was sleep related."*

- *"My GP was a help - I had gone two years without opening the curtains in the house following my wife passing away. I described a pressure pushing down on my head to the GP and he started me on the route to treating my anxiety - he listened and the weight was lifted off me just knowing someone understood and could help."*
- *"The same person helps - someone who knows me and I don't feel as though I am an inconvenience asking for a double appointment."*
- *"The GPs feel like the only avenue to access services - but should this not be opened up so that people who understand their needs/mental health condition can access different routes to help - quicker? The pharmacy advice has really helped me in the past but this isn't communicated widely enough so more people can be helped."*
- *"Choice is key - for me the first point of contact is the GP - maybe that is a generational thing - but it is becoming more difficult as staff always move on."*
- *"If it is not easy to access then people with mental health conditions will not try and crisis follows."*

It is felt that the crisis team is for people in secondary care and IAPT is for people not in crisis - but what happens about the gap in between. The question was posed about crisis prevention for people not currently in services.

Where do you want to be seen?

Public transport is such a big issue and a barrier to people accessing support.

- *"Some of my friends won't use the bus due their anxiety levels"*
- *"Local and in our community is the best place to access support."*
- *"The group acknowledged that there is a lack of service for crisis intervention and it would be better to have Mental Health CPNs attached to the GP practices and working closely with GPs. Seeing a CPN or Mental Health professional earlier may help both ease the pressure on GPs but also enable patient to see the right person sooner."*

It was reiterated that the focus is on secondary care and not prevention and that support services and information to prevent crisis is lacking. More focus should be placed on seeing people and supporting people in their community.

- *"Where is the sense in sending someone with a mental health concern to the busiest A&E department in the region?"*

Healthwatch Knowsley - Appendix 1 - Experiences of visiting the GP for people with a learning disability

In April and May 2019, Healthwatch met with members of the *BIG Group* in Knowsley to talk about experiences of people with a learning disability visiting their GP.

Who we spoke to and when:

- Kirkby BIG Group - 10 people (24 April)
- Brothers of Charity Self-Advocacy Group - 18 People (26 April)
- Knowsley Hub BIG Group - 8 people (3 May)
- Acorn Farm BIG group - 10 people (7 May)
- Stockbridge BIG Group - 5 people (7 May)

This is what they told us:

Healthwatch helps people talk about their experience with Health and Social Care

The BIG group means Being Involved.

Members of the BIG Group are self-advocates.

This report

This report has been written after meeting with 5 self-advocate groups.

Each group talked about what it was like to go to the Doctor when you are a person living with learning disability.

Making an Appointment

We talked about who makes an appointment with the doctor and what this is like.

Most people had help from parents and carers when making an appointment with the doctor.

It can be hard getting an appointment because the waiting list is too long. More appointments are needed.

Getting an appointment for an Annual Health Checks is a problem.

Letters should have pictures and be in easy read

Doctors give home visits to some people if they need it. This is good.

Going to the appointment

We talked about how we get there and who we go with

Some like to go to the doctors by themselves.

Some like to go to the doctors with their parents or carer.

At the appointment

We talked about how we told the doctor about our illness

Some people are happy to speak to a doctor on their own.

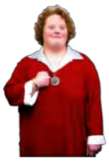
Other people feel more comfortable being helped by a parent or carer.

Some of us are nervous about going to the doctor.

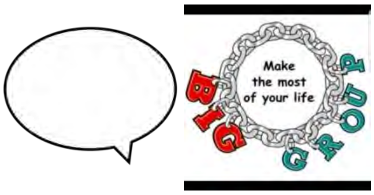
Some of us need blood tests but we don’t like needles.

Who was in the room?

Parents would be in the room to ask questions for the patient.



We could be alone in the room if we feel confident enough to speak to the doctor.



"I speak to the Doctor on my own- I got confidence to do this because of being in the BIG Group"

If we understood the doctor

We talked about how some doctors are good at speaking slowly and clearly.

Some doctors rush through the appointment and don't explain what has been said.

"I don't understand everything that the Doctor says, but I go with my mum and she understands and helps me"

What we did if we did not understand the doctor

Some people feel confident to ask the doctor questions.

Some people like their parents and carers to ask questions for them.

One doctor has a review with the patient to check that they understand what had been said during the appointment.

"The doctors are ok. They care but it doesn't always show."

Other people at the doctors

We talked about the other people who we meet at the doctors

We meet receptionists:
Some people thought that the receptionists could be rude and argumentative.

And that receptionists ask too many private questions.

Lots of people thought that all of the staff were very nice at their doctors.

We meet nurses:
The nurses are very nice and friendly with the patients.

Some people would rather see the nurse as they do not rush as much as the doctor.

Sometimes the nurses help more than the doctors.

“*Sometimes I am embarrassed to as the doctor questions, so I ask the nurse*.”

Nurses help with things such as putting dates of appointments into people’s phones.

Other places to get health information

We talked about other ways that we might make ourselves better if we feel poorly.

We can go to the local walk-in centre.

We can go to the pharmacy to get medicine to make ourselves feel better.

Our parents and carers can give us more information on how we can feel better.

Some people go to Willis House for health appointments.

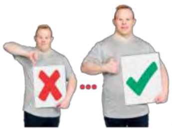
If it was an emergency, we would go to hospital.

"I felt ok going to the hospital, staff were fine and listened to me."

"I had been in a car accident and the ambulance turned up quickly and the nurses were waiting at the door for me - treated like royalty."

Groups like Healthwatch and BIG Group give us extra information about healthcare if we need it.

What is good about the Doctor



We talked about the best things about seeing our doctor

The doctor helps to make us feel better.

✓

The doctor can give us more information on how we can stay healthy.

The doctor can help us to be positive about our conditions.

What is not Good

One person was waiting for medication the Doctor had not done it.

A lot of things are online and for people with a Learning Disability it can make things more difficult.

The time limit on appointments can be a problem. Not everyone knows that you can have a longer appointment with the Doctor.

Sometimes you are not told what is happening next and this is worrying.

"I was waiting for eye drops from St Pauls and I had heard nothing."

What we have learnt

From our chats, we learnt that some of us had the same experience, such as:

- Waiting times can be too long at our Doctors and sometimes can be waiting for up to 3 weeks for the next available appointment.

- Nurses are very friendly at the Doctors centre and go the extra mile to make sure we are comfortable.

- It is good to visit the doctor with our parents or carers as they can ask questions for us on our behalf.

- Seeing the same doctor each time we go to an appointment is nice.

- It is good if we already know the doctor

- Lots of us get medication and tablets delivered to our homes by the chemist- this is good.

Other Important comments:

“I never get a passport or medication back from the hospital.”

“I go to Sheffield once a year to see a special team - I am happy to travel to see the right people.”

Healthwatch Knowsley - Appendix 2 - What is important to young people about health and care

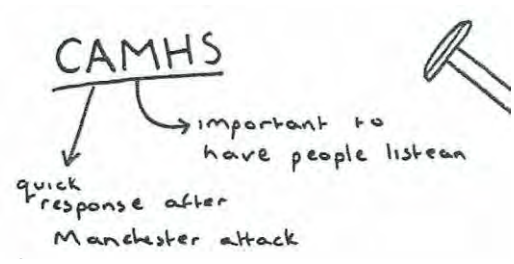
As part of our research activity, Healthwatch Knowsley conducted a focus group with young people to gain specific insight on the views of young people accessing services. These focus groups were conducted in collaboration with *Knowsley Youth Mutual*, and consulted 55 young people across three different settings. These included *Be Yourself LGBTQ+ community*, *Knowsley Youth Cabinet*, and *Halewood Youth Zone*. They provided feedback using a graffiti wall, a visual minutes book, newspaper stories and headlines, and the completion of surveys. Below is the feedback they provided:

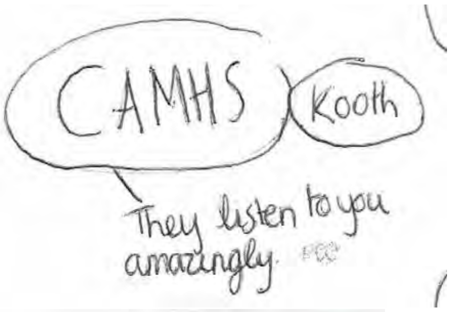
A graffiti wall was produced capturing the key themes discussed:

What was Good

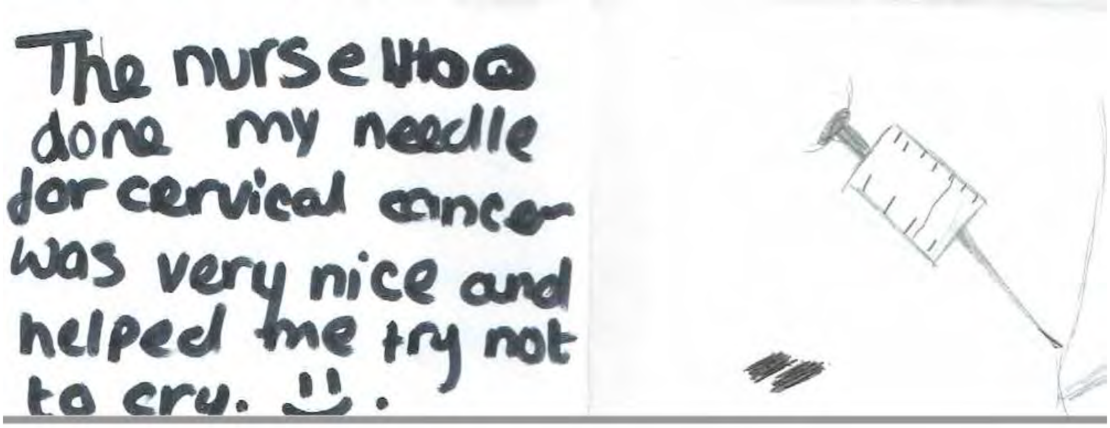
- Free services
- Increased 24/7 access
- Well trained staff
- Services for all ages
- Informative websites
- Nice staff and people from across the world working within the NHS
- Good aftercare and follow up
- Well equipped
- Job opportunities
- Respect for patients.

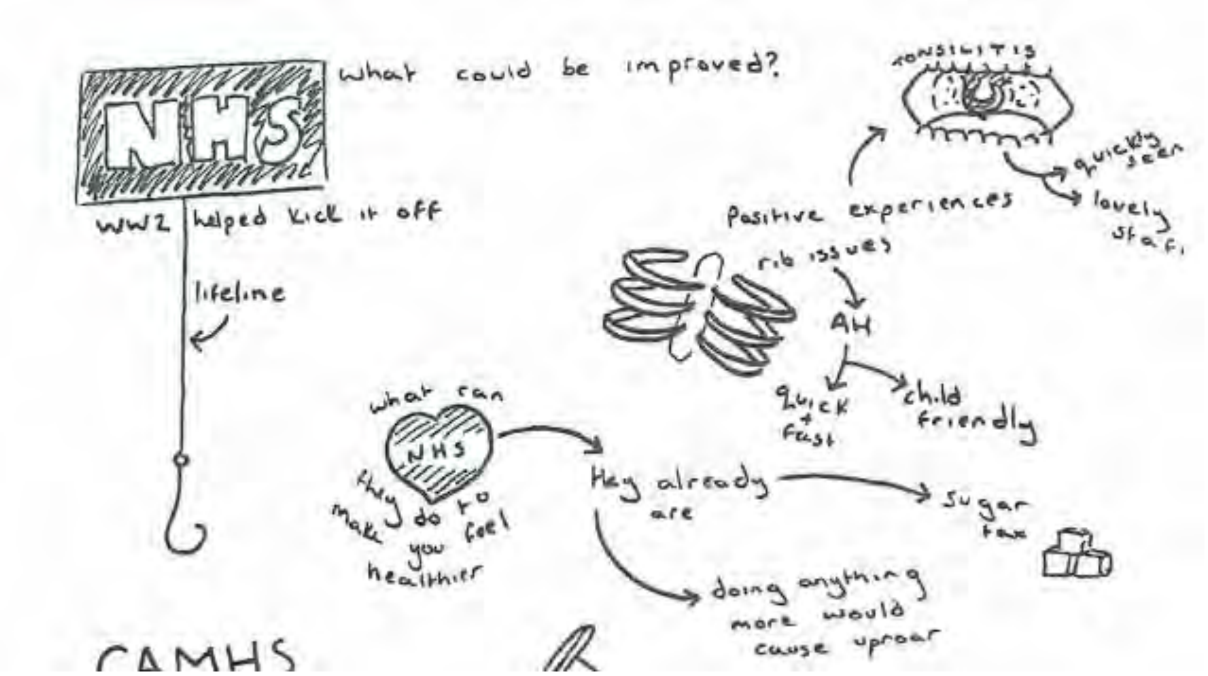
Further points included:





They listen to you amazingly.

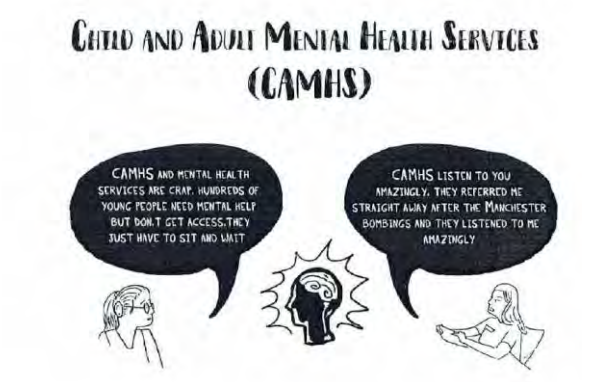

The nurse who done my needle for cervical cancer was very nice and helped me try not to cry. :) .

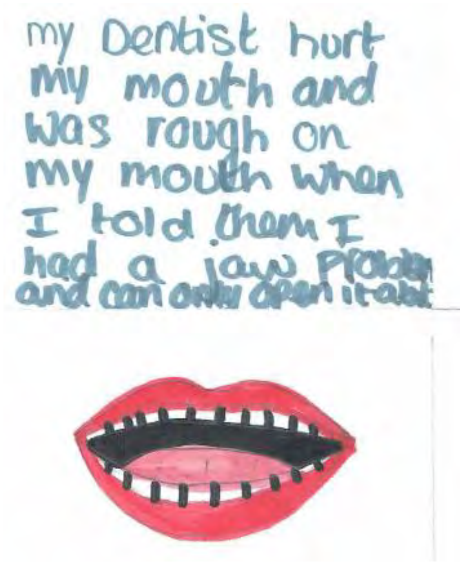


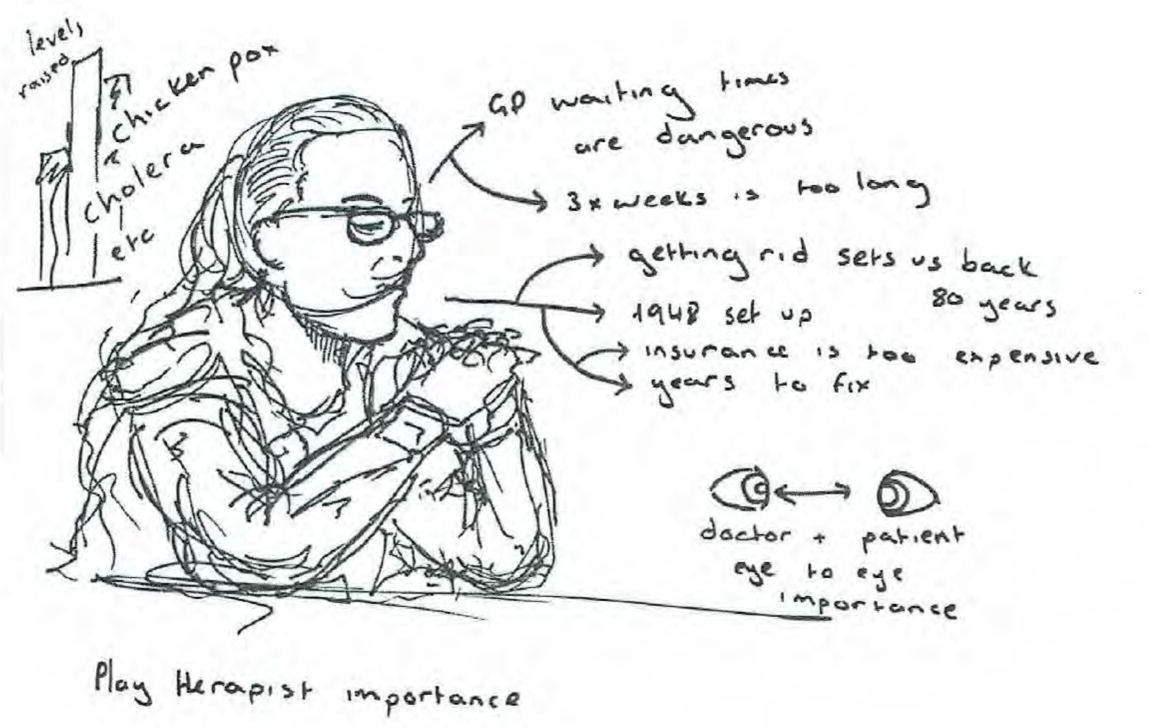
What didn’t work well?

- Long waits at GP Practices for appointments
- Rushed appointments
- Services aimed at adults and staff listening to adults not me
- More GPs needed
- Cuts and poor staff wages
- Car parking charges
- Long waits for CAMHS
- Inaccessible information

Further points included:



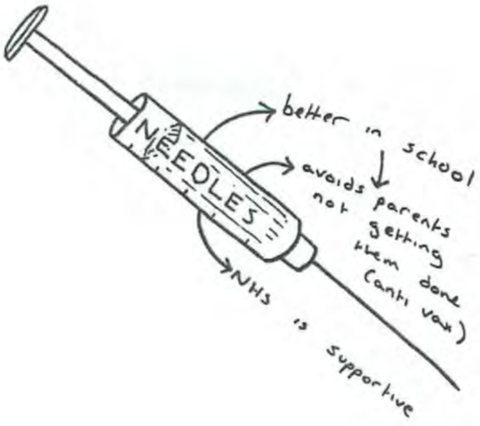


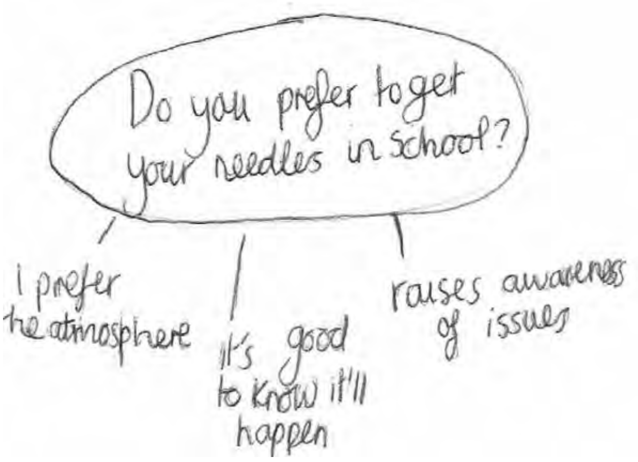


Who (Do you want to see)

- More female GPs needed

Where do you want to be seen?






My first high school school nurse was one I hated. She asked me why I thought I was trans. I didn't know why so I just told her a few ~~[illegible]~~ the things. One of these things was that I never liked my breasts since they started growing in. She then proceeded to tell me that that didn't make me trans. A SCHOOL NURSE told me I WASN'T trans. I showed I had clear dysphoria but she told me I wasn't trans. She made questioning my gender

Improvement:
More training in
LGBT

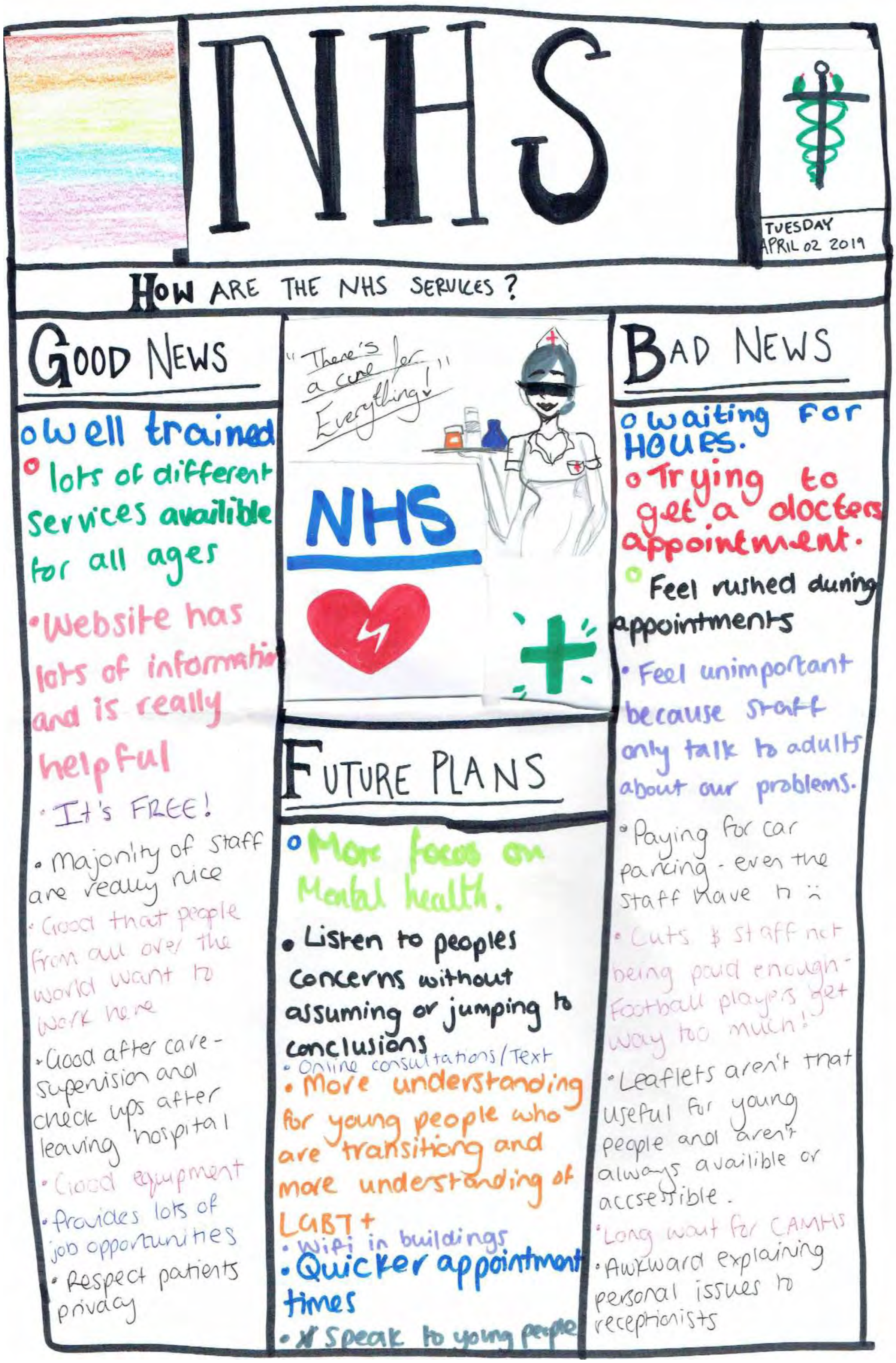

~~When I had~~ When I cracked My wrist in 2 ~~Wh~~ places I had to go to Hospital to the A & E department. I went to Alder Hey. I think Alder Hey was fine. The Drs & nurses got on with their jobs. I was given lots of information which was good. I had to wait a few hours for an X ray because it was very busy, it would of been nice to have things to do while I was waiting or be told how long I would be there for.

I had a suspicious mole lying on my chest and me and my mother were very concerned.
We went into the waiting room and the register lady was really nice, didn't mention the incident when we were booking the appointment.
When the nurse called out my name it was my mothers last name but that reason is unrelated to this situation

When we entered the examination room, it was very discrete.
She [the nurse] took me behind a curtain (with my consent → I didn't even want my mum to see what was going on)
She was very gentle, soft spoken and very kind. Her hands were cold, but gloves not really an issue.

Overall 10/10 would
have an infection
again!


GP waiting times
Can put peoples lives in danger
NI payments aren't that expensive it's a small price to pay not just for yourself but to keep your family healthy
If the NHS went it would be a travisty it's better to have the NHS than be unable to afford a doctor



NHS

TUESDAY
APRIL 02 2019

HOW ARE THE NHS SERVICES?

"There's a cure for Everything!"

NHS

GOOD NEWS

- well trained
- lots of different services availible for all ages
- Website has lots of information and is really helpful
- It's FREE!
- Majority of staff are really nice
- Good that people from all over the world want to work here
- Good after care - supervision and check ups after leaving hospital
- Good equipment
- Provides lots of job opportunities
- Respect patients privacy

FUTURE PLANS

- More focus on Mental health.
- Listen to peoples concerns without assuming or jumping to conclusions
- Online consultations / Text
- More understanding for young people who are transitiong and more understanding of LGBT+
- Wifi in buildings
- Quicker appointment times
- Speak to young people

BAD NEWS

- waiting for HOURS.
- Trying to get a docter appointment.
- Feel rushed during appointments
- Feel unimportant because staff only talk to adults about our problems.
- Paying for car parking - even the staff have to :(
- Cuts & staff not being paid enough - Football players get way too much!
- Leaflets aren't that useful for young people and aren't always availible or accsessible.
- Long wait for CAMHS
- Awkward explaining personal issues to receptionists

healthwatch

NHS Long Term Plan Report

Chapter 6 - Healthwatch Liverpool

what would you do?

It's your NHS. Have your say.

Liverpool

Liverpool is a city and metropolitan borough with a population of approximately 491,500.[5] It is the most ethnically diverse area in Merseyside.[6] Liverpool is ranked as the 4th most deprived local authority area in England. The most severe deprivation is found in the 'inner core', which encircles the City Centre and the greatest concentration of deprivation in Liverpool is in the north of the city.[7] This is reflected in health inequalities both within the city and when compared to the national average. People in Liverpool live shorter lives than the national average and spend a greater proportion of their life living with disability and poor health. The number of people diagnosed with long term health conditions in Liverpool is above national levels for cardiovascular disease (CVD), respiratory disease, diabetes, dementia, cancer and kidney disease.[8] According to the draft mental health JSNA (Joint Strategic Needs Assessment) 2019, Liverpool also has much higher than average rates of common mental health problems.

In Liverpool we received 217 survey responses, consisting of 193 general surveys and 24 specific condition surveys. There were also 32 attendees across two specific focus group events.

Statistics from PHE are for the Liverpool Local Authority area, pop: 467,000

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[5] https://www.nomisweb.co.uk/reports/lmp/la/1946157104/report.aspx#tabrespop

[6] https://www.merseytravel.gov.uk/about-us/corporate-information/corporate-responsibility/Documents/Liverpool%20City%20Region%20Demographic%20Information%20March%2017.pdf

[7] https://liverpool.gov.uk/media/10001/1-imd-2015-executive-summary.pdf

[8] https://www.liverpoolccg.nhs.uk/media/3066/one-liverpool-plan-2.pdf

Summary of Findings:

What matters most to people in Liverpool?

- Having access to the help and treatment needed when it is wanted was the most important factor people told us was required in living a healthy life. For example, people said they wanted more support and education with healthy eating and exercise. Having health professionals that listen was also considered very important.
- To help keep independence and stay healthy whilst getting older, people indicated that being able to stay in their own home for as long as possible was most important to them.
- Choosing the right treatment being a joint decision between the person and the relevant health and care professional is most important to people in Liverpool in managing and choosing support and treatment. Being offered care and support in other areas if people cannot be seen in a timely way in their local area was deemed as the second most important option. People also mentioned funding for local services and pooling budgets between the NHS and local authorities, as well as better communication and access to GP appointments as a method of support.
- People in Liverpool told us that being able to talk to their doctor or other health professional wherever they are and having absolute confidence that their personal data is managed well and kept secure, were both deemed as the most important when interacting with the NHS. We were told that people would like to be communicated with more quickly through the use of technology. GP appointments at more accessible times was also common theme.
- Older people said that they would like to see more links within the community to help reduce social isolation.
- Overwhelmingly, people who responded to the survey with Mental Health or long-term conditions such as diabetes and arthritis, found their experience of accessing support and treatment to be unsatisfactory, and experienced long waiting times. Most also said that the support did not meet their needs.

Survey results

The following sections now break down the results of the 217 responses across Liverpool to the surveys designed by Healthwatch England. The first sections use the 193 responses to the general 'People's general experiences of health and care services' survey, before breaking down the 24 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.

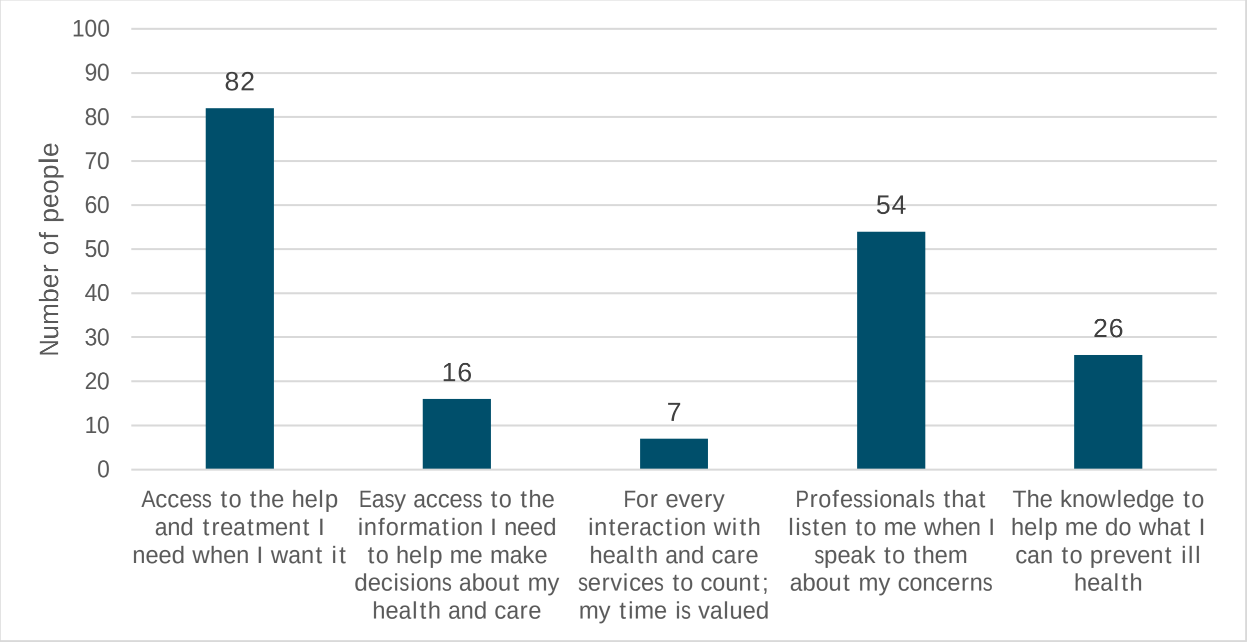
For each of these, people were asked to choose which of a number of options was most important to them. Following this, people were asked to rate each of the options on a scale of 'very important' to 'not important at all'. Therefore, more than one option could be considered 'very important'. Finally, 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, Chart 1 shows that having access to the help and treatment needed when it is needed was deemed to be most important by people responding to the survey. 185 people responded to this question.

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



However, when asked to rate on a scale of very important to not important at all, all other options were considered either very important or important as the Table 1 below shows. Up to 189 people responded to this question, though 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
Access to the help and treatment I need when I want it	163	23	1	2	0
Professionals that listen to me when I speak to them about my concerns	157	29	1	1	0
Easy access to the information I needs to help me make decisions about my health and care	131	46	5	0	0
Having the knowledge to help me do what I can to prevent ill health	122	46	13	0	0
For every interaction with health and care services to count; my time is valued	117	51	12	1	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 ordered into themes and summarised below:

Help to be healthy

Many people commented on their desire to lose weight and to attend exercise classes with some suggesting these should be made more easily accessible and cheaper. People also mentioned about community opportunities:

- *“Availability of healthy food choices that have good taste and appeal, easily identifiable, low fat, low sugar options.”*
- *“Information on healthy eating seems to be of significant importance in today’s society. Perhaps provide access to information that outlines cost effective ideas, suggestions and recommendations in making healthy meals for the family.”*
- *“In work health workshops and recipes for making healthier meals.”*
- *“Access to health provision e.g. cheaper offers for gymnasium, swimming to enable a proactive lifestyle.”*
- *“Connections to my community - health enhancing activities: walking, chatting, yoga, etc. Also, cafes and cycling lanes, etc.”*

Health education for self help

People also commented on receiving information about health care and self-help mechanisms:

- *“Use of media/TV/internet for information about healthy living, not a question of ‘Don’t’ but information to ‘do’, it is your health.”*
- *"Print out of what was said on each contact with health service.”*

- *"Giving ownership of health back to patient."*

Accessibility to help

People commented on accessing different resources and services specifically around individual needs and community wellbeing services:

- *"Being able to access all of the above when I am not in work... out of 9-5 hours."*
- *"Access to my GP when I need to speak to someone that knows me without jumping through hoops."*
- *"Access to meaningful art activities and art therapy."*
- *"For there to be more available access to complimentary health services that are otherwise touched upon but not acknowledged in a lot of areas I know that pharmaceuticals selling at the door are a thing of the past but refusing to not integrate these services within what could be a brilliant multi-disciplinary field do a lot of people a disservice who might not know nothing more than relying on their GP to have all the answers."*
- *"Easy access the first line consultation then quick response from referral, at present I am waiting seven weeks for a physio referral which in the meantime means I am causing more problems to my health."*
- *"A tool to help me assess my health needs and modify my individual lifestyle choices to link to what's available in the community. More community classes available to provide information/knowledge on topics."*

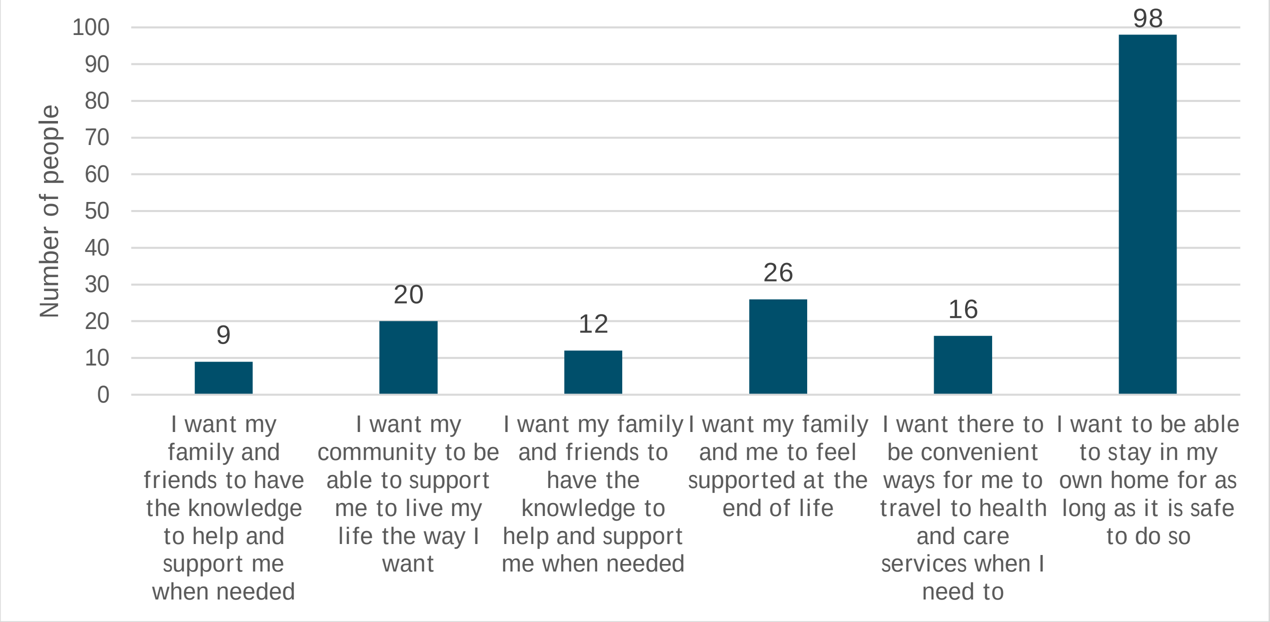
Approaches to leading healthier lives

- *"More of a focus on prevention rather than cure."*
- *"More multidisciplinary approaches so one person knows what everyone else is doing and the dots can be joined up for your healthcare better."*
- *"Having a local gym that is easy to access, like an outdoor one in Stanley Park - like other parks do, such as Sefton Park, Croxteth Park etc."*
- *"I believe people who should have retired when they had planned should have allowed 'exercise time', i.e. 'exercise in work for over 60s' - just 10 mins of yoga per working day would be ideal. Plant more trees. Create cycle lane. Reduce traffic/improve public transport."*

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). 181 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. In particular having a community who are able to support them to live their life the way they want to was deemed as very important, second to being able to stay in their own home for as long as possible. Up to 186 people responded to this question, though 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	152	29	3	1	1
I want my family and me to feel supported at the end of life	148	29	2	2	1
I want there to be convenient ways for me to travel to health and care services when I need to	133	37	8	5	0
I want my family and friends to have the knowledge, to help and support me when needed	114	58	8	0	3

I want my community to be able to support me to live my life the way I want	99	53	22	2	0

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

- *“Individuals who own their own house should not be made to pay fees for care homes.”*
- *“Support to stay in own home”*
- *“We need more accessible housing and proper funding for social care if we want more people to live safely at home and be supported to die there with dignity when the time comes.”*
- *“Better access for family carers training in specific needs of the patient”*
- *“Instead of private care assistants we should have proper NHS carers properly trained and spending the time they are supposed to, instead of being private enterprise when everything is for profit. I'm quite sure it would actually work out more cost effective for the NHS.”*
- *"For social services to stop thinking it's carers coming in or nursing homes. Also, to get rid of their ideas of everyone having to confirm to their ideals of no possessions and waiting to be washed and dressed.”*
- *“Having people at home rather than hospital is a cost cutting exercise - too many people are sent home too early with no support.”*

Financial Support/Funding

- *“Financially viable and comprehensive home support with living.”*
- *"An appropriate wheelchair. Currently wheelchair services can only provide a heavy manual wheelchair which caused me injuries just trying to use it. But I'm not eligible for a suitable lightweight active wheelchair. I don't have the money to buy my own as the voucher scheme comes woefully short of the cost.”*

Community Support

Community support was seen as important to ensure people had access to lead healthier lifestyles within the community:

- *“I think free exercise classes could be beneficial to assist with all types of health and could minimise isolation.”*
- *“More care in the community tailored to individual needs.”*
- *“Greater support in the community, longer GP opening hours.”*
- *"Ensuring care homes are regulated and are inspected at least once a month.”*
- *“More sheltered/supported housing options. I saw a new sheltered housing place being built by what looked like a private developer near Chester station - it has lots of community activities available for the people living in it e.g. a gym, a hairdresser, a cafe etc. It also had a nursing home type option incorporated into the same development; I think. I haven't seen anywhere similar in Liverpool. It would be good to be able to live in community but with support available as and when needed.”*

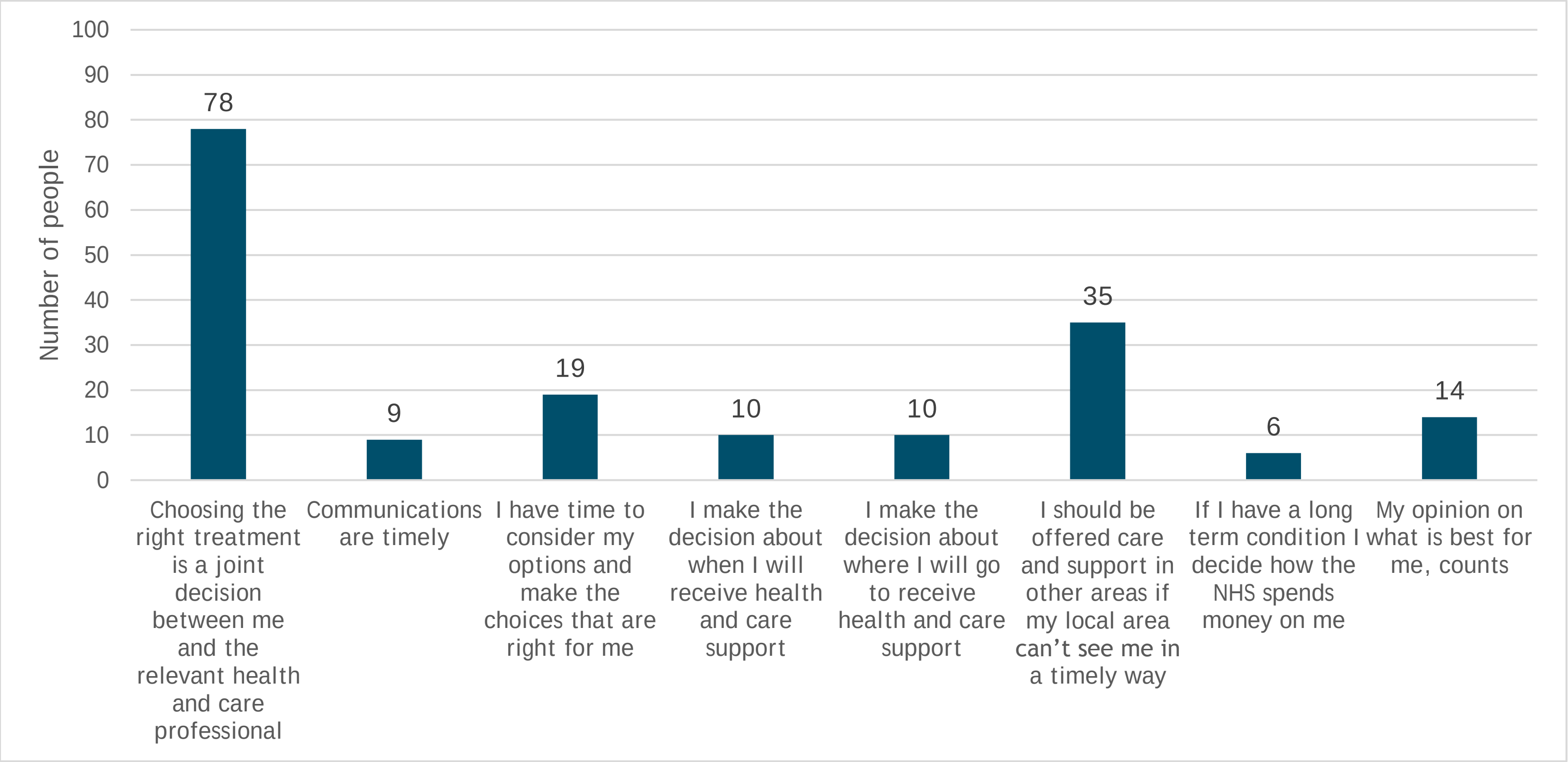
Advice and support

- *“Appropriate advice/treatment from local GP and his professional medical/healthcare staff.”*
- *“Stop ignoring people who need support. I have no family here and rely on the services to assist me. This has not happened in my case and my physical and mental health as a 68-year-old man living alone is suffering because of it.”*
- *“Again, for better communication between agencies, health care professionals so information/appointments/care is not missed or delayed.”*
- *“Better multi-agency working among professionals. Occupational and nutritional... Diet as well as exercise information and therapists available to all. Better help available with transport for every older person in all areas... Equal opportunities with transport to health care appointments, day care centres to alleviate loneliness and encourage social interaction which well known to help with better mental health and better wellbeing.”*

Managing and choosing support and treatment

Chart 3 shows that people we spoke to in Liverpool 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 in their local area was deemed as the second most important option. 181 people responded to this question.

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



When asked to select how important different factors were on a scale of very important to not important at all, people also deemed making the decision about where they go to receive health and care support and timely communications 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. This is detailed in Table 3 below, in order of the options that most people classed as being very important. Up to 186 people responded to this question, though not everyone 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 the relevant health and care professional	133	42	9	0	2
Communications are timely	122	49	10	1	1
I have time to consider my options and make the choices that are right for me	107	60	13	0	0
I should be offered care and support in other areas if my local area can't see me in a timely way	94	70	17	3	0
My opinion on what is best for me, counts	89	64	23	5	0
I make the decision about where I will go to receive health and care support	76	83	18	4	0
I make the decision about when I will receive health and care support	75	78	25	3	1
If I have a long-term condition, I decide how the NHS spends money on me	65	67	43	3	1

We also asked respondents to tell us one more thing that would help them to manage and choose how the NHS supports them. Answers have been collated and categorised under emerging themes.

Funding for local services

Respondents told us that they would like to see more budget shares between the NHS and local authorities. Others mentioned about more funding going into extra staff and effective online services. This also linked into comments that called for better treatment planning and public treatment spending.

Staff

Along with investment, it was recognised that funding challenges and demand for services was putting the NHS and particularly its staff under strain, which affected the staff service with patients. We received praise from various people regarding NHS staff, while others were asking for more staff consistency and staff training.

Appointments, Communication and Signposting

In regard to staff, a common theme people highlighted was the need for better communication both within the NHS and when talking to patients and signposting them. People told us that they would like their GP to have more time available to them in order to speak to their patient. Comments included:

Health support

People described the health support they need by easily accessing GP appointments and discussing the need for alternative therapies and a focus on prevention.

- *"I would like to see more alternative therapies been used. Such as Reiki, massage and the use of herbal based drugs."*
- *"Focus needs to be on prevention, especially in terms of obesity."*
- *"I think GPs should always say to their patients 'If your symptoms don't settle within a few days come back and see me.'" This does not always happen. Also, if investigations/blood tests etc are ordered there should be a structured way of patients obtaining their results in a timely manner."*
- *"More accessible ways of booking GP appointments such as being able to book in advance. more availability of GP appointments."*
- *"GPs having enough time to see patients - see them for longer if needed so they can discuss things fully. Then GPs having quicker referral access to other services - the idea of having physios and other health professionals based in GP surgeries is an excellent one as patients can get to see them for advice much more quickly."*

Health and financial funding

- *"My health and the best treatment for me is more important than cost. I know everyone has a budget but if my health is at risk then I do not want to be refused treatment because of the cost."*
- *"In thyroid illness people are just being left to rot, very ill. The basics need to be done right. Adequately staffed, financed and respected psychological services."*

Communication

- *"Contact numbers to speak to the right person or department - very difficult to speak to someone."*
- *"Communication/access i.e. use of emails from GPs and the phones should be more accessible."*
- *"It is essential that all health professionals involved in my care communicate with each other and with me so in a timely manner to enable a holistic approach to my care."*
- *"Giving people full facts about their conditions so they have a better understanding how they can treat themselves as well."*
- *"Better communication between multi agency responders."*
- *"Better communication between departments - having to repeat yourself because not all NHS professionals can access your records."*
- *"Decisions on treatment and care should, wherever possible be joint decisions between relevant clinicians and the patient/their families/carers."*

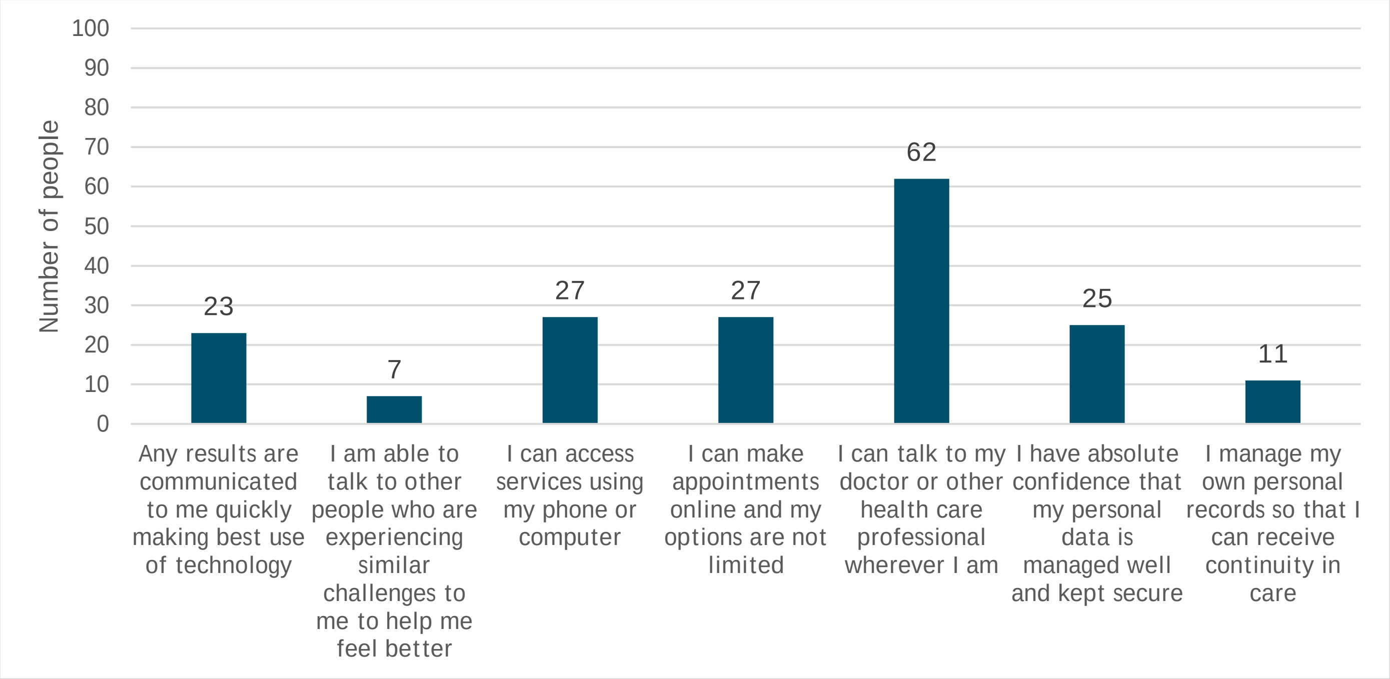
Engaging people in health service delivery

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.

People in Liverpool told us that being able to talk to their doctor or other health professional and having absolute confidence that their personal data is managed well and kept secure, were both deemed as the most important when interacting with the NHS (see Chart 4 below). 182 people responded to this question.

Chart 4: What is most important to you 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 (Table 4) people said that the most highly rated factor was results being communicated quickly making the best use of technology, followed by having confidence that their personal data is managed well and secure. However, all factors were deemed to respondents as being important or very important. Up to 186 people responded to this question, though not everyone responded to each option.

Table 4: 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
Any results are communicated to me quickly making best use of technology	121	49	8	4	0

I have absolute confidence that my personal data is managed well and kept secure	101	58	25	1	1
I can make appointments online and my options are not limited	100	54	26	5	0
I can access services using my phone or computer	95	61	24	2	1
I can talk to my doctor or other health care professional wherever I am	89	72	20	0	1
I manage my own personal records so that I can receive continuity in care	75	61	38	7	0
I am able to talk to other people who are experiencing similar challenges to me to help me feel better	52	59	52	18	2

Respondents were then asked to think about one more thing that needs to change to help them to successfully manage health and care. These answers have been categorised under emerging themes.

Technology

A number of people talked about not only the continued use of technology for a more accessible service, but also an awareness that not everybody is able to use technology:

- *“Less impersonal technology and more caring and competent human beings.”*
- *“Appointment systems to be up to date, have all the relevant/correct information and more accessible.”*
- *“More secure systems in place to protect notes! Mine were missing for 6 months.”*
- *“I would like to be notified of my results and not having to ring up to get them”*
- *“Online communications are useful such as booking appointments and managing prescriptions. However, sometimes you do still need to see someone face to face especially if it is a physical ailment that needs examining. However, digital communication is useful if you can't get to a doctor's appointment due to work commitments or you can't get out the house for some reason.”*

Communication

Communication was also an emerging theme amongst respondents and in particular, how they are communicated to:

- *“Staff communication for records and personal files.”*
- *“For health professionals to communicate with each other more effectively.”*
- *“A face-to-face consultation with a GP not via computer.”*
- *“Have confidence that health care professionals aren’t doing deals with companies who aren’t ethical.”*
- *“Advising people of preventative steps and healthy active lifestyle activities that they can do to help prevention.”*

GP Appointments

GP appointments were also mentioned by respondents, and for a number of reasons, including accessibility, i.e. ease of making weekend appointments; and the quality of appointments, including how much time people get to spend with their GP:

- *"Ongoing relationship with one doctor who knows me well and has time to plan care and able to get appointments when needed."*
- *"The most important thing to me is to have access to specialists who actually understand my illness. As with a lot of these questions, they are about bells and whistles rather than the core issue of having a doctor who can give treatment."*
- *"Being able to make GP appointments online. They are so scarce and limited, even weeks in advance."*
- *"Weekend appointments. I work all day every weekday and find it impossible to take time off."*
- *"Changing appointments is difficult. The system as it currently operates seems very wasteful of time and resources for both NHS and patient."*

Information provision

A number of people mentioned the importance of information and training:

- *"Waiting for results - it is not acceptable that professionals hold information on me for up to six weeks and I am unable to gain access to that information. Every time a test/biopsy/scan etc is carried out there should be guaranteed means and date for that information being given to the patient."*
- *"I could put my request in writing, but this suggestion was refused. This, in my opinion, is not making good use of recourses. If patients are willing to take the initiative to ensure they remain healthy, why are obstacles put in their way? I would suggest this obstructive way of doing things definitely needs to change."*
- *"Many Practice Nurses who do annual reviews for people with diabetes, don't always know much about it. They should at least have to do a course on managing diabetes. I know it`s not possible for them to know lots about many different conditions, but they do need to know the basics."*
- *"The questions are simplifications - yes I'd like my results in a timely way but for somethings like simple blood tests I'd be happy to get the results via technology, for other things e.g. cancer I'd rather hear from a person who could understand my concerns and provide any follow-up info needed.*
- *"Clear patient info on different health conditions and options, written with patients in mind, or signposting to the NHS website. I can find accurate info myself - a lot of people can't and google a symptom or condition."*

Further comments

- *"For me, I need a thyroid specialist because I have a rarer condition. But the NHS simply do not have these specialists, so I am sent home disabled. Since self-treating I have gone from being in bed most of the day to spending my days in the living room, doing gentle hobbies, going for walks, etc. People like me need the very basics of being treated."*
- *"When I required surgery, chemotherapy and radiotherapy after two instances of breast cancer some 10 years apart, my treatment, support, sharing of information, compassion and kindness were first class."*
- "Medical Cannabis is all over the news. As an alternative medication that has less harmful side effects. More research and funding into this. More patients should be able to access

this drug. It's not a cure but will make a lot of difference to children/adults with certain illnesses. It will improve the quality of their lives."
- "More emphasis needs to be placed on preventing ill health and investing in other organisations who can deliver this and are more effective in reaching specific communities."

In focus: what is important to older people about their health and care?

As part of our research activity, Healthwatch Liverpool conducted a focus group with older people living in the Dingle and Toxteth area of the city in order to gain specific insight into the views of people accessing services. Older people, particularly in disadvantaged communities, are less likely to use online platforms so are less likely to have come across the online questionnaire, and so it was deemed that a focus group would be a ideal opportunity to hear their feedback as to whether older people feel that Liverpool is an age friendly city. This focus group took place on 3rd May 2019, and was attended by 10 people.

The main themes raised were:

- Staffing - levels, quality and time they have to spend with patients.
- Waiting times - at both GP and hospital appointments.
- Transport.
- The importance of community - community-based activities and not being isolated.
- The NHS recognising the benefits of being connected to the community and introducing patients to a range of activities.
- At the point of no longer being independent, the importance of receiving consistent quality support, care and company at home.

What do you think would make health services better?

- Less waiting times.
- Professionals not making assumptions - listening to you, not using computer in appointments, not having 10 minutes only for appointments.
- Quality staff.
- Spending more money on services.
- Being able to understand and communicate with staff - improved communication.
- Staff explaining things better, especially treatment.
- Having doctors at hospitals of a weekend.
- "Passwords and I.T. access make booking appointments difficult."
- *"You have to go through a third party to sort out these problems which must cost the NHS more money."*
- *"Nurses have no time to spend with patients re emotional support - comes across as having no compassion."*
- A lack of support with personal care on ward after major surgery.
- Reduced waiting times for GP and hospital appointments.

- Better ways of communicating with deaf or hard of hearing - *"sometimes I can't understand what I've been told and have no one to help interpret."*
- *"Better aftercare after major operations especially night nurses who ignored my calls for pain relief when I was in a room on my own."*

What do you think would help people live healthier lives?

- Bonuses/benefits for people looking after their health.
- Using people's medical history to help - ex hereditary conditions.
- Better diet.
- Getting help before crisis point.
- Smoking cessation.
- Alcohol reduction.
- Staff being more personable/helpful in supporting people to look after their own health.
- Community groups and community support.
- Having hobbies and activities.
- Being able to get out of the house.
- Counselling.
- GPs referring people to activities and groups.
- Socialising.
- Exercise, dancing.
- Access to transport.
- A friendly environment where you are welcomed.

What do you think would make it easier for people to look after themselves better?

- Information on different forms of exercise, such as chair based/yoga.
- Home adaptations for people with mobility issues.
- Giving people information to manage their health.
- Better/more publicity for groups doing this.
- Having good neighbours/community.
- Seeing the same carers instead of having different people.
- Being treated with dignity and respect.
- Transport is really important for getting out and some community services provide transport.
- Not being housebound or isolated.
- *"I can only get out (of the house) because of my mobility scooter. Zimmer frames and walking sticks don't help you get to the shops."*

Do you think the support offered to people with long term health conditions could be better? How?

- Eye testing - help find out about conditions.
- Reducing isolation - helping people get out and be active.
- Technology - testing at home.

- Visits at home for people (especially with dementia).
- People receiving support need to be given more time when being visited by care workers or social workers - visits are rushed and carers need to be given a break.
- If GPs were more aware of what community services are available, this would mean people can stay in their own homes rather than going into care homes.

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 24 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	2
Cancer	1
Dementia	1
Heart and lung diseases	2
Learning disability	0
Long-term condition e.g. diabetes, arthritis	7
Mental Health	11

Table 6: Who are you responding on behalf of?

Condition	Myself	Someone else
Autism	1	1
Cancer	0	1
Dementia	0	1
Heart and lung diseases	2	0
Learning disability	0	0
Long-term condition e.g. diabetes, arthritis	6	1
Mental Health	8	3

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

Condition	Yes	No
Autism	1	1

Cancer	1	0
Dementia	1	0
Heart and lung diseases	1	1
Learning disability	0	0
Long-term condition e.g. diabetes, arthritis	3	4
Mental Health	5	6

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	Not applicable
Autism	0	2	0	0
Cancer	0	0	1	0
Dementia	0	0	1	0
Heart and lung diseases	2	0	0	2
Learning disability	0	0	0	0
Long-term condition e.g. diabetes, arthritis	1	5	1	1
Mental Health	0	6	5	0

Tell us whether the support met your needs and how it could have been improved.

Autism:

- *“Children with Autism grow into Adults with Autism. Not enough done for adults. My daughter did not respond well to groups and was excluded because of this.”*
- *“Lack of services and those that are available have very long waits.”*

Heart and lung diseases:

- *“Easier access to the same GP.”*

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

- *“My GP did not listen to me and my records became incorrect due to his write up of the appointment. I was given incorrect test results which meant delays to medication. I've had to go back numerous times to try and discuss the conditions with different GPs until one GP finally listened and put the correct plan in place for testing.”*
- *“I was diagnosed with genital herpes. I was very upset at the GUM [Genito-Urinary Medicine] clinic as I thought it was unmanageable and that I would not be able to have safe sex again without transmitting it. I was devastated and thought I would never be able to have a relationship or have children safely. The doctor, seeing that I was in tears and not going to leave his office, sent for another member of staff to come in, a woman. She*

tried to comfort me. I went home stunned and unable to cope. I was given a brief leaflet that made it seem all the more serious and final. It had no helpline on or further reading/support."

- *"Very little therapy available in the community hospital has therapists on every ward so go more rehabilitation there. Focus is supposed to be on early discharge and keeping patients at home/wrapping care around the patient but there is not enough money for community support so false economy."*
- *"I had a tumour on spinal cord removed and would have liked more physio and ongoing checks regarding mobility."*
- *"I was referred for tests and diagnosis at 16 so therefore went straight to an adult's hospital. At the time, I wanted the decision to be seen at a children's or adult's hospital and I feel I would have benefited from being seen at the children's hospital. There is not much support in the NHS for people aged 16-18."*

Mental Health:

- *"Still waiting for help that's the problem."*
- *"There have been assessments but no support yet. It is shambolic. I am not kept informed on anything and nobody is able to give a straight answer if I ask any questions."*
- *"I first tried to access help for my mental health as a teenager, I was given antidepressants and support from a counselling service but I had a very poor experience with the antidepressants I was given and my parents encouraged me to come off them as soon as possible. I feel like perhaps the doctor could have given me more support and choice, perhaps helping me try a different medication, and also helped my parents better understand my condition."*
- *"Was put on a waiting list to see CBT [Cognitive Behavioural Therapy] therapist when I was in dire need of immediate support. In the end my sister took me to A&E where I waited for hours in an extremely anxious state because there was nobody on site to see me."*
- *"Sometimes just told to go to A&E."*

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

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

Condition	Yes	No
Autism	1	1
Cancer	0	1
Dementia	0	1
Heart and lung diseases	1	1
Learning disability	0	0
Long-term condition e.g. diabetes, arthritis	7	0
Mental Health	4	7

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

Learning disability	0	0	0	0	0	0
Long-term condition e.g. diabetes, arthritis	3	2	1	1	0	0
Mental health	4	3	1	1	0	2

Please tell us about the length of time you waited.

Autism:

- *"My daughter was over 25 when diagnosed. We had struggled for years not understanding what was going on."*

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

- *"I'm still waiting for some conditions and it's been nearly 2 years. Other conditions I was diagnosed quickly in hospital and have since had no further support or treatment."*
- *"I waited 2 years for an operation for prolapsed womb and rectocele, I may as well not have operations it's just as bad."*
- *"I went to the GUM clinic and was seen the same day."*
- *"Waited months for appointments and then only got 1 follow up still have unmet needs. Hospital is better place for care."*
- *"For diabetes health check quite a while."*
- *"Nearly 2 weeks after assessment."*

Mental Health:

- *"A couple of months ago when my husband got angry and demanded something be done. Then a psychiatrist came to see me at home."*
- *"Still waiting and waiting and waiting, in the meantime mental health has gone very severe."*
- *"I had an assessment within 2 months but have been left waiting now for over a year for treatment. It has now materialised that my assessment was not followed up correctly and I have not actually been on a waiting list (having been told I was). I now have another assessment looming."*
- *"When the NHS would help, it would be about 6 months. Now, they just refer you to charities, which then take 6 months too, just for basic counselling."*

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	0	0	0	0
Cancer	0	0	1	0	0	0
Dementia	0	0	1	0	0	0
Heart and lung diseases	0	1	1	0	0	0
Learning disability	0	0	0	0	0	0

Long-term condition e.g. diabetes, arthritis	2	3	0	1	0	1
Mental health	6	0	1	1	0	3

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

Condition	Yes	No
Autism	0	2
Cancer	0	1
Dementia	1	0
Heart and lung diseases	1	1
Learning disability	0	0
Long-term condition e.g. diabetes, arthritis	0	7
Mental health	5	5

If you accessed support what aspect could be improved?

Heart and lung diseases:

- *“Ongoing support.”*

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

- *“Somebody could have just talked to me.”*
- *“Waiting time appalling.”*
- *“I would have found it more helpful to be offered different treatment options sooner rather than persistently being given CBT. I would have preferred to be able to see the secondary care team for longer rather than being discharged while I still felt I would benefit from more sessions.”*
- *“Better training to identify when a person is desperate for mental health treatment. Less waiting times. More trained staff. More signposting to mental health charities and websites.”*

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

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

Learning disability	0	0
Long-term condition e.g. diabetes, arthritis	5	2
Mental health	7	4

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

Please tell us more about the length of time you waited.

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

- *"The time you waited for an appointment to see a consultant. 3-6 months the aftercare was virtually none existent. At the women's hospital in Liverpool, I don't think they know what they are doing. I got told that I was having a hysterectomy and only had a womb repair. They tell you one thing and do another. I had my operation and had never even seen a consultant afterwards, that was last year in December and they gave me an appointment for June-July this year."*
- *"Waited 4 weeks and got a cancellation."*
- *"Fast because we paid the spinal surgeon privately in Walton Neuro Hospital."*
- *"I was seen quickly and was diagnosed quickly too. Waiting times in the clinic are always running late. I once asked for an early appointment and was given the first slot at 8am. They were running 40 minutes behind even then."*
- *"4 weeks for a consultation."*

Mental Health:

- *"About 6-8 weeks."*
- *"Three months."*
- *"I see a psychiatrist whilst I am waiting for psychological services. However, he was not apparently aware that I was not on the waiting list."*
- *"I think it only took a month or so to see the psychiatrist once I'd been referred."*
- *"What do you want to know? It was hell waiting."*

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	0
Cancer	0	0	1	0	0	0	0
Dementia	0	0	1	0	0	0	0
Heart and lung diseases	0	0	2	0	0	0	0
Learning disability	0	0	0	0	0	0	0
Long-term condition e.g. diabetes, arthritis	0	0	1	2	4	0	0
Mental health	0	1	0	6	3	0	1

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

Condition	Yes	No	Somewhat
Autism	0	2	0
Cancer	0	0	1
Dementia	0	0	1
Heart and lung diseases	1	1	0
Learning disability	0	0	0
Long-term condition e.g. diabetes, arthritis	0	6	1
Mental health	1	9	1

Please explain how the care did or did not meet your expectations and how could it be improved?

Autism:

- *“My daughter used to get support, and when it was decided that group meetings would be best, she was excluded. It was ludicrous to expect someone with Autism to attend groups. it is a communication and social disorder what were they thinking?”*

Heart and lung diseases:

- *“One nurse I saw was lacking in knowledge. She also recorded misinformation in my notes and was disinterested.”*

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

- *“I've had nothing.”*
- *"I had to research online for support. I was too embarrassed to tell my friends or family and felt totally alone. Looking for support online was awful. At first all I could find was a forum with very negative stories from people like myself who were suffering with the physical symptoms and had no information or support.”*
- *“It took me a while to find ‘herpes.org.uk’ and I signed up for their newsletter. I also emailed their team and got a very helpful email back giving me all the reassurance I needed and an invitation to attend support days. The charity is in London. I live in Liverpool. Nevertheless, I made that journey. Their support was invaluable.”*
- *“I also went to my GP as I had read that a tablet could stop my frequent outbreaks. The GP sent me away saying she didn't know the dosage. I had to go to the GUM clinic again (taking time off work) and get a long-term prescription."*
- *“Not enough - had to be referred back several times. Services are under resourced and do not have enough staff due to cuts.”*
- *“More help getting around.”*
- *“Fantastic care. The consultant was lovely recognised instantly that it was a scary experience for someone at just 16 years of age.”*
- *“I thought I would have got more help.”*

Mental Health:

- *“Someone should have talked to me kindly to ask how I felt to try to explain this illness. Or given me techniques to work on myself as opposed to being put in hospital and left without understanding.”*
- *“More understanding, not to be passed around.”*
- *“There has been no support as the assessment I had has led to me going on a waiting list for over a year. Now it appears I came off the waiting list and no one realised so I have a further assessment.”*
- *“I found the care I received from the psychiatrist unsatisfactory. I was given conflicting and confusing information about my actual diagnosis (‘traits of personality disorder’), I was offered a type of therapy called Structured Clinical Management and was then turned down for it because I didn’t meet some criteria but was not told exactly why. My medication was changed and I found the new medication very difficult, it increased my mood swings and made me very depressed and violent towards myself. I went to A&E three times in this period, twice because I was feeling suicidal and once because I had self-harmed by punching a wall and had a suspected broken hand.”*
- *“CBT therapy was right for me. Service was good.”*
- *“No support offered.”*
- *“Was good from my mental health support worker but GP was poor.”*

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	2	0
Cancer	0	1	0

Dementia	0	0	1
Heart and lung diseases	1	1	0
Learning disability	0	0	0
Long-term condition e.g. diabetes, arthritis	1	5	1
Mental health	0	10	1

Please explain how the care did or did not meet your expectations and how could it be improved?

Heart and lung diseases:

- *“I received a message to contact the surgery about my condition then this was denied. It caused me distress. I got a letter which I found upsetting saying I had not attended my annual review and missing my treatment. I had attended over two weeks earlier so no idea why the system did that.”*

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

- *“Incorrect test results given. No regular GP has meant no continuity and therefore, having to go through my history again and then running out of time before a treatment plan was put in place.”*
- *“There was a complete lack of care after my diagnosis in the GUM clinic in The Royal Hospital Liverpool. I left with my mental state in tatters and it could have been prevented by signposting to ‘herpes.org.uk’.”*
- *"Never received copies of letters despite filling in required forms.”*
- *“Increase staffing, deliver care locally rather than in big hospitals"*
- *“More check-ups at hospital on a six-monthly basis.”*
- *“It all did meet expectations. Rarely are appointments cancelled and they will always find time to slot me in if I ring up and say I'm not good.”*
- *“I had to chase people.”*

Mental Health:

- *“As is the case your sent to hospital not understanding what’s happening. I would have felt so much better feeling like a patient and not a prisoner.”*
- *“Having to chase for appointments all the time, being told top of the list, any day for appointment then to be told sorry still not at the top.”*
- *"The whole system is broken. It is chaotic and even the psychiatrist does not know what is happening.”*
- *“My GP is good, but they do not seem to be kept informed on what Mesreycare are doing. Merseycare themselves do not seem to know what is going on.”*
- *“Any other business that was run in this way would not survive."*
- *“I was discharged from the secondary care team back to IAPT [Improving Access to Psychological Therapies] after being turned down for Structured Clinical Management, it then took several months to get an appointment with them. When I finally was assessed by IAPT my diagnosis was changed again and I was offered a choice of online CBT for Obsessive Compulsive Disorder within a couple of weeks or a further wait to see someone face to face. Wanting some kind of support, I accepted the online CBT which was provided*

through a service called Silvercloud but I found it profoundly unhelpful. In fact, I would go so far as to say the system made my anxiety worse because there were delays in my submitted information being reviewed by the assigned therapist. After only two weeks I was put back on a waiting list to see someone face to face, a wait of several more months. When I finally did see a therapist I was offered EMDR [Eye movement desensitisation and reprocessing] therapy and jumped at the chance to try something new that might help but throughout the period I saw the therapist I was not able to self-manage my moods enough to start the treatment so I was eventually referred back to secondary care with a further ***wait. I feel like I've been passed from service to service with no choice*** *of what happens to me. It is frustrating and makes me feel like my distress is not being taken seriously."*

- *"Quicker response was needed. More staff in hospital A&E required to help mental health patients. Separate mental health clinics would be helpful."*
- *"None offered."*
- *"Better communication."*

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	0	0	0	1	0
Cancer	1	0	0	0	0	0	0
Dementia	0	1	0	0	0	0	0
Heart and lung diseases	1	0	1	0	0	0	0
Learning disability	0	0	0	0	0	0	0
Long-term condition e.g. diabetes, arthritis	4	1	0	0	0	1	0
Mental health	6	1	2	0	0	1	1

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	1	1	0	0
Cancer	0	1	0	0
Dementia	1	0	0	0
Heart and lung diseases	1	1	0	0
Learning disability	0	0	0	0

Long-term condition e.g. diabetes, arthritis	1	5	0	1
Mental health	0	7	1	3

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	1	1	0	0
Cancer	0	1	0	0
Dementia	1	0	0	0
Heart and lung diseases	0	1	0	1
Learning disability	0	0	0	0
Long-term condition e.g. diabetes, arthritis	0	3	3	1
Mental health	0	8	1	2

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	0
Cancer	0	1	0
Dementia	1	0	0
Heart and lung diseases	1	1	0
Learning disability	0	0	0
Long-term condition e.g. diabetes, arthritis	2	2	3
Mental health	0	5	3

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

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

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

Supporting you to have more control over your own care

Table 27: What level of support of 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	0	0	1
Cancer	0	1	0	0
Dementia	0	1	0	0
Heart and lung diseases	0	1	1	0
Learning disability	0	0	0	0
Long-term condition e.g. diabetes, arthritis	1	6	0	0
Mental health	4	5	0	1

What could the NHS do to help you stay healthy or manage any condition you have?

Heart and Lung Diseases:

- *"Employ well trained and optimistic staff who are properly recognised and paid not rushed and clearly stressed by the pressures. Stop asking me the same questions every time I'm seen which don't seem relevant. Simplify getting repeat prescriptions."*

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

- *“Communicate with me, listen to me and stay up to date on my condition and new treatments.”*
- *“Check-up regularly of individual conditions. each individual condition is not checked by your own doctors. you are just left to your own devices, to look after you own day to day health conditions.”*
- *"Rapid access in the community as soon as a problem starts so that it can be fixed before it leads to hospital admission & disability.”*
- *“Doctors should work in the community as well as hospitals."*
- *“I do my best to get around but would like more physiotherapy.”*
- *“It would be nice to see the healthcare charity related to my illness more involved with my care.”*
- *“Referrals to support groups.”*

Mental Health:

- *“Organise community groups or relaxation groups. Groups with information i.e.: CBT interventions.”*
- *“Act promptly when help is first required.”*
- *“Not be making things worse by leaving me with no idea of what is happening in my treatment.”*
- *“Access to services like the Life Rooms. I travel to the Life Rooms in Walton to access support services but it takes me over an hour to get there each time and I find the bus travel exhausting and frustrating. It would be beneficial if there were services like this available in more areas across Liverpool.”*
- *“Easier to get GP appointments.”*
- *“Be more aware of people with mental health needs.”*

If you have any further comments.

Heart and Lung Diseases:

- *“Reduce meaningless targets and make common conditions treatable at one place where you can get blood tests ECG [Electrocardiogram] etc rather than going all over the place which is very hard for the poor.”*

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

- *I have a lots of health conditions and they should be getting checked individually. I just feel like my needs are not getting met. Basically, you are not even classed as a human being. You are just a number. My GP practice has no respect for their patients and certain doctors in my practice talk down to their patients. I have mental health condition and anxiety on one visit to my GP I told him I felt suicidal and was going to act on the voices that I was getting and he replied, well if you want to do that is up to yourself, the doctor should be there to help you. I just felt I had wasted my time going to doctors, I am frightened to go back to my GP practice. GPs should be regularly monitored every so often, the patients aren't getting the service they should be getting”.*
- *"Patients with the majority of long-term conditions are ignored - diabetes and arthritis are only a few of them but get most attention.”*
- *“More support needed to stay healthy and in work"*
- *“All NHS organisations need to adopt an 'acting as one' approach. Sometimes, I am in other parts of the country for extended periods of time. It would be comforting to know*

that if I see a GP in a different area or need to attend a different hospital, they would have access to my records and that for me, as the patient, it would just be like visiting my usual practice/clinic."

Mental Health:

- *"I searched to find help for myself."*

In focus: what is important to people with long-term health conditions about health and care services?

As part of our research activity, Healthwatch Liverpool conducted a focus group with people who attend *Sunflowers*, an independent charity which supports people with long term health conditions, particularly cancer. *Sunflowers* has a building in south Liverpool which people can attend for a variety of groups and activities including holistic therapies and counselling. People with long term health conditions are more likely to use health services and so be affected by any changes in the NHS. Care and treatment of people with long term conditions is a major focus of the NHS Long Term Plan. This focus group took place on 8th May 2019, and was attended by 22 people. Below is a summary of the themes and issues they raised:

What do you think would make health services better?

- GPs - a number of people gave feedback regarding GP services, specifically wanting easier access to GP appointments and suggesting that some GPs need to listen more to their patients and be more approachable.
- Administration - some people felt that there is too much of a focus on administration in the NHS and that employing admin staff is at the expense of clinical staff.

What do you think would help people live healthier lives?

- Lifestyle - a large number of comments focused on people improving aspects of their lifestyle including diet and exercise.
- Education - some people felt that education, particularly for children and young people, was an essential aspect of people living healthier lifestyles.

What do you think would make it easier for people to look after themselves better?

- Social opportunities - some people felt that access to social opportunities, such as the groups offered at *Sunflowers*, was important in helping people look after themselves.
- Education - this theme was again raised, particularly in relation to diet.

Do you think the support offered to people with long term health conditions could be better? How?

- Positive - some people felt that they had received good care and support from the NHS.
- GPs - this theme was again raised, particularly in relation to availability of appointments.

healthwatch

NHS Long Term Plan Report

Chapter 7 - Healthwatch Sefton

Sefton

Sefton is a metropolitan borough of Merseyside and its local authority is Sefton Council. The Borough consists of a coastal strip of land on the Irish Sea and extends from the primarily industrial area of Bootle in the south to the traditional seaside resort of Southport in the north. In the southeast it extends inland to Maghull. Sefton's 22-mile-long coastline boasts some of Merseyside's best beaches characterised by a wide sandy foreshore backed by dunes; along with significant areas of docks, estuary, shore, dune, and woodland. Sefton has a population of approximately 274,600. 23.1% of Sefton's population is 65 years old or over (63,300) and Sefton is ranked 18th out of 326 local authorities for the number of residents aged 65 or over.

Sefton life expectancy at birth is significantly lower than the England average for both men and women. Life expectancy is 10.5 years lower for men and 11.7 years lower for women in the most deprived areas of Sefton than in the least deprived areas. Cancer makes the largest contribution to the gap in life expectancy between Sefton and England for both males and females.[9]

In Sefton we received 230 survey responses, consisting of 208 general surveys and 22 specific condition surveys. There were also 22 attendees across two specific focus group events.

Sefton

Cheshire & Merseyside
Health & Care Partnership

"Be the reason someone receives better care today"

If Sefton was a village of just 100 people...

34 Children are overweight or obese by year 6

20 Adults suffer from depression

9 5-16 year olds have a MH disorder

29 Will die from cancer

68 Adults are over-weight or obese

3 Adults under 40 have Type 2 diabetes

60 people are living with a long term condition

10 Will die from heart disease

16 Are smokers

82 Is the average age that women will live to

32 People take less than 30 mins exercise a week

78 Is the average age that men will live to

10 People are over 75

Statistics from PHE are for the Sefton Local Authority area, pop: 177,000

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[9] Source: Sefton People & Place Introductory Profile, February 2019, Produced by Insight, Business Intelligence, & Performance.
https://www.sefton.gov.uk/media/1533553/sefton_people_place_profile_mar19.pdf

Summary of Findings:

What matters most to people in Sefton?

- Having access to the help and treatment needed when it is wanted was the most important factor people told us was needed in living a healthy life. For example, people said they wanted more education about how to pursue a healthy lifestyle, and to access support resources.
- To help keep independence and stay healthy whilst getting older, people indicated that being able to stay in their own home for as long as possible was most important to them. People mentioned that they would like more support in the local community and in their home, as well as financial support for adaptations to their home.
- Choosing the right treatment being a joint decision between the person and the relevant health or care professional is most important to people in Sefton in managing and choosing support and treatment. Being offered care and support in other areas if people cannot be seen in a timely way in their local area was deemed as the second most important option. People believed that the NHS requires more funding for staff and online services, as well as better communication and signposting to services.
- People in Sefton told us that being able to talk to their doctor or other health professional wherever they are and having absolute confidence that their personal data is managed well and kept secure, were both deemed as the most important when interacting with the NHS
- A number of people talked about not only the continued use of technology for a more accessible service, but also an awareness that not everybody is able to use technology.
- Better access to GP appointments, for example through weekend appointments, was a common theme of comments.
- People with specific conditions felt that they would rather see someone they had seen before even if it meant having to wait for a diagnosis or support. Those with dementia, or looking after someone with dementia, told us that the wait for their initial assessment and diagnosis was slow, but that the wait between being diagnosed and receiving treatment was fast.
- People in Sefton commented that they would like to see more accessible services in the community, for example through the creation of health and wellbeing centres and ‘one-stop shops’ where various services can be accessed.

Survey results

The following sections now break down the results of the 230 responses across Sefton to the surveys designed by Healthwatch England. The first sections use the 208 responses to the general 'People's general experiences of health and care services' survey, before breaking down the 22 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.

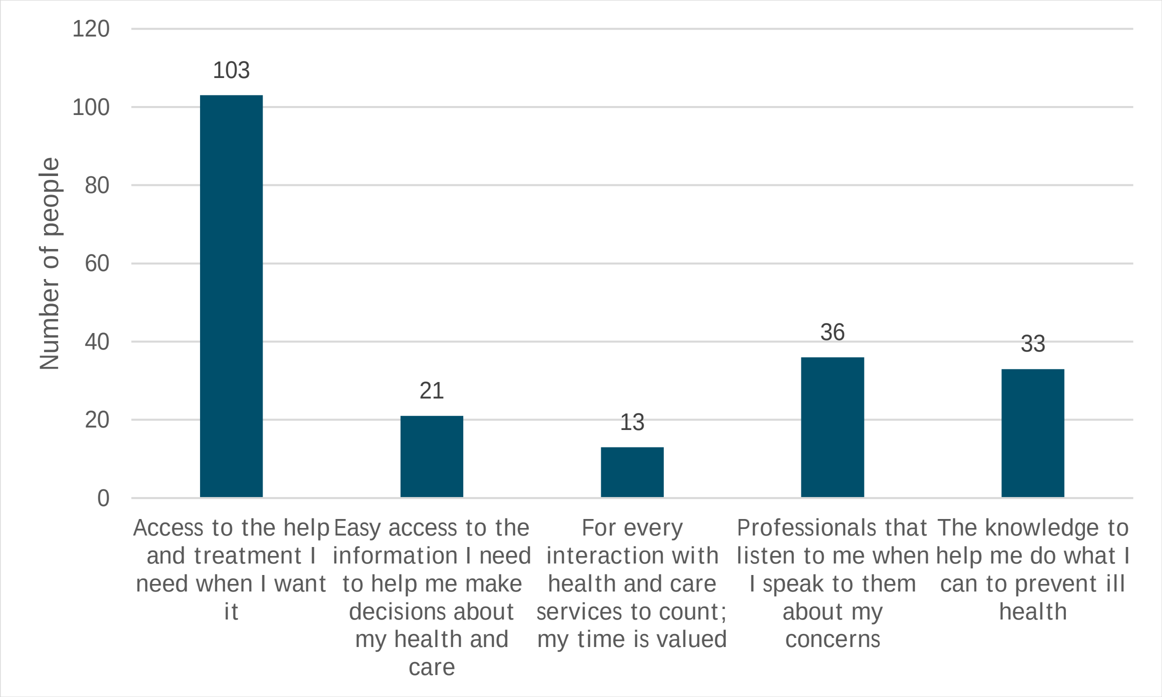
For each of these, people were asked to choose which of a number of options was most important to them. Following this, people were asked to rate each of the options on a scale of 'very important' to 'not important at all'. Therefore, more than one option could be considered 'very important'. Finally, 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, Chart 1 shows that having access to the help and treatment needed when it is needed was deemed to be most important by people responding to the survey. 206 people responded to this question.

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



However, when asked to rate on a scale of very important to not important at all, all other options were considered either very important or important as the Table 1 below shows. Up to 206 people responded to this question, though 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	164	40	2	0	0
Access to the help and treatment I need when I want it	159	46	1	0	0
Easy access to the information I need to help me make decisions about my health and care	141	60	5	0	0
For every interaction with health and care services to count; my time is valued	135	60	10	0	0
Having the knowledge to help me do what I can to prevent ill health	132	66	7	0	0

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 ordered into themes and summarised below:

Help to be healthy

Many people commented on their desire to lose weight and to attend exercise classes with some suggesting these should be made more easily accessible and cheaper. People also mentioned about transport and community opportunities:

- *“Workplace allowing time/space to talk about/prioritise health.”*
- *“Facilities in the community to help me maintain a healthy life. Although a number of such facilities are available in Sefton - usually provided by voluntary groups with limited funding. Many that were available last year have now closed including importantly a number of the physical exercise classes suitable for people like me with disabilities.”*
- *“Free diet sheets for healthy eating for people on a limited budget, not everybody knows what are best foods for them or if they have medical conditions, certain foods might react badly with them or cause them to put on weight, etc.”*

Health Education

People also commented on receiving information about health care and self-help mechanisms:

- *“Better education about major health issues, Blood pressure, Diabetes, Stroke. We know lots about heart attacks and cancer but not a lot about the above.”*

- *"Health services use language that is easy to understand - they use far too much jargon that makes it seem like a big secret that I'm not supposed to know or ask about."*
- *"Clear and concise information in easy access places like GP and Health Clinics, but not lots of leaflets. One leaflet with easy to follow guidance. Possible links to the internet but also addresses or telephone numbers of services and if possible, a named individual. Communication is the key to better health."*
- *"Consistent health messages rather than the sometimes-contradictory advice given out via public health and NHS England."*

Accessibility to help

People commented on accessing different resources and services specifically around individual needs and community wellbeing services, this covered much around affordable health and wellbeing services:

- *"Reasonably priced/easy access counselling."*
- *"Access to help and treatment when I need it, free leisure facilities and personalised free lifestyle reviews."*
- *"Affordable and easier transport to self-help activities."*
- *"Be able to get fruit and veg at reasonable price if you are on a limited income or have to use a food bank."*
- *"The council putting more effort into making public open spaces safe and pleasant spaces to spend time in."*
- *"Being able to access GP appointments outside working hours e.g. evenings and weekends."*

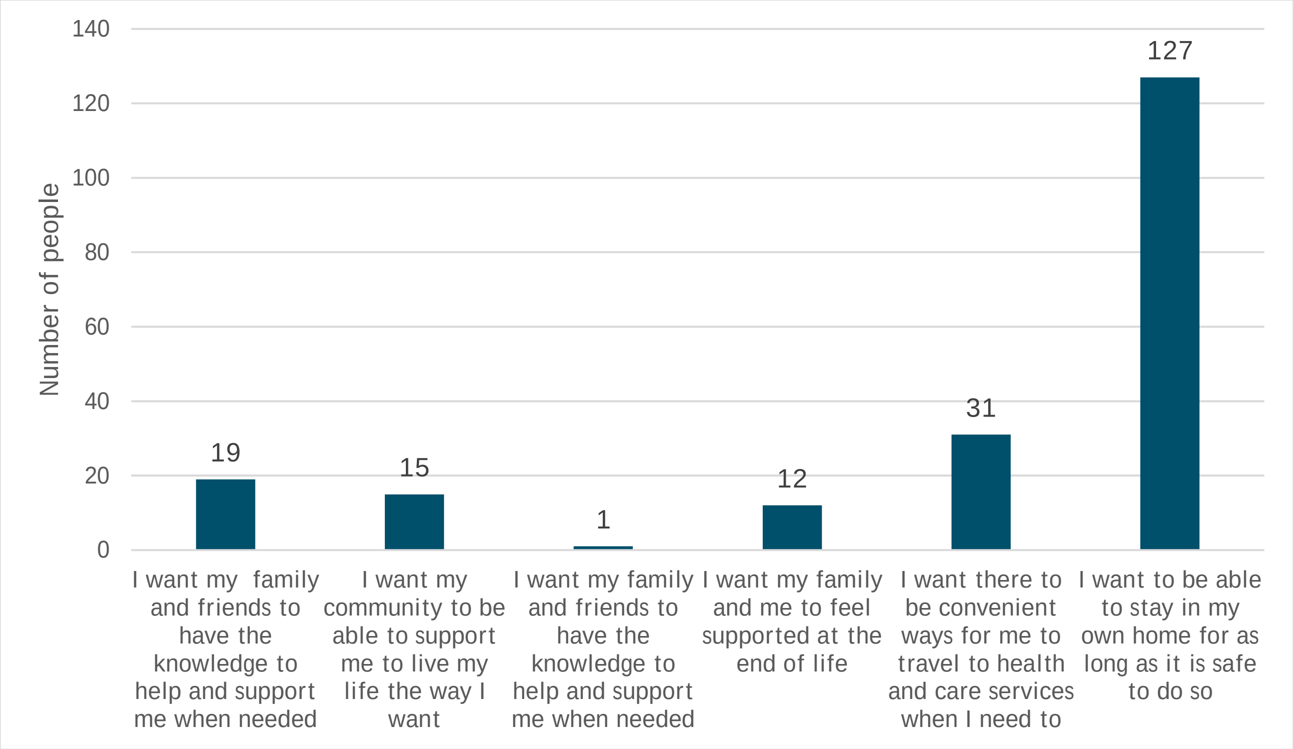
Approaches to leading healthier lives

- *"Local services that are accessible. I currently miss out on treatment for long standing health issues because I cannot get to the clinics, they are very far away and inaccessible. Better resourced services, more money for staff, sites and equipment needs to be allocated to both primary and secondary care as waiting times for both are appalling. I have been on waiting lists for several services that are essential for many months."*
- *"A more joined-up approach to allow affordable and accessible council-run services. The local swimming pool is now largely booked with groups and costs have increased significantly. This makes it difficult for people like me, who work full time and have a 2+ hour commute, to the pool. The council has been threatening to increase the cost of the bowling green to the point that it would be prohibitive for the largely retired members of a club to continue. This would remove the gentle exercise and social benefits they enjoy. The council budget and NHS are entirely separate. The impact of decisions is not."*

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). 205 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. In particular having a community who are able to support them to live their life the way they want to was deemed as very important, second to being able to stay in their own home for as long as possible. Up to 203 people responded to this question, though 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	171	28	4	0	0
I want my family and me to feel supported at the end of life	151	46	3	1	1
I want there to be convenient ways for me to travel to health and care services when I need to	140	56	7	1	0
I want my family and friends to have the knowledge, to help and support me when needed	133	59	9	0	2

I want my community to be able to support me to live my life the way I want	122	56	22	1	1

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

People informed us of the support they would value seeing in the home:

- *"Availability of practical help for working-age people with acute illness who live alone."*
- *"Stop making elderly residents move location to access their care at the end of their lives... we don't provide adequate home care so they move to residential care ...then as they deteriorate they have to be moved to a nursing home... and if there is further deterioration they are moved again at the very end into hospice or hospital. What's wrong with escalating care up and down appropriately in a person's own home... it would be a lot cheaper and better for the people involved."*

Financial Support/Funding

- *"Some appropriate financial incentive to stay at home safely e.g. to make adaptions to home or employ appropriate carers."*
- *"Stop the cuts to social care. They are currently so underfunded as a consequence of government austerity that they can no longer meet statutory duties. Combined with cuts across all public services, transport, etc. vulnerable people are being left behind and the harm suffered is directly proportional to how many public services are relied upon."*
- *"More access to community transport. People are being isolated due to lack of transport."*
- *"Better funding for the NHS allowing them to see people more frequently and give more attention to detail."*
- *"It is not my family and friends' job to support me, they are not health professionals. Fund the health service properly."*

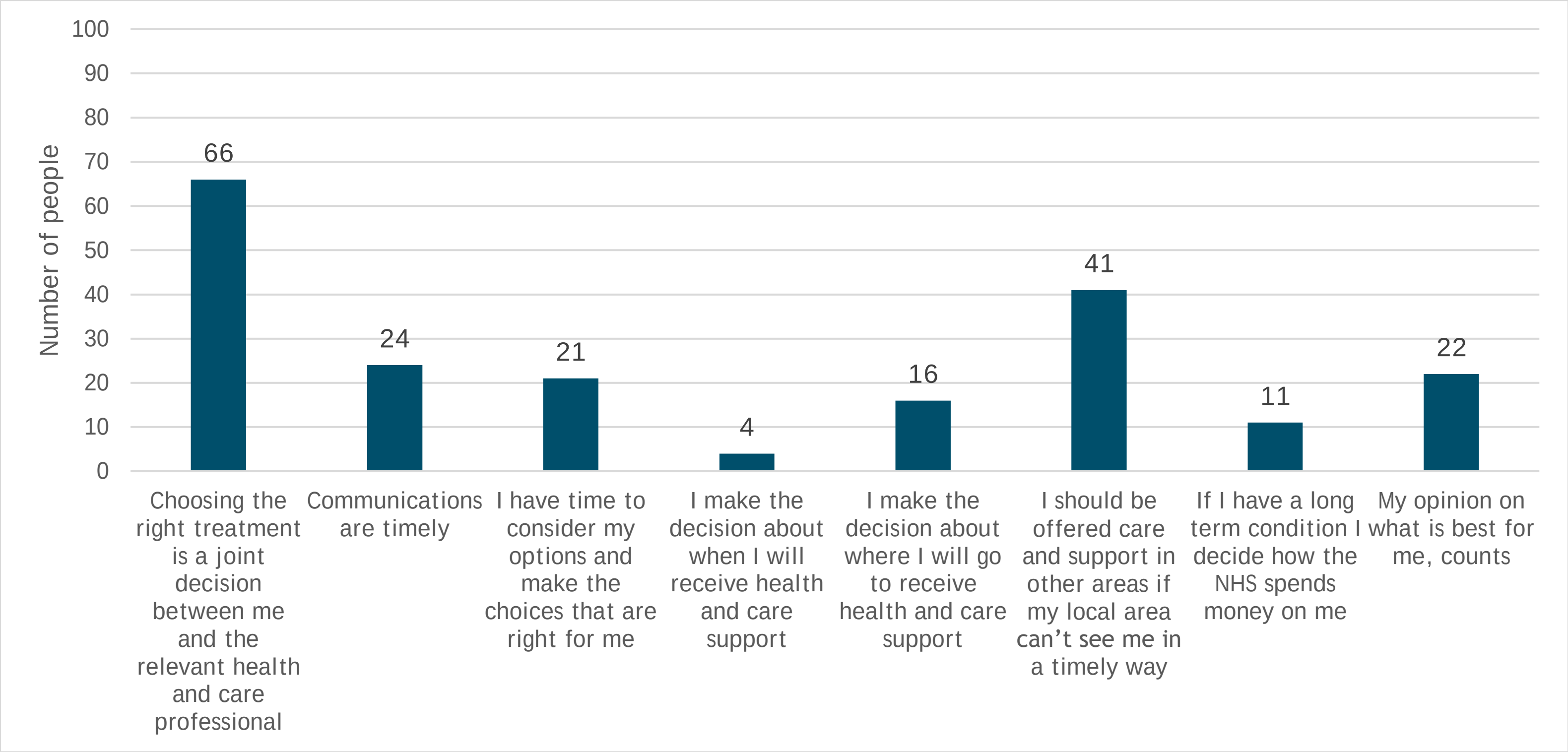
Community Support

- *"My neighbours and community help to retain my independence."*
- *"To be well informed and have documents in place that make the medical profession aware of views. My father had an end of life advance directive and these should be in place for all people not just at end of life as family can then support the wishes of the individual in case of medical emergencies."*
- *"Easy access to community services. Help us to be safe and secure with good people around us."*
- *"Improved public transport - particularly buses in Southport. Routes have been cut which means there is no local bus service any more to my GP surgery - there were at least three options up to about two years ago."*
- *"Access to exercise facilities. People such as Community Connectors to alleviate loneliness."*

Managing and choosing support and treatment

Chart 3 shows that people we spoke to in Sefton 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 in their local area was deemed as the second most important option. 205 people responded to this question.

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



When asked to select how important different factors were on a scale of very important to not important at all, people also deemed that making the decision about where they go to receive health and care support and timely communications 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. This is detailed in Table 3 below, in order of the options that most people classed as being very important. Up to 206 people responded to this question, though not everyone 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 the relevant health and care professional	131	71	4	0	0
Communications are timely	129	65	8	1	1

I have time to consider my options and make the choices that are right for me	123	69	11	0	0
I should be offered care and support in other areas if my local area can’t see me in a timely way	113	76	9	3	1
I make the decision about when I will receive health and care support	109	72	19	4	0
My opinion on what is best for me, counts	108	81	14	1	1
I make the decision about where I will go to receive health and care support	106	83	12	4	0
If I have a long-term condition, I decide how the NHS spends money on me	88	78	30	4	1

We also asked respondents to tell us one more thing that would help them to manage and choose how the NHS supports them. Answers have been collated and categorised under emerging themes.

Funding for local services

Respondents mentioned about more funding going into extra staff and effective online services. This also linked into comments that called for better treatment planning and public treatment spending. For example:

Staff

Along with investment, it was recognised that funding challenges and demand for services was putting the NHS and particularly its staff under strain, which affected the staff service with patients. We received praise from various people regarding NHS staff, while others were asking for more staff consistency and staff training. For example:

Appointments, Communication and Signposting

In regard to staff, a common theme people highlighted was the need for effective communication both within the NHS and when talking to patients and signposting them. People also told us about the need for better information and information accessibility. Comments included:

Health support and information

- *“To have all the options explained and a recommendation with reasons given to help decide on basis of proper informed consent.”*
- *“That care is joined up and that patients don't have to follow up appointments or referrals.”*
- *“Personal records easily available.”*
- *“If I have a long-term condition or need long term care, I am automatically enrolled in some kind of mental health care help, mindfulness, psychology, counselling.”*

- *“Understanding how health is structured so I know who to contact. Too many changes and when living on a border with two local authorities, nightmare, as often referred to wrong provider.”*
- *“Options available via parent access app. App is limited to what you can do and differs in other areas. For example, test results are not shown on the app.”*

Communication:

- *“Effective communication contains actual information about who you are seeing, for how long and why. Too many letters just say ‘x clinician at y place’ often I have no idea what I am going for, how long I can expect to spend there or what the appointment is about. As a carer I need information about how long to plan to be away otherwise I just can’t attend.”*
- *“More effective and sympathetic communications from health providers, both GP surgeries and hospitals. They sometimes seem to forget that patients (their customers) have lives to live beyond treatment requirements.”*
- *“Better communication between health agencies, social care and other bodies who can make services better.”*
- *“Stop GPs making automatic referrals to local services… they should ask whether speedier access is more important than location and allow patient to choose. End postcode lottery access.”*

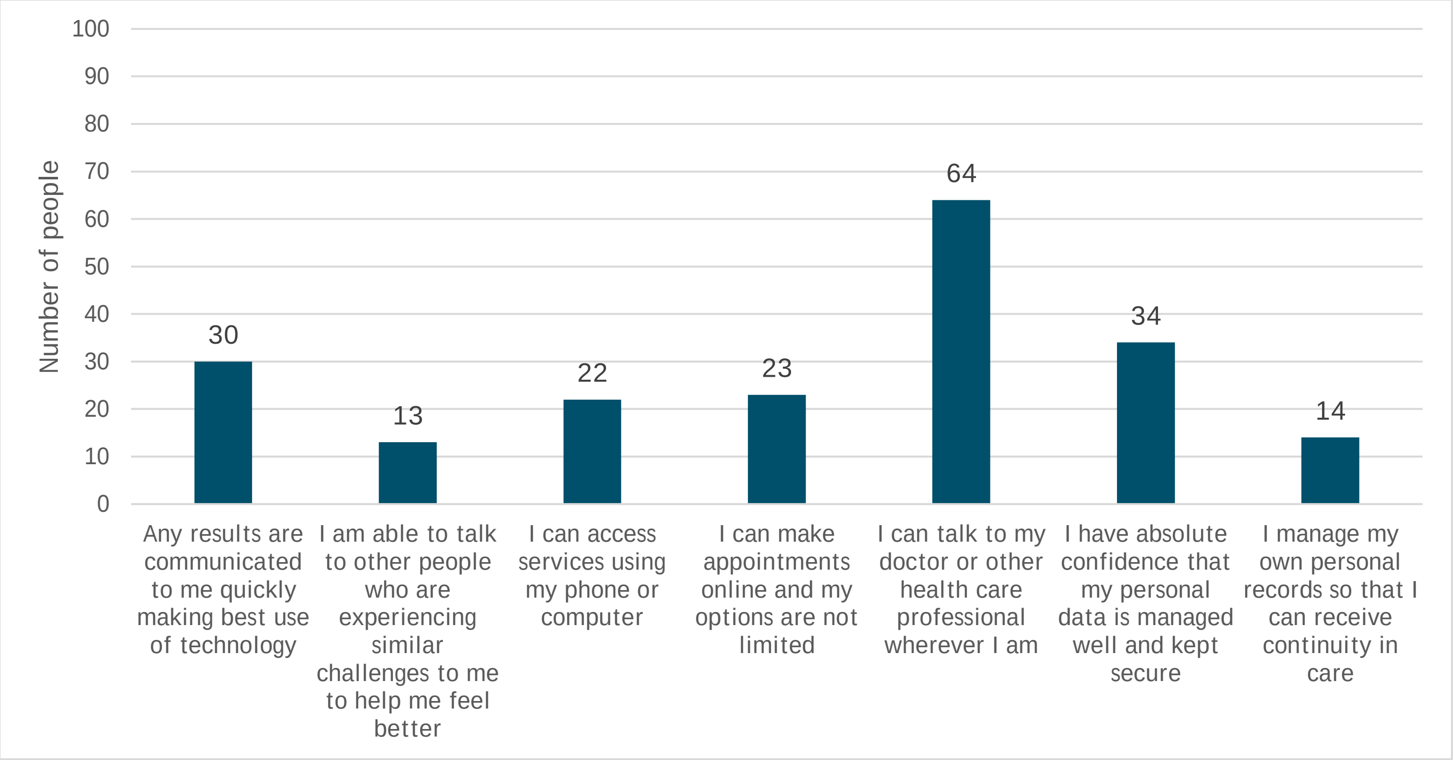
Engaging people in health service delivery

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.

People in Sefton told us that being able to talk to their doctor or other health professional wherever they are and having absolute confidence that their personal data is managed well and kept secure, were both deemed as the most important when interacting with the NHS (see Chart 4 below). 200 people responded to this question.

Chart 4: What is most important to you 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 (Table 4), people said that the most highly rated factor was having confidence that their personal data is managed well and secure. However, all factors were deemed to respondents as being important or very important. Up to 204 people responded to this question, though not everyone responded to each option. Up to 203 people responded to this question, though not everyone responded to each option.

Table 4: 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 have absolute confidence that my personal data is managed well and kept secure	122	61	20	0	0
Any results are communicated to me quickly making best use of technology	121	63	12	4	3
I can talk to my doctor or other health care professional wherever I am	110	59	31	2	1
I can make appointments online and my options are not limited	106	52	22	11	10
I can access services using my phone or computer	99	77	15	11	2
I manage my own personal records so that I can receive continuity in care	94	61	32	9	6
I am able to talk to other people who are experiencing similar challenges to me to help me feel better	90	67	41	4	2

Respondents were then asked to think about one more thing that needs to change to help them to successfully manage health and care. These answers have been categorised under emerging themes.

Technology

A number of people talked about not only the continued use of technology for a more accessible service, but also an awareness that not everybody is able to use technology:

- *"Digital services."*
- *"I am registered on the Patient Access website which purports to let me see my medical records. However, in reality I can see the bare minimum. I would like to be able to access my entire records, firstly to see if there are any inaccuracies, and secondly to remind myself what has been said at various times. As this is my own data, I am surprised that this is not possible."*
- *"Not always able to access information/appointments online. Option should be given to ensure appointments are clear and maybe appointment cards given."*
- *"Access to appointments are helped by texts. You can access GP appointments or consultation. Unfair you don't get the same options if you do not use internet to make appointment."*

Communication

Communication was also an emerging theme amongst respondents and in particular, how they are communicated to:

- *"Joint communications available across hospitals and GP services."*
- *"Effective communication that can be relied on. Due to age, capacity, skill, economic reasons, not everyone can access computers, internet and smart phones. It is important that these people should not be discriminated against in the rush to embrace technology."*
- *"The NHS really needs to think about how it interacts with people like me with disabilities and put as much investment into people who have the time necessary to engage with patients with limited understanding and not just rely on new technology."*
- *"Need for verbal communication, i.e. phone calls to make medical appointments, as online do not give enough word count to explain what my symptoms are."*
- *"For all departments to have a joined-up approach, making information on the individual accessible across the NHS. This would provide a better understanding of the patient, particularly those with more than one condition."*

GP Appointments

GP appointments were also mentioned by respondents, and for a number of reasons, including accessibility such as the ease of making weekend appointments; and the quality of appointments, including how much time people get to spend with their GP:

- *"Telephone appointments don't work as my GP is unable to say when they will take place so I can't guarantee that I'll be available to talk. The receptionists seem to have their roles reduced, necessitating a GP appointment that is really a waste of time. I signed up to be part of a patient forum but I'm not home from work when it takes place."*
- *"I often encounter difficulty when requesting medical appointments and feel screening methods are employed that are completed by reception staff. I do not feel this is appropriate."*

Further comments

- *"That I can actually understand what staff are saying both in terms of complexity, sometimes there is no proper explanation offered unless requested and often spoken about in technobabble; and in some cases, the ability to speak English to a high enough standard particularly when attempting to discuss complicated/sensitive matters."*
- *"Rather than give my details to every healthcare professional I should be able to just give my NHS number so my medical history can be found. I keep my medical details in my wallet."*
- *"Health professionals should be aware of other support groups who can provide emotional support."*
- *"A freephone or free-post address for all communications. People get confused with the Dept of Health and NHS England."*
- *"More information needs to be given to family members so that they can support me in the best possible way. Rather than one member getting the information, adult children should also be informed."*
- *"The NHS is the thing that makes me most proud about this country. It is an amazing service. It needs to be protected from privatisation and also from people not using it sensibly. It needs to be more joined up and also healthy choices need to be ingrained from an early age. However, many people work long hours and are on low pay and it's not always easy to choose the healthy options. Stresses are higher as we live in a 24-hour society."*

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

As part of our research activity, Healthwatch Sefton conducted a focus group with members of the general public in order to gain specific insight into the views of people accessing services. This focus group took place on 29th April 2019, and was attended by 10 people. Below is a summary of the themes and issues they raised:

General thoughts on the plan

- *"The plan for the NHS contains good ideas but the plans for future working should already be happening."*

Primary Care - GPs, continuity of care and appointments

- *"I think there is a lot of waste of both money and time. As patients we don't want to keep seeing different doctors and having to tell our story over and over again. Primary care is still a sticking point in terms of the GP you get to see. Consistency is important from a patient point of view but it is less and less likely that you do."*
- *"Does the named GP actually exist? I went into my GP and was told at reception that the doctor I usually like to see had left. There was no communication about this."*
- *"Open ended appointments are needed for on-going conditions such as blocked ears that make hearing difficult, eye appointments and fall clinics for the elderly."*

Acute care and outpatient appointments

- *"Follow up eye appointments can slip by. They tell you they will see you in 2 months but you then don't receive an appointment."*

Taking services into community settings

- *"Screening - This should be taken out into the community e.g. town centres and supermarket car parks."*

Community services

- *"Podiatry - people end up having to pay for this privately as the wait is too long to get seen."*

Mental Health - transition from CAMHS to adult services

- Waiting times are too long.
- Impact on family/family frustrations.
- Mental health on both the family and young service user.
- If you move areas, you then have to go and try and find the services in that area.
- Spoke to 16-18-year-olds who are left to drift, look at the family impact.
- This age group need services where they can go and speak to someone in between appointments. This listener needs to be linked in with their health professionals.
- Mental health with young people is also linked to chronic health conditions.
- They need to be seen in their own community or in a place they go to.
- *"Why not try using a trained volunteer to fill the gap, a listening ear to avoid or calm frustration and possibly give support."*

Mental Health

- *"Mental Health in schools - Does every school have a nurse? Who pays for it? Do the school pay out of funds or do the CCG pay?"*
- *"Mental Health is not funded properly."*

- *"NICE guidelines for this do not have percentage success rates."*
- *"Nursing staff with mental health problems are not supported."*
- *"Staff in NHS hospitals do not have sufficient mental care facilities."*
- *"Proper provision of mental health facilities prevents physical problems."*
- *"Improved waiting times are needed and additional funding so that everyone who needs to can access mental health support. There needs to be access to both emergency and non-emergency services from infancy to university."*
- *"Emergency Mental Health - People who suffer breakdowns and want to kill themselves have to go to A&E as there are no other services. People don't go.*
- *"Maybe someone could open a 24/7 community-based service. A community health one stop shop. I know someone who was told to go to A&E and he just went home and hung himself."*

Cancer

- *"There is still a reliance on radiotherapy and chemotherapy."*
- *"There should be more openness to adopt other methods of therapies."*
- *"Results only run up to five years for survival rates, this should be lengthened."*

More joined-up working in the community

- *"Health Units in empty shops - Birmingham Healthcare have a GP surgery, walk-in centre, sexual health and dentistry on the lower ground floor of Boots, High Street, near New Street Station."*
- *"Ainsdale health & wellbeing centre - There are lots of services all under one roof. You can be prescribed onto the pain team by your GP."*
- *"Pain clinic plus - If a new person comes into our service, we have a chat over a hot drink and a biscuit, this reduces anxiety. We are based with other services for people to access."*
- *"Community idea - to have a building (possible council one that is not in use) where all professionals and community groups could come together. This could also include IT and phone support for patients. NHS could approach larger organisations that may sponsor the cost in return for promoting their services. There could be a one stop shop for everything that people would use. There are community groups doing this already but the NHS needs to come on board and work together. The flu clinics offer different services and they are called Health Fairs in the north of Sefton. One stop shop for services needs to be adopted in all areas."*
- *"Community working together - We need to be a community working together with the NHS. We all need to know about what services are out there and where to signpost patients to."*

Better support for Young Carers

- *"How will this be done? Who will provide this support?"*
- *"Many young carers are below the radar and the NHS needs to ensure that those providing support are identified."*
- *"Has any strategy been outlined?"*
- *"GP Surgeries could support this by identifying young carers and then ensuring the right care is put into place."*
- *"Schools can play a part in identifying young people who are not in school and finding out why."*
- *"A place for young carers to go and talk to each other is needed locally for them."*

Schools and Education

- *"Education programmes at schools are needed, e.g. what causes stress, younger children also need this not just older children."*

GPs working as networks and working better with acute services

- *"Better links are needed between hospitals and GP surgeries for people with chronic conditions. A team should work around you; the patient should be at the centre. People with chronic conditions need community-based groups where they can go and talk to each other."*
- *"Better communication is needed between hospitals and GP surgeries in general."*
- *"Personalisation (getting more involved in your own care) and self care."*
- *"My GP will ask me 'What would you like to happen?' That is a change in culture, making you the manager in your own health."*
- *"Pharmacy services - more education needed on this. This is a very good service. Patients should be encouraged to monitor and look after their own health but there are difficulties in this as the general public are not medical professionals so they would have to start as basic monitoring, taking ownership of one's own health."*

Specialist NHS Trusts

- *"Specialist Trusts - understand why specialist Trusts are needed but patients have to travel there. If by NWAS [North West Ambulance Service] there is already enough strain on them coping with emergencies."*

More services needed in North Sefton

- *"We need a walk-in centre in Southport."*

Use of IT

- *"Not all of us can use or have access to IT. For the NHS to provide tablets or connections to IT to individual patients and train them how to use it. That way they can manage their own health from their own home where possible. This can also include equipment at home to monitor own blood pressure or blood sugars. This would also support transport issues. Other people in the group felt some older people needed a phone contact as they can be scared of technology or not be able to use it. It needs to be tailored to an individual. Pre-paid dongles could be used and that way patients could only access the apps they were given permission for."*
- *"It is important that all services use the same IT system so that information can be shared across differing providers and systems."*

Primary Care networks/sharing of best practice

The plans for primary care networks within the plan are good and locally they seem to mirror our locality model. Working together as networks could make a huge difference. This will work well in Sefton as it's an urban area but could be not so great in a rural setting. Working together should help in the coordination of referrals.

Best practice should be shared and rolled out to all areas within a borough so that there is no postcode lottery. This would drive quality forward. Example given relating to the work of the falls prevention team in North Sefton. Practices should be standardised. Another example was a GP in Southport who piloted a diet to support the control of diabetics. This was successful but was not rolled out.

Funding for the Long Term Plan

- *"NHS needs to use this money they have wisely and show that they have listened to people. How much will Sefton receive of the £20 billion? £20 billion doesn't seem enough. Will the plans amount to invested change if there is a change in government? Is this additional funding or part of an existing budget taken from other parts of the NHS? Funding is not a bottomless pit."*
- *"This plan could actually produce savings but funding is taken from one area and given to another. It would be important that the public gain oversight of how much of the national funding is given to each local 'Place' area."*
- *"£20 billion is not enough and there needs to be more investment in nursing staff."*
- *"Reassurance is needed that the plan will continue no matter what government is leading the country. This needs to be a cross party plan."*

NHS Staff

- *"There needs to be more of a focus on staffing, both in the investment of training and education and also in the emotional health and wellbeing of staff."*
- *"More emphasis/education needs to be provided to patients in accessing services in the community rather than telling your story over and over again."*
- *"Many of the issues relate to the system and NHS staff should not be blamed."*
- *"Staff shortages in 'acutes' is a problem, with a lack of quality time for staff and management to plan properly. There is a lack of planned resources."*
- *"Absenteeism with nursing and ambulance staff has the highest incidence of any business in the UK."*
- *"Outsourcing contracts is a big issue without equal pay."*
- *"There is a lack of honesty with staff about future expenditure."*

How do we want to be engaged moving forward?

It was felt that PPGs [Patient Participation Groups] are a good way to engage with patients. This allows patients to have a say within their own GP practice on issues. If looking at the primary care network model, locally PPGs could come together and form a PPG network for that locality so that they can be utilised as a point of reference."

The Friends and Family test was seen to be good but all patient feedback needs to be joined up. This practice is becoming more of a common approach with patients accepting that this is in place. Healthwatch ask for patient feedback. The GPs and Trusts need to ensure Healthwatch feedback is included all together. People complete feedback but then don't hear back. It puts people off leaving feedback. GPs and Trusts need to ensure patient feedback on what they have heard and acted upon is visible and accessible to patients."

Feedback on a personal patient point of view needs to be personal to the individual.

People often want to share what doesn't work well and would rather complain than share what has worked. During Healthwatch engagement stands however patients will say that everything went well and then as you talk with them, they start to share more and more feedback about what didn't go well.

Sometimes there can be a trust issue in sharing any feedback.

There is also the 'so what' element. People share comments but then do not receive any feedback on what impact it has had.

It was felt that local people need to be engaged on wider system changes and issues if it affects them. It is important that everyone knows about changes but information is shared at a level at which the general public can understand. It would be very important to ensure that patients in receipt of a service are engaged as they are users at the point of delivery. Patients are fed up of being asked to fill in surveys, and feel 'surveyed out'. However, despite people sharing their frustrations, it is important that they continue to be engaged and heard and every avenue needs to be used. It is still important that voices are heard.

Further comments

- *"Cancer services at Aintree University Hospital should be given credit, at every stage along the way. Great care was received."*
- *"Without support of the NHS, I would be dead."*
- *"In relation to urgent care, 111 was prompt and excellent."*
- *"The Clinical Commissioning Group in the north is working well."*
- *"Southport Hospital is poor in delivering but has pockets of best practice."*
- *"Two family members have died. One, there was no diagnostic information provided and with the second, they had been given a blood transfusion whilst on warfarin."*
- *"I have had excellent care at Aintree for the past 12 years. Smouldering myeloma which is not active, care has been very good. There was a communication issue and I am not sure the doctor read my notes beforehand."*

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 22 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	1
Cancer	2
Dementia	7
Heart and lung diseases	1
Learning disability	0
Long-term condition e.g. diabetes, arthritis	6
Mental Health	5

Table 6: Who are you responding on behalf of?

Condition	Myself	Someone else
Autism	0	1
Cancer	2	0
Dementia	2	5
Heart and lung diseases	1	0
Learning disability	0	0
Long-term condition e.g. diabetes, arthritis	6	0
Mental Health	2	3

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

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

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	Not applicable
Autism	0	1	0	0
Cancer	2	0	0	0
Dementia	2	1	4	0
Heart and lung diseases	1	0	0	0
Learning disability	0	1	0	0
Long-term condition e.g. diabetes, arthritis	2	1	3	0
Mental Health	1	2	2	0

Tell us whether the support met your needs and how it could have been improved.

Autism:

- *“Initially after receiving a diagnosis of ASD [Autism Spectrum Disorder] the paediatrician offered no support or advice other than to buy a book of suggestions of how to proceed. When a difficult time arose, there was no suitable help at all. GPs are not the right place to go for help, waiting lists for mental health assistance are unacceptably long and possibly not the correct treatment. Many professional health care practitioners quite simply do not have sufficient knowledge of ASD and the problems it can cause. Immediate help by a specific Autism specialist would help. The Police and Ambulance services are not suitable. Mental Health services are not helpful when they claim they are not qualified to treat ASD and suggest the Police are the appropriate department.”*

Cancer:

- *“Liverpool Royal University Hospital sorted out my bowel cancer.”*

Dementia:

- *"By better listening and conversation."*
- *"Very disjointed. Long delays."*
- *"Took a long time to get diagnosis. I felt the doctor could have explained things more clearly, in layman's terms."*
- *"The condition of dementia was not very well supported at first. It was hard to get a diagnosis and when we did get one, we didn't know what support was available."*

Heart and lung diseases:

- *"My actual diagnosis was after a CT angiogram- lung nodules. I had some weeks waiting for a string of tests: PET scan, gastroscopy (highlighted by the PET scan), two failed CT guided lung biopsies, one VATS procedure."*
- *"My consultant chest physician did not listen to me. He did not take into account my own views. A tertiary referral to an interstitial lung specialist took 16 weeks!"*

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

- *"Between the diagnosis of cancer and waiting for a specialist opinion was a period of anxiety."*
- *"There was no support. I ended up paying for a private consultation to try to get some information sooner to help with the anxiety of receiving such a diagnosis."*
- *"Felt that I didn't get time to ask questions and that was a big rush when I was first diagnosed. Have never seen a doctor about my condition only practice nurses."*
- *"Told no treatment possible."*
- *"It was excellent. My only problem was that I had to buy my own blood tester (but was not charged VAT)."*
- *"Went for a blood test and found I was pre-diabetic which progressed to Diabetes and was placed on medication."*

Mental Health:

- *"Did not get support for my child who was suffering with anxiety attacks and unable to go out, she was in a very bad state with several hospital visits when she experienced these panic attacks."*
- *"Doctors referred me to Access Sefton but Probation referred me to Mersey Care - Life Rooms, which has been a god send to coping with anxiety and depression."*
- *"Initial diagnosis of depression not psychosis was good but little support after that other than medication. One to one support was needed but a waiting list of six months for counselling was not helpful."*
- *"Wasn't able to receive CBT or counselling."*
- *"Our support has increased considerably since moving to Sefton it was poor to non-existent in Cheshire East."*

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	1	0	0
Cancer	1	1	0	0	0	0
Dementia	1	1	4	1	0	0

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

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

Condition	Yes	No
Autism	0	1
Cancer	0	2
Dementia	2	5
Heart and lung diseases	1	0
Learning disability	0	0
Long-term condition e.g. diabetes, arthritis	4	2
Mental Health	0	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	0	0	0
Cancer	0	0	0	0	0
Dementia	0	0	1	1	0
Heart and lung diseases	0	0	0	1	0
Learning disability	0	0	0	0	0
Long-term condition e.g. diabetes, arthritis	0	3	0	1	0
Mental Health	0	0	0	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	1	0	0	0	0	0
Cancer	0	0	1	1	0	0
Dementia	0	5	0	2	0	0
Heart and lung diseases	1	0	0	0	0	0
Learning disability	0	0	0	0	0	0
Long-term condition e.g. diabetes, arthritis	1	2	1	1	0	1
Mental health	1	1	1	2	0	0

Autism:

- *“Approximately two years.”*

Dementia:

- *“It was some time ago, but the wait to see a specialist was way over 18 weeks.”*
- *"Dementia - two years after first raising concerns”.*
- *“A few months.”*
- *“Initial referral came quickly. Diagnosis took long time.”*
- *“My dad didn't know what was available and was very much in the dark as what the diagnosis meant and where to go for help.”*

Heart and lung diseases:

- *"Failed CT guided biopsy (x2) - got to the back of the queue and wait again,”*
- *“It took months to get a diagnosis."*

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

- *"I was waiting for a number of weeks to see a haematologist after I received the diagnosis of lymphoma.”*
- *“I did talk to a Lymphoma nurse at The Christie Hospital, Manchester (out of my area) as there was no one obviously available locally with knowledge."*
- *“Arthritis - three months after first asking for help."*
- *“Six months”*
- *“Was picked up from a urine sample when visiting Hospital clinic for another condition.”*

Mental Health:

- *“We waited whilst the doctor tried to get help from Alder Hey but as my child did not self-harm, we were low priority even though my child was in a very bad way at the time.”*
- *“Attended A&E and was referred to Assessment unit.”*

- *"I didn't wait too long but the CBT counselling didn't materialise. I needed further support and went straight to the crisis team who were brilliant."*
- *"Had to wait for appointment with mental health team."*

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	1	0	0	0	0	0
Cancer	0	0	0	2	0	0
Dementia	0	0	2	5	0	0
Heart and lung diseases	1	0	0	0	0	0
Learning disability	0	0	0	0	0	0
Long-term condition e.g. diabetes, arthritis	1	2	1	2	0	0
Mental health	1	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	0	1
Cancer	1	1
Dementia	4	3
Heart and lung diseases	0	1
Learning disability	0	0
Long-term condition e.g. diabetes, arthritis	3	3
Mental health	2	3

If you accessed support what aspect could be improved?

Dementia:

- *"There was a long delay between diagnosis and post diagnostic support."*

Mental Health:

- *"There needs to be more staff in all aspects of service."*

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

Condition	Yes	No
Autism	0	1
Cancer	1	1
Dementia	7	0
Heart and lung diseases	1	0
Learning disability	0	0
Long-term condition e.g. diabetes, arthritis	3	2
Mental health	1	4

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	0	0	0	0	0	0
Cancer	0	0	0	1	0	0
Dementia	0	1	6	0	0	0
Heart and lung diseases	1	0	0	0	0	0
Learning disability	0	0	0	0	0	0
Long-term condition e.g. diabetes, arthritis	0	2	1	0	0	0
Mental health	0	1	0	0	0	0

Cancer:

- *"A matter of weeks."*

Dementia:

- *"More than the 18 weeks."*
- *"Initial waiting time for seeing consultant was quite quick. Waiting time when consultant referred me to a second consultant was met by logjam which needed intercession from my MP to resolve."*

Heart and lung diseases:

- *"16 weeks+ to see the interstitial lung specialist at University Hospital Aintree."*

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

- *"A period of anxiety. I decided to pay to see a consultant haematologist myself to speak to."*
- *"I was initially referred to wrong specialist and had to wait again to see the right consultant."*

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

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

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

Autism:

- *"There was no care provision at all in Sefton until around five years ago. By this point various problems had been allowed to become accepted behaviour and will most probably never be changed."*

Dementia:

- *"At the beginning we were offered day care which was good, but when the situation got worse, a diagnosis of residential care was given, but the time given to agree to the place, was not enough to properly assess and consequently the care was not good."*
- *"I know places are limited, but a little more time to look and visit, without pressure would be good."*
- *"Delays. Most information had to be researched independently."*
- *"More information needs to be advertised in all areas of the hospital and GP surgeries. Help should be automatic and then should come to the house of the person diagnosed."*

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

- *"Firstly, it took some years to get a diagnosis (cutaneous lymphoma) with a diagnosis being given of cancer then withdrawn on more than two occasions."*
- *"There was not communication from my initial needle biopsy of my neck swelling with the ENT surgeon - he gave me the diagnosis of non-Hodgkin's lymphoma, and when I asked what happens next, he said he would send me for a CT scan - end of discussion and consultation! No communication skills, no offer of any support."*
- *"Regular blood tests and other various tests e.g. optician."*

Mental Health:

- *"No support from school, did not have any pastoral care, cuts in staff meant no one at school trained to deal with children undergoing emotional problems. Doctor referred child but not taken up by hospital as not deemed a priority, long list of children waiting for counselling because of lack of resources."*
- *"No ongoing support other than self-care."*
- *"The GP did not do a lot for me but the crisis team were fantastic."*
- *"If you ring for help/appointment can take weeks to be seen."*

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

Please explain how the care did or did not meet your expectations and how could it be improved?

Dementia:

- *“There can always be better communication.”*
- *“People don't seem to communicate with each other. Often the case is "left hand doesn't know what the right hand is doing" Services/care not joined up.”*
- *“Too early to say.”*
- *“For a while it was just not there.”*

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

- *“Anyone receiving a diagnosis of serious cancer should have an appointment within 48 hours to discuss possible implications for that individual. To have to wait a number of weeks is too long.”*
- *“No treatment offered.”*

Mental Health:

- *“After getting no help we ended up paying privately for counselling as we felt our child was at breaking point.”*
- *“The GP was not great but the crisis team were good.”*
- *“Depends on what you call timely, letters etc take weeks or more to come through if at all seems to be delays in preparing reports/letters and typing them.”*

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	0	1	0	0	0	0	0
Cancer	1	0	0	0	0	0	0
Dementia	2	4	0	1	0	0	0
Heart and lung diseases	1	0	0	0	0	0	0
Learning disability	0	0	0	0	0	0	0
Long-term condition e.g. diabetes, arthritis	1	1	4	0	0	0	0
Mental health	4	0	0	1	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	0
Cancer	1	0	0	0
Dementia	0	5	2	0
Heart and lung diseases	0	0	0	1
Learning disability	0	0	0	0
Long-term condition e.g. diabetes, arthritis	0	5	0	1
Mental health	1	3	1	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	1	0	0
Cancer	0	1	0	0
Dementia	0	6	1	0
Heart and lung diseases	0	0	0	1
Learning disability	0	0	0	0
Long-term condition e.g. diabetes, arthritis	0	3	1	2
Mental health	1	4	0	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	0
Cancer	0	0	0
Dementia	3	2	1
Heart and lung diseases	0	1	0
Learning disability	0	0	0
Long-term condition e.g. diabetes, arthritis	2	3	0
Mental health	1	3	1

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

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

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	0	1	0
Cancer	0	0	0
Dementia	4	0	2
Heart and lung diseases	1	0	0
Learning disability	0	0	0
Long-term condition e.g. diabetes, arthritis	5	0	1
Mental health	2	3	0

Supporting you to have more control over your own care

Table 27: What level of support of 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	0	0	1	0

Cancer	0	0	1	0
Dementia	1	5	0	0
Heart and lung diseases	0	0	0	1
Learning disability	0	0	0	0
Long-term condition e.g. diabetes, arthritis	2	2	0	2
Mental health	3	2	0	0

What could the NHS do to help you stay healthy or manage any condition you have?

Autism:

- *“Improve almost every aspect of their services. Provide sensible, factual advice and follow it up.”*

Dementia:

- *“Review health/fitness/appropriateness of medication at regular intervals.”*
- *“Better communication.”*
- *“Easier, accessible appointments to GP.”*
- *“Staff need to be trained to deal with people with dementia. Wards for just people with dementia.”*
- *“Easier appointments. Lower waiting time.”*

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

- *“There is no availability for phlebotomy. Last time I was unable to get an appointment in the week ahead and I went to the 'drop in service’, where I waited for 90 minutes for phlebotomy. The lady was so rushed she did not bother to read the form properly and I had to tell her she had missed out a blood bottle (as I get the same tests regularly), resulting in an additional venepuncture! The haematology clinic now asks for the bloods to be taken prior to the OPD appointment- try to organise it! Not enough resources.”*
- *“Ability to speak to somebody when I need to.”*
- *“Good painkillers that do not have bad side effects - Drugs to cure condition.”*
- *“Regular support, that I am currently receiving.”*

Mental Health:

- *“I don’t think we have adequate resources to deal with our children’s mental health problems in the Sefton area, I felt let down and helpless trying to get support when my child most needed it.”*
- *“Ongoing counselling or psychiatric help.”*
- *“More talking support.”*
- *“Need access to support and care when required.”*

Further comments

Heart and Lung Diseases:

- *"What was a great service at University Hospital Aintree - having full respiratory function tests one day and I managed to get an out-patient appointment for the next day in the respiratory medicine dept. "*
- *"It would have been useful to have a copy of my respiratory test results at the time (I asked!) Why the secrecy?"*

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

- *"What a waste of time and resources to attend a busy haematology clinic (£160) to be told that your blood tests are normal! Time and time again.... Why cannot this be sent to the patient, or receive a text message? I sit for 2 hours in a crowded outpatient clinic (every 3 months) to get the result. No-one examines me. I have had lymphoma for some years. In remission. I Am asked the same questions each visit and have enough sense to know what amounts to a relapse. If there is no need to examine, why cannot a phone consultation e.g. with a nurse suffice? The blood test form can then be sent out for three months' time etc."*
- *"Even worse is the situation where a consultant has to see you just to keep you in the system. (Dermatology, lymphoma malignancy). I have now been given a yearly appointment; however, it is not as if I cannot see if I have lumps and bumps in my skin. Why not just have a system where known cancer patients can self-refer back directly to the specialist? The patient knows best!"*

Mental Health:

- *"Mental illness services in Sefton are better funded than Cheshire but are still in need of investment and recruitment I appreciate that there are shortages of trained individuals seeking permanent employment. This need addressing at a national level and research on why graduates chose to train in the professions and why graduates do not enter a career from their degree. i.e. there is a very high drop-out rate from medical and nursing graduates. Why?"*

In focus: how will the Long Term Plan work in our community for children and young people in supporting them to start well?

As part of our research activity, Healthwatch Sefton conducted a focus group with members of staff from local Clinical Commissioning Groups, Sefton Metropolitan Borough Council, service providers, and people from the voluntary, community and faith sector. This focus was chosen by Sefton Transformation Team as they wanted to learn more about current gaps in children and young people's services and look for creative ways to improve pathways. This focus group took place on 7th May 2019, and was attended by 12 people. Below is a summary of the themes and issues discussed:

Services to support starting well

- Progress has been made in integrating early intervention and prevention services, an example of this being the ACE programme. Sefton Council in partnership with Knowsley and Liverpool have adopted the Adverse Childhood Experiences (ACE) toolkit, developed and robustly tested, which provides an evidenced based assessment of the impact of childhood trauma. These can include emotional abuse, sexual abuse, physical abuse and emotional neglect.
- The ACE programme is great but the demand for this is high.
- There needs to be programmes/packages for the whole family. The whole family needs to be supported and included.

- There are no longer free sporting activities for children and young people. This is linked to the savings which Sefton MBC has had to make. Years ago, there would have been sports clubs and activities during school holidays and after school and they are no longer available for free. Now there are costs attached and many families are unable to fund this. This is why children tend to stay at home more and don't undertake exercise. The barrier is the cost of getting involved.
- More funded exercise activities need to be available. This may encourage and motivate families to get involved. The added benefit of funding activities is that this may help to increase the number of children and young people taking part in exercise activities and will support the obesity agenda.
- There needs to be more education and support in place to encourage children and young people not to engage in gun and knife crime. The same needs to be in place for drugs and alcohol.
- In general, there needs to be more accessible services for young people across the borough and this will take a lot of work.
- Youth centres have been closed/taken away and there needs to be more leisure provision.

Learning disability and Autism services

- There was a discussion about what is the offer for people with learning disabilities or autism.
- There appears to be different levels of support for different children and young people.
- There is some social support. Aiming High is in place but this is currently being reviewed as part of restructure work.
- Sexual Health Promotion has been providing input for some time now and there is good partnership working.

Mental Health services (CAMHS)

- For children and young people within the service, the service is good. There is however, a massive gap for those children and young people who do not meet the criteria.
- Mental health support for children and young people not in education or training is one of the big gaps in the borough.
- There needs to be more services in place which support children and young people who do not meet the criteria for CAMHS.
- There should be more access to information and support which is available online. Examples given were more question and answer areas and access to local information.
- *"We are not supporting the children who are 'in bed now'. We need to capture the voice of vulnerable children and young people."*
- There needs to be an increase in referrals into the service from clinicians in sexual health.

Sexual Health services

- Children and young people are becoming sexually active earlier and there is a problem with STIs. A lot of work is being undertaken in this area but it doesn't appear to be working.
- There is a local gap in the availability of support groups for young mums in the area. There used to be more support and earlier targeted intervention is needed.
- It was observed that there is increasing sexualised behaviour in children and young people.
- What is working well more joined up commissioning within the Public Health Team. This has meant better dove-tailing of tendered specifications that cross-reference each other e.g. 0-19 Team Health & Sexual Health collaborative work delivering C-Card and Chlamydia screening. The tender includes preventative (sexual health promotion) as well as the specification for a clinical service. This is quite unusual - but joined up again. Sexual health

has just reorganised times and a new location has been opening in Bootle (April 2019). Monitoring of this is underway for patient satisfaction.

- It is harder to negotiate with services who are not being performance managed by KPIs on which Sexual Health can support. Initially this has been an issue with council services, but this has recently been a much-improved situation since the Early Help reorganisation. Joint training and roll out of sexual health are now signed up to and being introduced.
- Travel issues across a borough wide service.
- Keeping up to date on the service changes of other organisations.
- For a community service, closer partnership working and agreement to share or sign up to other Trust policies and PGD (Patient Group Directions) would be useful. Initially the service was part of the same PCT as other community health (HVs, school nurses etc) and it was easier for these teams to adopt or share targeted work. Community Health is now delivered by our ICO, Mersey Care & NW Boroughs (might be more).
- More joint working built into service specifications.

Health and social care support within educational settings

- There is increasing evidence that children and young people are sharing indecent images of their bodies via text, etc. and the impact on children and young people's mental health needs to be addressed.
- There used to be PSHE sessions/days held in school and they were really good in targeting issues/raising awareness. They were really good and more sessions like this need to be held.
- Local hospitals have educational programmes and they should be run in schools, where they will have large audiences.
- In some primary schools they used to hold sessions called 'circle times'. The sessions provided an opportunity to have open and honest discussions. They don't hold sessions like this in secondary education where they are needed the most.
- There needs to be more targeted discussion times/sessions for male students.
- For children with Diabetes, this long term condition is being supported more and more with the use of technology (e.g. pumps). Teachers don't have the experience to understand or deal with this. For children and young people with Diabetes, blood sugars can have a direct impact on behaviour and teachers don't appreciate this or take this into account.
- Example provided of psychological input in the Diabetes clinic, 'Solution focused therapy'. This therapy is centred on working through a problem and then working on a solution together. This service would be valuable to all children and young people with long term conditions.
- Some schools have a school nurse on site and some do not. A standardised approach needs to be adopted across all schools. They need to be more visible. It was felt that there should always be a medic on site.
- A better coordinated approach to these settings is needed in the way Healthy Schools used to do. This could allow for quality control on external providers within schools but also to allow for joint delivery of risk prevention work etc.

healthwatch

NHS Long Term Plan Report

Chapter 8 - Healthwatch St Helens

what would you do?

It's your NHS. Have your say.

St Helens

Historically part of Lancashire, St Helens is now part of Merseyside and became a Metropolitan Borough in 1974. The Borough of St Helens covers approximately 12 square miles and has a population of more than 178,000 people. Previously a thriving industrial town, St Helens now faces high levels of unemployment. The quality of life for people in St Helens varies, with significant inequality in life expectancy between the most affluent and most deprived areas; 7 years for men and 9 years for women. Challenges faced include an ageing population, poor mental health, high suicide rates, alcohol dependency, respiratory conditions and high rates of cancer. The number of people who are overweight, obese or living unhealthy lifestyles are also a concern.[10]

In St Helens we received 416 survey responses, consisting of 272 general surveys and 144 specific conditions survey responses. There were also 23 attendees across two specific focus group events.

St Helens

Cheshire & Merseyside
Health & Care Partnership

"Be the reason someone receives better care today"

If St Helens was a village of just 100 people...

38 Children are overweight or obese by year 6

18 Adults suffer from depression

10 5-16 year olds have a MH disorder

27 Will die from cancer

72 Adults are over-weight or obese

3 Adults under 40 have Type 2 diabetes

58 people are living with a long term condition

12 Will die from heart disease

19 Are smokers

81 Is the average age that women will live to

26 People take less than 30 mins exercise a week

78 Is the average age that men will live to

9 People are over 75

Statistics from PHE are for the St Helen's Local Authority area, pop: 177,000

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[10] *Source: St Helens Joint Strategic Needs Assessment 2018.* https://info4.sthelens.gov.uk/strategic-assessments/jsna

Summary of Findings

- When considering how to live a healthy life, having access to the help and treatment needed when it is needed was deemed to be most important by people responding to the survey.
- However, 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 needed.
- We asked respondents to think about one more thing that would help them to lead a healthy life. Emerging themes included factors relating to GP appointments (accessibility and quality), environment and infrastructure, support with health and wellbeing and prescriptions.
- 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.
- 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. Emerging themes included factors relating to home and community support (particularly relating to complex conditions) and end of life.
- People 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.
- 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. Other factors included information and advice and funding.
- People in St Helens 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. Making use of technology to book appointments and to communicate results quickly and having absolute confidence that personal data is managed well and kept secure were also considered important by people.
- Other factors relating to technology, communication and accessibility were also deemed as important to respondents.
- Specific focus groups around mental health services showed that community mental health services were good, waiting times were too long and there should be more support offered for families and carers.

Survey results

The following sections now break down the results of the 416 responses across St Helens to the surveys designed by Healthwatch England. The first sections use the 272 responses to the general 'People's general experiences of health and care services' survey, before breaking down the 144 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.

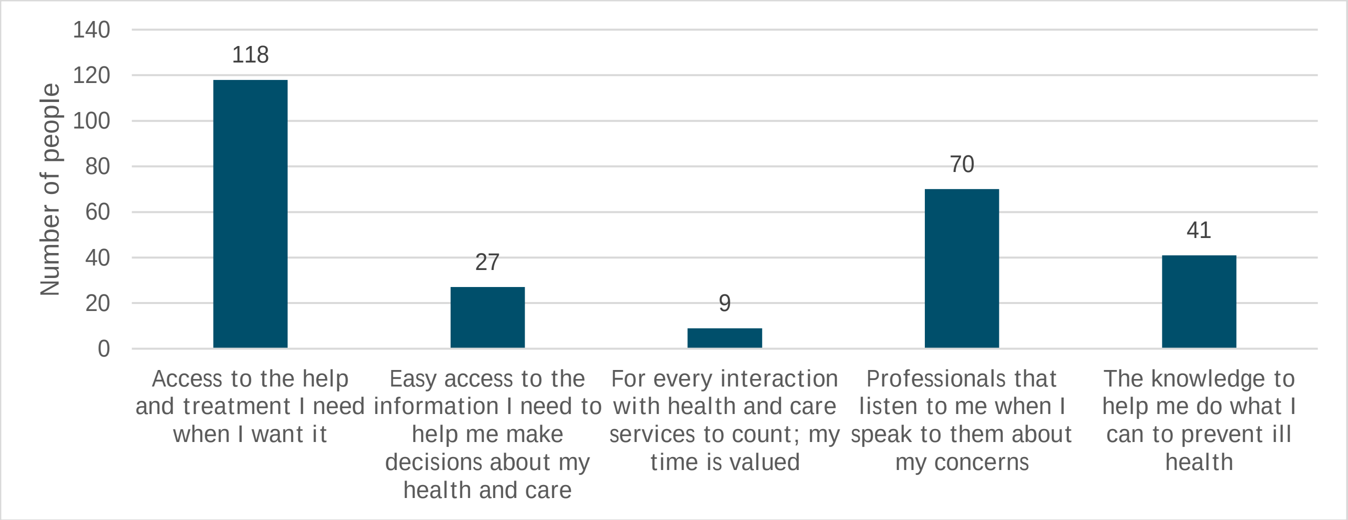
For each of these, people were asked to choose which of a number of options was most important to them. Following this, people were asked to rate each of the options on a scale of 'very important' to 'not important at all'. Therefore, more than one option could be considered 'very important'. Finally, 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 needed was deemed to be most important by people responding to the survey (see Chart 1). 265 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 needed. However, it is also important to note that all 5 statements were deemed as very important or important, as the table below shows. Up to 271 people responded to this question, though 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	230	33	5	1	0
Access to the help and treatment I need when I want it	227	41	2	0	0
Easy access to the information I need to help me make decisions about my health and care	179	78	12	2	0
Having the knowledge to help me do what I can to prevent ill health	178	81	1	3	1
For every interaction with health and care services to count; my time is valued	173	78	12	3	0

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:

GP Appointments

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

- *“Being able to see a doctor. As soon as I am ill.”*
- *“Reducing GP waiting times for an appointment and being referred to the correct hospital department to see specialists instead of readily handing out medications.”*
- *“Access to GP appointments when required. Consultant telephone appointments (similar to GPs). Cross hospital communication.”*
- *“Easier access to health care e.g. better GP appointments, easier to obtain.”*
- *“I think shorter waiting times and the ability to get a doctor’s appointment when needed.”*
- *“Be able to get a Doctor’s appointment when I need one”*
- *“Waiting for mental health team, especially when in crisis.”*
- *“To be able to see a doctor in emergency or even get an appointment when I need one.”*
- *“Less waiting time to see doctors.”*
- *“To get help when I need it the most.”*

- *"Ready availability of relevant knowledge."*
- *"Easier access to GP services."*
- *"Less waiting lists for referrals with agencies."*
- *"To be able to actually get doctors' appointments."*
- *"More available doctors' appointments."*

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

- *"More places to go if I am ill."*
- *"NHS is great but needs more staff, money and resources. I am happy with the treatment they have given me so far."*
- *"Get an appointment with your preferred doctor."*
- *"More counsellors that actually listen to me without using C.B. T. & actually listen to what I say."*
- *"To have a choice of support groups for conditions."*
- *"An annual invitation for a general check-up. This would help to pick up any problem more quickly and efficiently."*
- *"Health carers having time to speak to me to check my health."*
- *"More support and local, easy/easier access for help with mental health."*
- *"Professionals who take time to listen is paramount, as well as being believed. My cancer was missed until I only had weeks to live because my GP disregarded my symptoms. Further, greater access to mental health practitioners. It seems quite common to have treatment but left to get on with things. Some access to a counsellor would be helpful. Also, more counselling facilities to teenagers who seem to be struggling."*
- *"Speedy healthcare"*
- *"Access to additional resources to prevent ill health."*

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:

- *"More money to make the right choices."*
- *"Better access to fresh fruit."*
- *"Locally based exercise classes."*
- *"Free gym for over 18's."*
- *"Access to affordable healthy foods and leisure facilities."*
- *"Less takeaways and fast food outlets would help (less temptation)"*
- *"Discounted gym membership."*
- *"Access to free fitness activities or better cycling paths."*
- *"Easier access to free/local leisure and exercise facilities."*
- *"More opportunity to be active. Better sports and social facilities."*
- *"Free classes for exercising."*
- *"Access to physical health groups."*
- *"More accessible and affordable community activities for adults."*
- *"Affordable access to fitness classes, provision made by employer."*

- *"More safer cycle routes."*
- *"It would be to continue my weight loss, to reduce risk of diabetes."*
- *"Access to affordable exercise options."*
- *"Stop putting chocolate and unhealthy options at the end of check outs."*
- *"Cheaper healthy food, as not everyone can afford to buy healthy food."*

- *“Having a balanced diet.”*
- *“More exercise classes for the elderly.”*

Support with health and wellbeing

Respondents also commented that they would like support and advice to help them improve their health and well-being, whilst others mentioned they would like more support to maintain good services and wider aspects of their health. Comments included:

- *"Support to lose weight.”*
- *“More information on living a healthy lifestyle.”*
- *“Meal plans and diets supported by health visitors and doctors (our doctors).”*
- *“I am lucky, I am very healthy. Keep investing into the NHS.”*
- *“Having others around me supporting and encouraging me to eat healthily and be active.”*
- *“Developing my knowledge further to help promote wellbeing.”*
- *“My local NHS is excellent for all aspects of physical care, but mental health services are poor and limited.”*
- *“Online access to healthy lifestyle information.”*
- *“Access to diet plans. Nutrition advice in schools and colleges.”*
- *“A drop-in centre where I could seek help with weight loss.”*
- *“Better education and information about food nutrition and an easier way to make informed choices regarding food consumption.”*
- *“I think more help to lose weight.”*
- *“Healthy eating guidance at an early age.”*
- *"Cheaper organic food.”*
- *“Fortunately, at the moment, I don't think I have any significant health issues but I would appreciate an annual general check-up just to make sure that there is nothing of concern. This could also alert me to any likelihood of problems developing.”*

Prescriptions

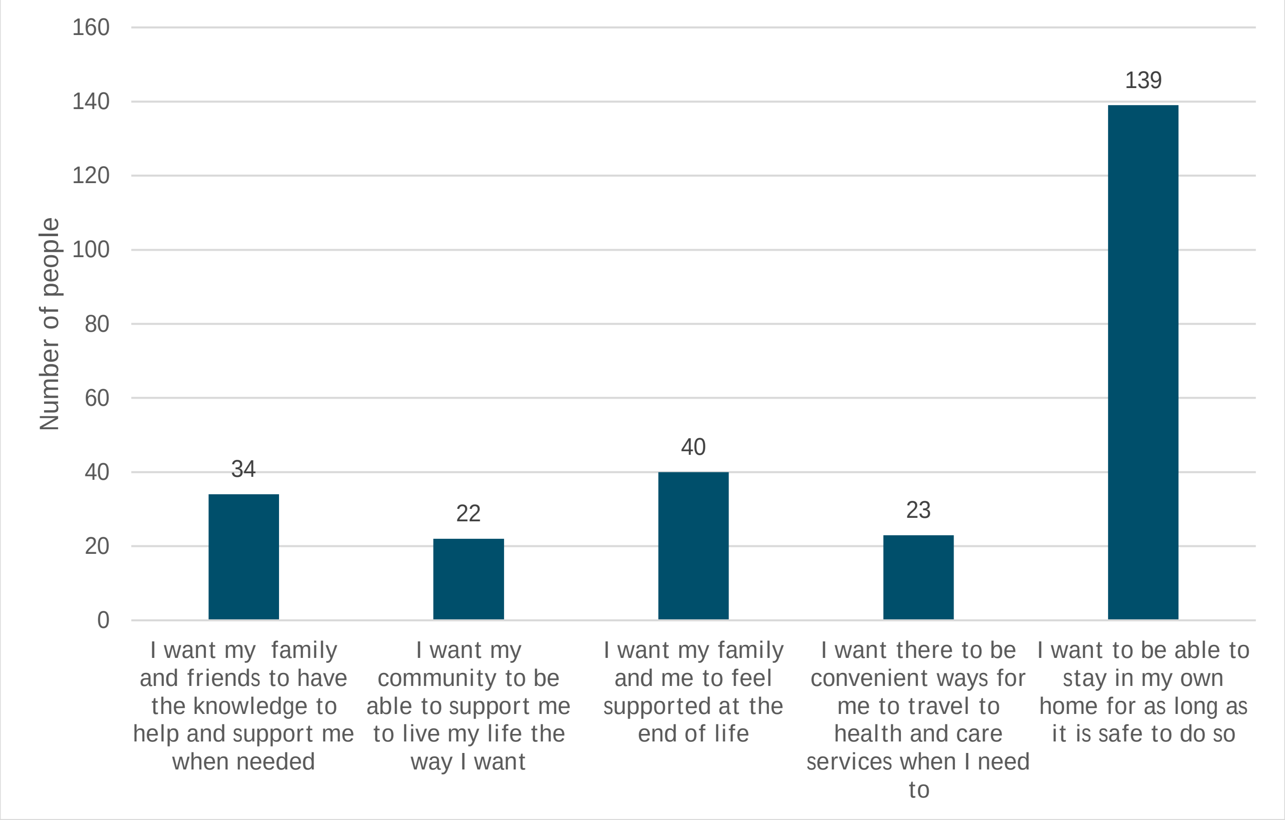
Where medication formed part of people’s healthcare, some told us that easier and cheaper access to their prescriptions or working towards a situation where they would not need them would be beneficial for them:

- *“Free prescriptions.”*
- *“Easier to get my prescriptions. I have to go in my doctors every month and order it. I work and look after my child. I want my prescription to be automatically sent to my pharmacy each month.”*
- *“Hospital prescriptions should be allowed to be dispensed at a chemist there for freeing beds quicker.”*
- *“Free or discounted prescriptions and less waiting lists for referrals with agencies.”*
- *“The cost of prescriptions is very high. I have 4 items on it every month. It's not cheap to have a chronic illness.”*
- *“GP's recommending patients access groups that encourage healthy lifestyles, counselling and mentoring rather than prescription medication.”*
- *“The return of proper physio therapy sessions, prescription pain killers would be vastly reduced.”*

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). 258 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 269 people responded to this question, though 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 my family and me to feel supported at the end of life	219	38	1	2	3
I want to be able to stay in my own home for as long as it is safe to do so	213	50	2	4	0

I want my family and friends to have the knowledge, to help and support me when needed	192	64	8	1	2
I want there to be convenient ways for me to travel to health and care services when I need to	183	70	13	0	1
I want my community to be able to support me to live my life the way I want	147	94	20	7	0

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 question, 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:

- *“Properly regulated care assistance in the home, the companies that care is contracted to are shocking, the standard of care is neglectful and extremely poor.”*
- *“Community nurses to have greater power/higher decision making to help older people at home, who are receiving treatment. Rather than an over reliance on GPs and locums.”*
- *“The correct accommodation.”*
- *“Home safety, such as aids and adaptations and information on this.”*
- *“More health care by professionals in your own home e.g. more Doctors' visits, more involvement by social services, health visitors and community nurses.”*
- *“Access to home support services. Support from experienced and well-trained staff.”*
- *“A Community Psychiatric Nurse to come and see me.”*
- *“A professional call regularly to check all is ok.”*
- *“Adapt more accommodation for mobility and extra support to aim for provision of independent living.”*

Community Support

A number of respondents commented on the need for community support to enable them to stay healthy as they get older, mentioning that already available services could be recommended more widely:

- *“Better community services.”*
- *“Community health care is vital. This needs to be adequately resourced if people are to stay in their own home.”*
- *“Community health workers.”*
- *“More community services that are cheaper for pensioners.”*
- *“Free community transport for older people.”*
- *“Community exercise classes - aged/ability related.”*
- *“Stay in community as long as safe to do so!”*
- *“More community care NHS more access to keeping myself and others as much as independent as possible if poorly or disabled.”*
- *“I would like to highlight the programmes put in place by our St Helens Council Sports Development Team. Now in my late 60s, I have taken part in their "Couch to 5K"*

programme. As a result, not only can I complete a 5K run but this year I also took part in (and finished!) the St Helens 10K. Both my fitness and self-esteem have improved dramatically. This should be recommended."

- *"Recently available local activities, to be widely recommended."*

Care for complex conditions and end of life

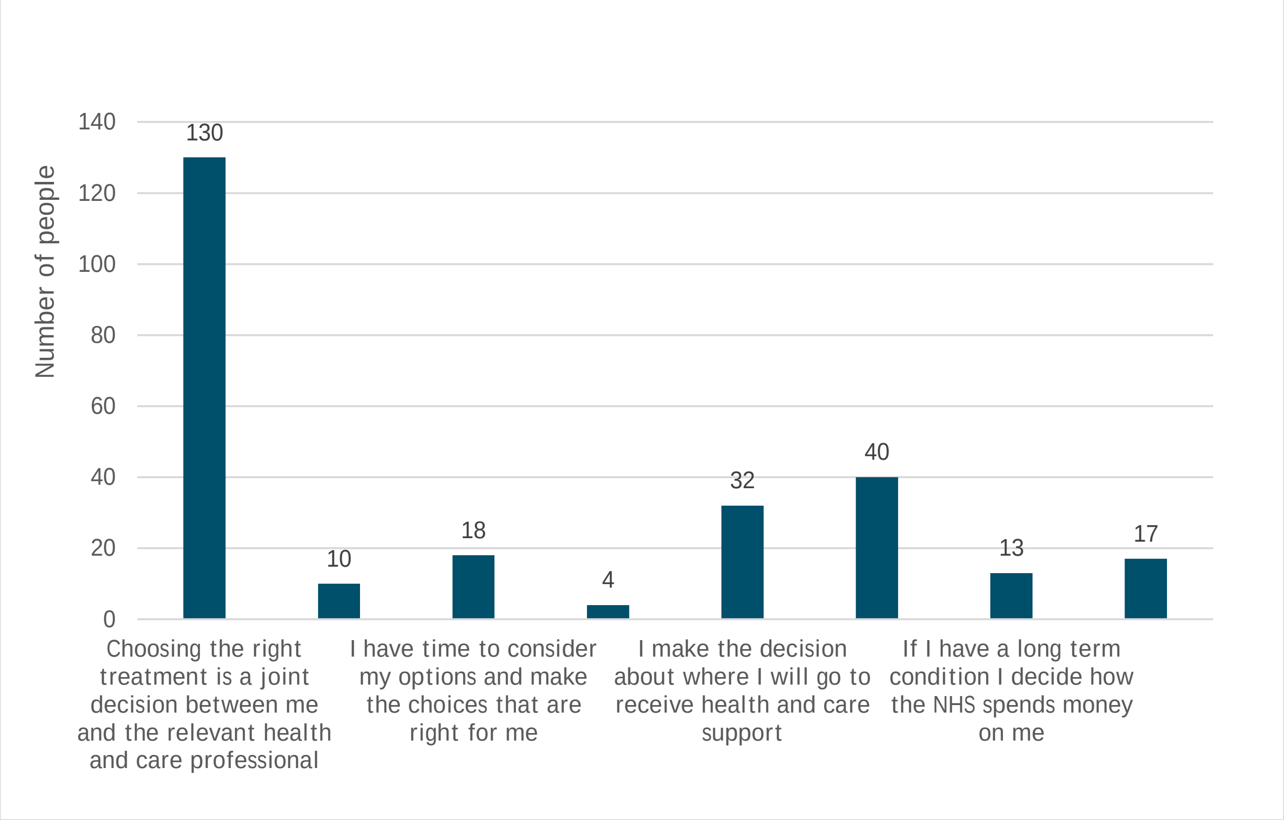
Some respondents went into more detail about care in the later stages of life, expressing a desire to have more control over their options and managing complex care at the end of life.

- *"More palliative care available."*
- *"Having options for living if health ever becomes too much for my family to care for."*
- *"Be able to choose when and where to die when I'm older."*
- *"Knowing I had a right to die at a time of my own choosing."*

Managing and choosing support and treatment

Chart 3 shows that people we spoke to in St Helens 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. 264 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 and choosing the right treatment as a joint decision between them and the relevant health and care professional as very important, as well as having ample time to consider their options for care. 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 269 people responded to this question, though not everyone 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 the relevant health and care professional	171	78	18	1	1
Communications are timely	168	81	16	1	0
I have time to consider my options and make the choices that are right for me	160	80	25	0	0
My opinion on what is best for me, counts	145	90	26	4	2
I should be offered care and support in other areas if my local area can't see me in a timely way	144	103	14	5	1
I make the decision about where I will go to receive health and care support	123	98	36	10	2
I make the decision about when I will receive health and care support	116	100	44	8	1
If I have a long-term condition, I decide how the NHS spends money on me	91	84	72	10	9

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:

- *"Communications are correct and joined up across those involved in treatment e.g. hospitals, GPs."*
- *"Good timely and clear communications."*
- *"To listen to what I say."*
- *"Ability to have one to one with healthcare professional."*
- *"Better access to GP appointments, and GPs having sufficient time to undertake a thorough consultation."*
- *"My opinion being listened to."*
- *"Find a GP that actually cares about my health. Contact me at regular intervals to see if I'm OK besides me just putting in prescriptions, because I may not be able to attend the surgery with the way that I'm feeling e.g. depressed, anxious & stressed."*
- *"Being given different treatment options/plans when possible to see which would be more beneficial."*
- *"Better communication, for example I was referred to hospital four months+ and I have never heard anything."*
- *"To listen to you when you're telling them about your problems."*

Information and advice

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

- *"More information about what is available."*
- *"More information on what is available and a single point of contact."*
- *"Know where to go for what."*
- *"Relevant local availability of knowledge and support."*
- *"A greater understanding of what services are available and how they can be accessed."*
- *"Have more information to make the choice and more time with professionals to they can support you."*
- *"Round the clock help and advice services."*
- *"It would be to have an NHS in each or certain areas for us to go and get the information we need as although it is on the Internet it can be properly explained by a doctor or GP."*

Funding for, and availability of services locally

Furthermore, people told us that they would like to access appointments in a quicker, more efficient manner over a greater range of times. Additionally, people told us they would like to spend more time discussing their health with professionals. For example:

- *"I would like to be seen in a week if needs be."*
- *"Faster access to GPs."*
- *"Ability to have more of one to one with healthcare professional."*
- *"Better access to GP appointments, and GPs having sufficient time to undertake a thorough consultation."*
- *"Speedier access to GP, even by telephone. I'm having to wait two weeks for telephone consultations."*
- *"If you are referred to a service this referral should be dealt with in a timely manner and professionally."*
- *"Better online access to appointments."*
- *"More access to provision weekend/out of hours."*
- *"I would like to be able to choose to see my own GP instead of who is in that day."*
- *"Easier access to GP (i.e. during non-traditional working hours)."*

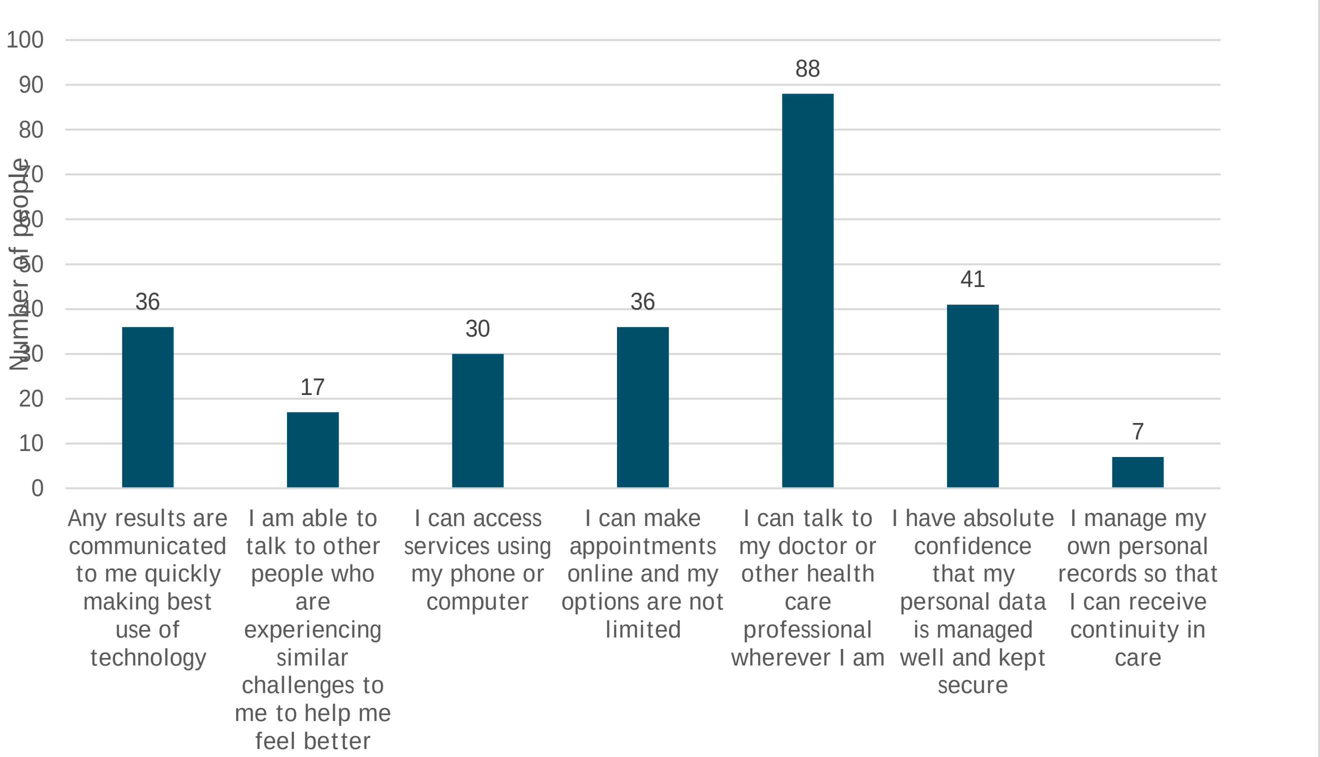
Engaging people in health service delivery

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 St Helens 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. Making use of technology to book appointments and to communicate results quickly and having absolute confidence that personal data is managed well and kept secure were also considered important by people. 255 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 266 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
I have absolute confidence that my personal data is managed well and kept secure	180	58	25	2	1
I can talk to my doctor or other health care professional wherever I am	160	76	24	4	1
Any results are communicated to me quickly making best use of technology	158	85	16	2	3
I can make appointments online and my options are not limited	148	72	30	7	5
I can access services using my phone or computer	134	95	30	5	4
I manage my own personal records so that I can receive continuity in care	110	95	48	9	4
I am able to talk to other people who are experiencing similar challenges to me to help me feel better	94	96	53	17	6

Accessibility

Responses regarding the use of accessibility in health and care were mixed, where some people told us that they would like to see faster referrals and quicker access to GPs and other primary care services. They also commented that they would like to see more accessible services and information regarding test results and available services in their area. Comments included:

- *“To have your own doctor Instead of multiple people you don’t know.”*
- *“Being able to get a GP appointment quickly is the most important thing to helping me manage my health. “*
- *“Easy to understand words.”*
- *“Booking appointments is still very difficult, as I feel that I have to telephone for hours or travel to the doctors before they open to book an appointment as its quicker than telephoning.”*
- *“Easier access to pharmacies for prescriptions - Nightmare!”*
- *“Easier access to diabetes professionals.”*
- *“Easy information to access what is available.”*

- *"To be able to request private tests directly e.g. blood test for a genetic screen without having to go through a GP."*
- *"More doctors' appointments available, more education i.e. diet."*
- *"GP appointment earlier than 10 days."*
- *"Better/faster access to information/services."*
- *"Someone who would advocate medically for me."*
- *"Mandatory health checks. Wellbeing checks that monitors all areas of my health rather than just the areas of concern."*
- *"We need to get away from having to telephone the GP every morning to try and get an appointment."*
- *"We should be able to pre-book."*
- *"Access to care more locally."*
- *"Doctors with no appointments. Not like a walk-in centre where you need a few stitches etc. Say if you have a stomach bug and need to see a doctor that day."*
- *"Having doctors nearer to where you live."*

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 with a range of services, whereas others felt that they would like to see less technology and more face to face communication, being mindful of those who are less capable with the use of technology. Comments included:

- *"It would be great to book an appointment online and be able to choose between a doctor or nurse, whilst knowing who can prescribe/help you with treatments."*
- *"For my GP surgery to more technologically minded. You used to be able to book appointments online, which was an asset when I was looking for a new surgery, but it no longer works. This is really disappointing, as it can take up to 4 hours to get through to the GP, only to be told there are no 'on the day' appointments left and the nearest pre-bookable appointment is a month away."*
- *"Make GP arrangements on current day via computer, rather than constantly ringing before 8.30 am to speak to a receptionist."*
- *"Online consultations and online pharmacy."*
- *"It is important to me that individuals are not disadvantaged because they cannot or do not wish to use computers or other technology. Access for face to face consultations should always be available."*

Communication

Some commentary concerning communication crossed over with that on accessibility and technology. People shared with us their preferences on most effective methods of communication, closer two-way communication with their GP and relationships between their GP and other services that they use:

- *"Better communications for my doctors. Cannot get through."*
- *"Having closer clinics to go to get help and support."*
- *"Have more knowledge of what's going on if I am ill and be told results quick enough."*
- *"Being able to receive test by text/phone, freeing up appointments for patients with faulty results."*
- *"Communication currently is poor; I have received appointment letter with appointment dates in the past!"*
- *"Perhaps there is now too much emphasis on telephone consultations. I know that the traditional face-to-face consultations I have had recently have been more beneficial."*

- *"Better communication methods available between GPs and patients."*
- *"The NHS also using technology better, e.g. more online consultations or outpatient appointments either more local or by on line."*
- *"For healthcare professionals to ensure that they give me information in a format i can understand."*
- *"To have copies of letters to/from healthcare professionals so that I am kept fully informed."*
- *"Better ways to communicate with health professionals e.g. being able to leave messages rather than having to wait for appointments, also better ways to access hospital feedback rather than waiting weeks for GP appointments to discuss results."*

What people expect during service transformation and change

Respondents to the survey also provided us with an insight into their thoughts around what already works well and what could be improved upon. A number of these comments have been highlighted below:

- *"I use the NHS a lot for long-term health issues. Accessing a GP quickly is very important, face to face, please, not Skype or the phone. My GPs do listen to me mostly. I have concerns about the treatment I get at hospital as an out-patient as I have long waits, a long commute there and I tend to see different health professionals with different views on how my illness should be managed, meaning progress is frustratingly slow and treatment inconsistent. Continuity of care and access to different/newer treatments would be a massive help in managing my health when existing options have been exhausted, for example, liaising with other doctors elsewhere in the NHS who may have a different approach to treating an illness."*
- *"Too much management and not enough staff - not enough people at the sharp end - too much middle management."*
- *"Funding needs to be looked at making sure it will not harm the NHS. We also need to encourage more UK residents to join and work for the UK as I think taking the best people from other countries is wrong."*
- *"Mental Health Services need huge investment!"*
- *"Taking responsibility for one's own health is crucial and to have the relevant knowledge is central, including widening our perspectives to include eastern medicine explained and interpreted in a western light."*
- *"Ideally we might expect more resources and a greater availability of resources, but we should acknowledge that possibilities for improvement are finite."*
- *"Patient knowledge is essential, having this is a measure of how well local services are available and funded."*
- *"My husband has cancer and his treatment and care has been fantastic. Thank you to all."*
- *"In our experience, we have absolute confidence in saying that the NHS has provided us with exceptional care. We cannot praise the work, dedication of all departments in the care and aftercare received by my husband enough. Any improvements would be welcome to an already outstanding service."*
- *"Increasing use of community services needed should be focused on independent living, improving wellbeing."*
- *"I have many complex needs and I am non-verbal, so I totally rely on others to convey my needs and how I am presenting. Experience of people with learning disabilities would be an advantage to any health professional."*
- *"Current systems often make me feel like a number or statistic rather than an individual. Staff are usually caring and obviously trying to help but often thwarted by the systems within which they have to work."*

In focus: what is important to local people about Health and Care Services?

As part of our research Healthwatch St Helens carried out a focus group with local people to gain some further insight into their views concerning the NHS Long Term Plan. It was an opportunity to hear the views of a wide range of people, who didn't necessarily fall into a particular category.

The focus group was held on the 24th April 2019 at The Beacon, College Street, St Helens. The focus group was attended by 12 members of the public and facilitated by four Healthwatch St Helens staff.

The focus group was also attended by two members of the St Helens CCG Engagement team who delivered a presentation about what's happening locally to improve services. Below is a summary of the key points raised during the session:

- People in general cannot get appointments to see a GP without waiting for 3 weeks+. When they do get an appointment, it is rarely the same GP.
- Communication is identified as poor between health professionals. Patients report professionals having no idea of test results.
- Poor referral systems to specialists/consultants.
- Comments about acute care providers are generally positive, from the appointments coming through quickly to extended hours.
- Hospital appointments are now available in the evenings and at weekends. Don't need to take time off work.
- Additionally, people felt that is was important to consider:
- Improving and expanding community services to keep people well and support people to stay out of hospital
- Treating mental health equally in terms of funding, research staff training.
- Having regular and ongoing appointments for people to learn about nutrition is the key way to maintain healthy body and mind.

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 144 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	12
Dementia	3
Heart and lung diseases	18
Learning disability	4
Long-term condition e.g. diabetes, arthritis	57
Mental Health	47

Table 6: Who are you responding on behalf of?

Condition	Myself	Someone else
Autism	2	1
Cancer	10	2
Dementia	1	2
Heart and lung diseases	16	2
Learning disability	2	2
Long-term condition e.g. diabetes, arthritis	51	5
Mental Health	43	4

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

Condition	Yes	No
Autism	0	3

Cancer	9	3
Dementia	3	0
Heart and lung diseases	9	6
Learning disability	2	2
Long-term condition e.g. diabetes, arthritis	18	39
Mental Health	16	29

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	Not applicable
Autism	0	0	1	1
Cancer	8	3	1	0
Dementia	2	0	1	0
Heart and lung diseases	12	1	2	1
Learning disability	2	1	1	0
Long-term condition e.g. diabetes, arthritis	27	10	16	1
Mental Health	9	18	19	0

Tell us whether the support met your needs and how it could have been improved.

Autism

- *“My local GP had little understanding of autism making getting an appointment to be tested a challenge.”*

Cancer

- *"I spent 3 months going to the GP and was repeatedly given antibiotics but no blood test. My friend took me to A&E.”*
- *“I was admitted, quickly diagnosed spent most of the next 6 months in hospital. Whiston hospital were superb.”*
- *“When I was first diagnosed with cancer, I saw a consultant 10 days later, the operation and radiotherapy plan was put in place and commenced two weeks later.”*
- *“Felt a little shell shocked and needed a helping hand to process the information - more help to do this would have been good.”*
- *“Needs not always met. Information about my condition was poor. Felt unsupported at times”.*
- *“Everyone was very helpful and caring.”*
- *“Felt that once I got diagnosis of terminal cancer, I was left abandoned, nothing can be done.”*

- *"My support was brilliant."*
- *"Not able to talk, feel I was not taken seriously."*
- *"Support was comprehensive and very helpful."*

Dementia

- *"Both my husband and I are profoundly deaf and we required someone to ring for us and request an interpreter at the appointments and 6-week course."*

Heart and lung diseases

- *"I was referred to a consultant quite quickly."*
- *"Happy with the support given - and available. Annual attendance at GP Asthma clinic - reminder letter always sent out.; medication always ordered through Patient Access."*
- *"Good support always to meet my needs."*
- *"Bad communication between hit and miss surgeons."*
- *"My Brother was diagnosed with a heart attack and as the family have a history of heart issues (heart attack and stroke) he was seen immediately and had 5 stents put in place. As a result, his children have also undergone appropriate tests so a very positive outcome."*
- *"Waited too long before getting appointment to see consultant after undergoing relevant tests, scans etc. Therefore, suffered a heart attack."*
- *"My support was brilliant."*

Learning disabilities

- *"My child's condition is a result of duplicate chromosome. Unfortunately, his condition had not been as widely researched as we would have wanted, ergo the assistance available was not the greatest."*
- *"Long time getting the right support. Information given about my daughter's condition in a very blunt manner."*

Long-term condition e.g. diabetes, arthritis

- *"Type 1 diabetes is a neglected condition - grouped with type 2 diabetes and managed at primary care level, which practice nurses do not have the skills or experience to do. Education courses provided over a number of weeks in the day time don't work for working age people - the main group of type 1 diabetics."*
- *"Getting a diagnosis was too long and took over 6 months before a consultant decided to do some bloods."*
- *"My GP referred me to hospital appointments all came through within 3 weeks."*
- *"Had a stroke and was taken to a hospital outside the borough. When discharged there were a few problems being discharged back to my own borough, but once these were resolved the care was good."*
- *"I find the support I get for my diabetes isn't too bad but as for mental health it is disgraceful. I've been left untreated and neglected by mental health services. No help or support at all."*
- *"No real support for people with scoliosis - GP didn't know who to refer me to - pain clinic eventually. Bad communication between hit and miss surgeons."*
- *"Had a stroke and fell. Managed to ring 999, came straight away."*
- *"Took quite a while initially to have an MRI scan and diagnosis - after 6 months of physio and reached a plateau. Recently due to deterioration I've had investigations and another scan which have been quicker."*

- *"No. It took a long time to be referred to a dermatology specialist, following a severe flare-up of eczema."*
- *"Able to see GP regularly, now it is only telephone consultations, no real feedback from others tests that have been done."*
- *"Needs were completely met."*
- *"I got referred and was seen really quickly."*
- *"No-one listened to what I was telling them."*
- *"Lots of backwards and forwards to establish care needed. Then having to argue and demand meetings with people who can make decisions, regarding funding. Practical help with items needed was much easier."*
- *"It's a constant fight to access the treatment required."*

Mental Health

- *"Waiting lists too long and then a limited time for appointments. I felt just as I was becoming used to the counsellor and opening up, my sessions were over and was told if I needed anymore, I would have to go back on the waiting list."*
- *"I have received no support other being 'observed'."*
- *"Standard methods not tailored to meet individual needs. GP not interested until repeated visits."*
- *"Faster access to mental health team and more individual help rather than standard methods."*
- *"Doctors referral for help with mental health. 1st day dismissed. 12 months later re-referred. Got help 6-12 weeks CBT."*
- *"Most of the time I get the help and support I need, but some of my referrals I struggle with because I find it hard to talk on the phone when making self-referrals would prefer it to be done by doctor."*
- *"I find the support I get for my diabetes isn't too bad but as for mental health it's disgraceful. I've been left untreated and neglected by mental health services. No help or support at all.*
- *I didn't know where to go for the help and was not confident sharing information."*
- *"Access to services is quite difficult in order to assess your needs it requires you seeing a GP then talking to an assessment officer to then be placed on a waiting list for treatment which can be anything up to a few months. When in crisis and suffering the only service is A&E which is not ideal with a mental health condition. Services need to be more accessible and support a wide range of conditions more quickly and efficiently."*

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	1	2	0	0	0
Cancer	7	1	1	2	1	0
Dementia	1	2	0	0	0	0
Heart and lung diseases	10	3	4	1	0	0
Learning disability	0	0	3	1	0	0

Long-term condition e.g. diabetes, arthritis	12	16	18	6	4	1
Mental Health	3	11	16	11	5	1

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

Condition	Yes	No
Autism	2	1
Cancer	7	5
Dementia	2	1
Heart and lung diseases	12	6
Learning disability	3	1
Long-term condition e.g. diabetes, arthritis	37	19
Mental Health	30	17

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	0	1	0
Cancer	1	4	1	0	0
Dementia	0	1	1	0	0
Heart and lung diseases	2	3	4	1	1
Learning disability	1	1	0	0	1
Long-term condition e.g. diabetes, arthritis	5	16	11	2	2
Mental Health	2	15	10	2	1

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	0	2	0	0	0	1
Cancer	2	3	1	4	2	0
Dementia	0	0	1	2	0	0
Heart and lung diseases	2	3	1	8	4	0
Learning disability	0	2	1	1	0	0
Long-term condition e.g. diabetes, arthritis	6	14	15	15	5	0
Mental health	12	13	12	7	3	0

Please tell us about the length of time you waited.

Autism

- *"Due to a GP error it took a while to get an appointment."*

Cancer

- *"GP very poor just kept writing a prescription and saying go away. Did not try to get to the bottom of the problem."*
- *"Within one month of diagnosis I had had the operation and started radiotherapy."*
- *"Within a couple of weeks."*
- *"No-one available to answer my questions."*
- *"I was seen quite soon after my GPs referral - probably about one month."*
- *"Slipped through the net first time but was seen very quickly after diagnosed."*
- *"Not taken seriously was my view because I can no longer talk."*
- *"On diagnosis it was almost immediate."*

Dementia

- *"After waiting for a test/assessment appointment about 6 weeks".*

Heart and lung diseases

- *"I got support as soon as I left the hospital, so didn't have to wait."*
- *"Within weeks."*
- *"Immediate at first then regular short periods. 1st class support."*
- *"Three weeks."*
- *"Waited over six months. Paid privately to see consultant before seeing NHS consultant. I had my heart attack a day before finally getting appointment for NHS consultant waiting 9 months since diagnosis."*
- *"Can't remember exactly how long I waited. Ended up paying privately to speed processes of diagnosis and treatment."*

- *"Moved quicker than expected."*
- *"4 months"*

Learning disability

- *"We have had numerous incorrect diagnoses due to the lack of research in this particular area."*
- *"3 months"*

Long-term condition e.g. diabetes, arthritis

- *"Immediate support on leaving hospital."*
- *"I got support as soon as I left the hospital, so didn't have to wait."*
- *"I had different appointments, time waiting 3 weeks to 8 weeks."*
- *"When dealing with my hyper mobility was not too bad as it was seen to pretty quickly by my GP."*
- *"For arthritis it was fast."*
- *"6 months"*
- *"Years"*
- *"As I had a fall, they discovered I had a stroke, which left me immobile. It was all immediate. In Walton then Whiston then rehab."*
- *"From start to finish - months and months."*
- *"Not long with GP but too long for different departments in hospital."*
- *"Around six months as originally thought just muscular. Felt I had to fight to explain the amount of pain I was in."*
- *"The first GP I saw kept deferring referral and then referred me to somewhere that only deals with life threatening conditions, so naturally I was rejected. My correct GP is excellent."*
- *"From start to finish matter of months."*
- *"My GP didn't know what to do with me - just various meds, changing them all the time."*
- *"Service fragmented not able to get to what is needed."*
- *"6 months between each appointment."*

Mental Health

- *"It takes a lot for me to ask for help and when finally, I manage the strength to do it, not physically but mentally, to be told, they understand and they will put me on a waiting list, that will be around 6 months. Go home and we'll contact you when an appointment becomes available, is not very helpful, in fact it's devastating."*
- *"Mindsmatter - waiting times a joke, I wanted to explain how I felt, too much like a job, no friendliness."*
- *"For mental health I would say slow."*
- *"I didn't wait very long to get a diagnosis."*
- *"I waited so long I ended up going to another agency."*
- *"Quick for surgery. Slow for mental help."*
- *"6 months for initial assessment, 12 months for placement (NHS IAPT services). 6 months for assessment (non-NHS service) 6 months for initial assessment following re referral then another 12 months for one to one placement (NHS IAPT services)."*
- *"Each admission was timely but follow up was poor and difficult to access."*
- *"Wait was not too long but back up has not happened."*
- *"Long enough for a GP appointment."*
- *"8 weeks"*
- *"4 months"*

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	0	1	0	1	0	0
Cancer	0	0	2	5	4	0
Dementia	0	0	1	2	0	0
Heart and lung diseases	1	2	2	3	6	4
Learning disability	0	2	1	0	1	0
Long-term condition e.g. diabetes, arthritis	4	10	20	11	5	4
Mental health	11	9	17	8	2	0

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

Condition	Yes	No
Autism	1	1
Cancer	10	2
Dementia	1	2
Heart and lung diseases	14	4
Learning disability	3	1
Long-term condition e.g. diabetes, arthritis	39	16
Mental health	28	19

If you accessed support what aspect could be improved?

Cancer

- *"I tried to talk to my GP practice about what happened. Response - Your condition was rare. You should have made a stronger representation and been more demanding. I did not know what was wrong. I was treating them with respect."*
- *"The nurses are over-worked and need more staff."*
- *"Take people with communication problems seriously, they are not stupid."*

Heart and lung diseases

- *"Publicise better."*
- *"Improving availability of NHS consultant appointments."*
- *"Information/communication."*

Long-term condition e.g. diabetes, arthritis

- *“Answering phone calls on the numbers we are given instead of voicemail.”*
- *“Discharge process too quick for my family.”*
- *“Waiting times.”*
- *"The dermatology department need to start listening to patients.”*
- *“Each time I went, I saw a different specialist and information was not passed on.”*
- *“I had tests which were fruitless and sometimes the same tests repeated."*
- *“Improving availability of NHS Consultant appointments.”*
- *“Length of time treatment lasted.”*
- *“Staff that are willing to treat and support the needs of patient. Not pass it all to others.”*

Mental Health

- *“More personalised access and treatment. Not all mental health issues are the same.”*
- *“More time on appointments needed and groups could be an option.”*
- *“To have the same counsellor and better informed about appointments and where to go.”*
- *“Not have to wait too long for length diagnosis.”*
- *“A phone call at least once a week or a fortnight to see how people with mental health are doing. Answering phone calls on the number we are given instead of voicemail.”*
- *“Access to therapy.”*
- *“Being listened to with respect.”*
- *“Ward not safe - people brought in alcohol and knives."*
- *“Increase the staff at Peasley Cross.”*

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

Condition	Yes	No
Autism	0	1
Cancer	11	1
Dementia	2	1
Heart and lung diseases	13	4
Learning disability	3	1
Long-term condition e.g. diabetes, arthritis	50	7
Mental health	32	15

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	0	0	0	0	0	0
Cancer	0	0	4	4	3	0

Dementia	0	0	1	1	0	0
Heart and lung diseases	1	3	3	2	3	0
Learning disability	1	1	1	0	0	0
Long-term condition e.g. diabetes, arthritis	6	8	17	14	3	1
Mental health	8	8	9	5	0	2

Please tell us more about the length of time you waited.

Cancer

- *“It was very stressful having to wait 10 days to see a consultant.”*
- *“2 weeks”*
- *“Seen within days.”*
- *“Once started it got moving, problem was getting started.”*
- *“Matter of weeks”.*

Heart and lung diseases

- *“Weeks”*
- *“Short time due to urgency”.*
- *“Months”*
- *“Seen within days.”*

Learning disabilities

- *“3 weeks”*
- *“3 months”*

Long-term condition e.g. diabetes, arthritis

- *“Operation fairly quickly. Physio very slow.”*
- *“I was in hospital at the time for a period of 6 months.”*
- *“A long time.”*
- *“A few months.”*
- *“I waited several months to be seen, when I was in severe pain and not sleeping all night.”*
- *“The referral had not been sent on and it was only from initiating a call to check progress this was discovered; tests and consultant appointment was delayed due to this.”*
- *“Due to delays several trips to A&E required for urgent care.”*
- *“Person seen lacked skills required to meet needs.”*
- *“Poor accountability as to delays.”*

Mental Health

- *“Usually months. Up to a year.”*
- *“6 months between GP and psychiatrist.”*
- *“At least 2 weeks to a month.”*
- *“When seeing mental health took too long. Week before I saw anyone. Anything else with my GP no longer than 15 mins - 1 hour.”*
- *“I understand they have waiting lists but sometimes with mental health it is urgent.”*
- *“It wasn't long before I saw a psychiatrist.”*

- *"I was assessed and treated within a couple of weeks."*
- *"Still waiting for CBT (16 months)."*

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	2	0	0	0
Cancer	4	4	4	0	0	0	0
Dementia	0	0	0	3	0	0	0
Heart and lung diseases	5	2	1	7	2	1	0
Learning disability	0	1	1	0	0	1	1
Long-term condition e.g. diabetes, arthritis	10	9	11	17	2	5	2
Mental health	3	3	10	14	5	9	3

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

Condition	Yes	No	Somewhat
Autism	0	0	2
Cancer	7	4	1
Dementia	2	0	1
Heart and lung diseases	12	3	1
Learning disability	1	1	2
Long-term condition e.g. diabetes, arthritis	26	14	17
Mental health	9	20	16

Please explain how the care did or did not meet your expectations and how could it be improved?

Autism

- *"Little understanding on autism."*

Cancer

- *"Lack of referral to a specialist and generally poor care by the GP."*
- *"I was not offered any support; it would have been useful to have spoken to a nurse who would outline treatment options and what to expect."*
- *"I didn't feel as I was a person, a conveyor belt."*

- *"Care worker never manning phone. Left messages, but she never returned calls."*
- *"Everything was explained clearly and I felt more at ease."*
- *"I was treated relatively quickly after diagnosis."*
- *"Felt abandoned."*
- *"The support for cancer patients is thorough and beneficial to the patient."*

Dementia

- *"It met my expectations, we had three information sessions about dementia."*
- *"It was ok when it was finally in place."*

Heart and lung diseases

- *"As the asthma is in the 'mild' and not 'severe' category, a basic level of care has been adequate."*
- *"I had support from my daughter. So, this helped me a lot. I now attend Harry Blackman House."*
- *"Nothing could have been improved."*
- *"No-one knows what to do to help."*
- *"Seeing the same doctor more than once."*
- *"Speedier access to Consultant via NHS."*
- *"It did meet my expectations."*
- *"Very little information. Need more information at diagnosis."*

Learning disability

- *"Long waiting time."*
- *"Ineffective outcomes at appointments."*

Long-term condition e.g. diabetes, arthritis

- *"Very good, fast reactions, impressive."*
- *"Arthritis care cannot fault it."*
- *"Access could be quicker."*
- *"No-one knows what to do to help."*
- *"Would have liked someone to give me advice on how to ease my pain."*
- *"Mis-diagnosed and left without medication."*
- *"It was too far away, had to travel."*
- *"Length of time waiting - could be improved and some attitudes of the consultant as he tended to see me as an employee as I worked at the hospital. Never referred for pain management."*
- *"I was quickly given the physio and the surgical support which the consultant recommended."*
- *"Seeing the same specialist - continuity."*
- *"Practitioners listening to patient and not disbelieving them."*
- *"I could have saved both the NHS and myself time and money if procedures had been better explained. (Had two blood tests to tell me what I already knew.)"*
- *"I have poor mobility and nearly blind - I could not get to appointments without help."*
- *"We had District Nurses for some of the care and if we could have some nurses on a rotation it would have made care easier."*
- *"Speedier access to Consultant via NHS."*

Mental Health

- *“Felt very let down and abandoned, didn't know who else to turn to.”*
- *“After six sessions I was abandoned.”*
- *“When discharge - living alone at home - promised home treatment care for 6 weeks. Lasted less than one week. No continuity in team. Health care assistants - no nursing input.”*
- *“Taking Family concerns seriously and not just expecting them to deal with it alone.”*
- *“More understanding GP.”*
- *“Not tailored to needs of individual.”*
- *“More available appointments and quicker appointments.”*
- *“It did meet my expectations and don't feel it would be improved.”*
- *“Was referred to eating disorder assessment, was good and help offered was more than I could ask for.”*
- *“Mental health given medication. When suicidal spoke to someone, he asked some questions and that was it. More explanation and phone numbers.”*
- *“Shorter waiting lists needed more money needs to go into mental health.”*
- *“Provisions about home treatment team not met. Lack of continuity in staff. No CPN or other professional support ongoing.”*
- *“Just wasn't listened to.”*
- *“Due to severe anxiety and depression going out to hospital appointment was not appropriate, was not offered home visit.”*
- *“Medication was simply not enough for the state I was in. As my Mental Health worsened, I had to take several weeks off work as I was unable to even leave the house.”*

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	1	1
Cancer	7	2	3
Dementia	2	0	1
Heart and lung diseases	12	3	3
Learning disability	1	2	0
Long-term condition e.g. diabetes, arthritis	22	17	14
Mental health	10	27	9

Please explain how the care did or did not meet your expectations and how could it be improved?

Cancer

- *"GP very poor.”*
- *“Hospital excellent.”*

- *"I feel that GP's need to radically up their game. They are more concerned with how the practice runs for their convivence than they are with patient welfare."*
- *"Once the treatment commenced, I received excellent care."*
- *"They would make arrangements to visit me and not turn up. No phone call to tell."*
- *"It seemed to follow and fit into a well-developed system."*
- *"First class treatment."*
- *"Needed to push to be treated."*

Heart and lung diseases

- *"Everything really good."*
- *"The care met and continues to meet my expectations very well."*
- *"During and after suffering my heart attack. I could not fault the service and support I received from Liverpool Heart and Chest Hospital and cardiac rehabilitation in St Helens."*
- *"First class treatment."*

Long-term condition e.g. diabetes, arthritis

- *"Very impressed, only hope all get the same."*
- *"As it was out of borough I didn't realise or understand why I couldn't have my scans and bloods done locally with information being passed through the system for my appointments with my consultant."*
- *"Very supportive, helpful staff, explanation of treatment etc."*
- *"Was supposed to have regular appointments and discharged without my knowledge with Mental Health service. Not discharging patients when they need help the most. Regular appointments should be kept not discharging patients without their notice."*
- *"From a carer's perspective, felt left out of the communication process via letters as my mother would forget. Also discharge from hospital at St Helens (rehab unit) was on the same day as a visit and I couldn't accommodate."*
- *"Access to my records digitally so I can see what's said."*
- *"Referral for pain management could have been arranged. More emotional support."*
- *"Less waiting time."*
- *"I strongly felt that I was being given the care which was needed."*
- *"Never received feedback of test results from hospital or GP."*
- *"Appointment letters received for appointment dates in the past."*

Mental Health

- *"Phones often on answerphones. Appointments made - but not communicated by either letter or phone. Huge gap between a general enquiry and crisis team."*
- *"They never rang back when they said they would."*
- *"Wider training re Mental Health for all point of access members of NHS staff."*
- *"A week is a long time for someone with Mental Health issues to wait - rash decisions may have been made within that sort of time frame."*
- *"Helped me to set some aims in life and ways to cope/achieve."*
- *"Not having to wait too long for appointments."*
- *"I received consistent communication from all of the services that I came into contact with. They were very helpful and supportive. It could not have been improved."*
- *"Doctors need to know more about addiction instead of just prescribing more drugs."*
- *"Need to be listened to more."*
- *"Mindsmatter were excellent."*
- *"If sessions were cancelled you were not always told, also the right to obtain a copy of letters was not always fully explained."*

- *“Never get an appointment when needed.”*
- *“Minds Matter seem to be snowed under and need more staff etc.”*

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	0
Cancer	6	5	1	0	0	0	0
Dementia	0	2	1	0	0	0	0
Heart and lung diseases	12	2	1	0	0	1	2
Learning disability	2	0	2	0	0	0	0
Long-term condition e.g. diabetes, arthritis	35	9	5	0	0	6	2
Mental health	19	11	13	0	0	3	1

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	2	0	0	0
Cancer	2	4	2	4
Dementia	2	0	1	0
Heart and lung diseases	4	9	5	0
Learning disability	2	1	0	1
Long-term condition e.g. diabetes, arthritis	12	29	6	9
Mental health	13	19	10	4

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	1	1	0
Cancer	2	2	3	5

Dementia	1	1	1	0
Heart and lung diseases	3	8	5	2
Learning disability	1	1	1	1
Long-term condition e.g. diabetes, arthritis	6	27	16	7
Mental health	6	19	16	6

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	1	0	0
Cancer	5	4	2
Dementia	1	0	2
Heart and lung diseases	4	7	3
Learning disability	2	0	2
Long-term condition e.g. diabetes, arthritis	19	23	11
Mental health	10	27	8

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	1	0	0
Cancer	4	5	2
Dementia	1	1	1
Heart and lung diseases	6	5	3
Learning disability	0	3	1
Long-term condition e.g. diabetes, arthritis	22	23	7
Mental health	14	16	10

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	1	0	0
Cancer	4	5	2
Dementia	1	1	1
Heart and lung diseases	6	5	3
Learning disability	1	2	1
Long-term condition e.g. diabetes, arthritis	21	22	9
Mental health	13	13	12

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	0
Cancer	5	3	3
Dementia	1	0	2
Heart and lung diseases	4	7	3
Learning disability	2	1	1
Long-term condition e.g. diabetes, arthritis	26	17	8
Mental health	22	9	12

Supporting you to have more control over your own care

Table 27: What level of support of 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	0	1	1	0
Cancer	1	6	3	2
Dementia	0	3	0	0
Heart and lung diseases	3	14	1	0
Learning disability	2	1	0	1
Long-term condition e.g. diabetes, arthritis	11	37	4	3
Mental health	10	32	4	1

What could the NHS do to help you stay healthy or manage any condition you have?

Cancer

- *"I would like to see much improved GP services, both in terms of their attitude to patients and the availability."*
- *"Ensure GPs have more knowledge of treatment options for cancer."*
- *"Tell me what I can do to stay healthy."*
- *"Be more consistent."*
- *"Inform me of latest breakthrough in medicine."*
- *"Locally available services seven days a week."*
- *"Keep monitoring me regularly."*
- *"I have lots of needs due to my disabilities and how they affect me."*

Dementia

- *"Nothing can be done, it's self-payment for care home."*
- *"More information available in British Sign Language."*

Heart and Lung Diseases

- *"Co-ordinate between the hospital and the GP where Shared Care is allocated. We have had to ask for copies of letters sent between the GP and the hospital."*
- *"Keeping in contact and sending/emailing or promoting on-line access to any relevant and updated information."*
- *"My notes have been confused with another person's a couple of times - this worries me."*
- *"See same doctor more than once."*
- *"Regular check-ups."*
- *"More information."*

Learning Disability

- *"Sports and nutritional support for a child with special needs."*

Long-term condition e.g. diabetes, arthritis

- *"Be available in whatever form, whether that be online, telephone, via GP appointment."*
- *"I want other options than just surgery."*
- *"Information on what and where."*
- *"Good communication and regular visits from appropriate medical professionals as I reside in a care home and I am wheelchair bound."*
- *"Access to consultants online save travelling."*
- *"Listen and not just give out prescriptions."*
- *"Provide specific exercise classes on an ongoing basis."*
- *"Regular check-ups from your GP or medical practitioner."*
- *"See advert after advert saying get checked. Then you cannot get access to service."*

Mental Health

- *"Have more people trained in mental health care and support."*
- *"Have patient participation groups like at GP."*
- *"More support for people with Mental Health and their families."*
- *"Better provision for Mental Health conditions."*
- *"Supportive GP has really helped."*

- *"Provide more support workers around Mental Health for those that really need it. Access to social workers and occupational health. Home support for lonely people."*
- *"Mental Health needs to be looked into more and people suffering need quicker response and help to start them on their way to recovery."*
- *"Be able to get support as soon as possible."*
- *"More awareness for medical professionals."*
- *"Walton Centre has lots of information but long waiting times."*
- *"Listen to me. Don't ignore my concerns."*

Further comments:

Cancer

- *"Poor diagnosis and poor prescribing by GP's wastes time, money, and goodwill."*
- *"I was obviously very distressed when I was told the cancer had spread, I asked the GP three times if it was treatable, this was met with a blank expression and tacit response! My husband and I were devastated, if he had not persuaded me to seek further information and support, I would have opted to take an overdose as I truly believed I was facing an imminent, painful death."*
- *"NHS superb. Just short of staff."*
- *"I cannot thank staff of NHS enough from consultants to cleaners - all do a vital job."*

Heart and Lung Diseases

- *"Knowing how and where to access support when needed and being confident it will be provided".*
- *"I feel that having a supportive GP at Windermere Avenue has really helped me as he listens to me."*
- *"I have always had good treatment and support."*
- *"Hospital I had my operation was like a 5-star hotel - Broadgreen in Liverpool."*

Learning Disability

- *"I feel that having a supportive GP at Windermere Avenue has really helped me as he listens to me."*

Long-term condition e.g. diabetes, arthritis

- *"I have had hospital treatment for the past 19 years at various NHS hospital, I have always been cared for in an excellent manner."*
- *"I would like some support for people with scoliosis."*
- *"From a carer's perspective I was only informed that Mum had a massive stroke causing her fall downstairs later on a consultant review. This resulted in three fractures in her neck so the focus was on getting her bones to heal."*
- *"I have lost all faith in the NHS and shall not be seeking and help or support from dermatology specialists again. It has taken me four years of pain and suffering to find my own cure*
- *"Better and faster communication required between specialist and GP so they are aware of changes in treatments/medications quickly."*
- *"It's getting the patient needs to meet the NHS Service not service meet patient."*

Mental Health

- *"My experiences of NHS for physical ailments, including diabetes and surgery, have been excellent. But I have had to turn to private therapy for mental health. I am lucky to be able to afford this - unlike so many"*
- *"I currently work in a pharmacy in St Helens and regularly come into contact with patients who have felt let down by various services throughout the borough - there are of course some who have massively benefitted from services too - however those who have felt let down always outnumber these patients. Not sure if there could be any sort of solution devised with pharmacy settings to help with oversubscribed services, such as the Mental Health team, and further information relating to healthy living is always welcomed - currently we are promoting NHS awareness months, weeks and days - but this may be more effective if there is anything that is being highlighted within the town itself or maybe a plan made between pharmacies and the CCG. Also, more interconnectivity with pharmacies and the CCG would be highly welcomed."*
- *"I think the NHS do a great job considering the resources they have."*
- *"The NHS do a wonderful job most of the time. There are a lot of people suffering with Mental Health and the situation needs addressing. It is easy to hide Mental Health and con people into thinking you are fine."*
- *"My only main concern is waiting times and quick access to specialists. Also takes a long time to speak to someone as GPs have little time and it's stressful."*
- *"The biggest issue I can see is lack of parity between physical and mental health in terms of funding, training and research. Any experience of NHS for physical issues, Diabetes and Surgery has been excellent. My experiences in Mental Health have been really poor. My recovery, after 20+ years, was achieved with MIND."*

In focus: what is important to people who access mental health services about Health and Care services?

As part of our research Healthwatch St Helens carried out a focus group with local people to gain some further insight into their views concerning the NHS Long Term Plan. The target group for this focus group was people who use Mental Health services, their families and friends. It was an opportunity to hear their views as St Helens has a high number of people accessing Mental Health services and there have been particular issues around accessing IAPT services.

The focus group was held on the 30th April 2019 at The Beacon, College Street, St Helens and was attended by 11 people who use Mental Health services or know someone that does.

Four members of Healthwatch St Helens facilitated the session, supported by two colleagues from St Helens CCG Engagement team who provided a presentation on what is happening locally to improve services.

The main issues or themes arising from the event were:

- Waiting times for Mental Health services - waiting times are so long that people are going private; *"Having to self-refer when you are at crisis point is no good. Someone should do this for you."*
- Community Mental Health services are good; *"The wellbeing/lifestyle nurse in Mental Health is fantastic."*
- More support is needed for people caring for someone with a Mental Health issues; *"Family carers need to be equipped to care in the community, plus emotional support for carers."*
- Mental Health professionals should be in every GP surgery.
- There is not enough funding for Mental Health compared to physical health; *"Make bigger investment in Mental Health services, both adult and children's services."*
- CBT is seen as a 'cure-all'.

healthwatch

NHS Long Term Plan Report

Chapter 9 - Healthwatch Warrington

Warrington

Warrington is situated upon the river Mersey and is the largest town in the county of Cheshire, but has its own unitary authority of Warrington Borough Council. It is made up of small suburbs and villages as well as more densely populated areas around the town centre.

The population has increased over the past 30 years because of new town developments, and now numbers 209,700 residents. It is estimated that by 2025, there will be around 221,000 people living in Warrington.

Quality of life is generally good in Warrington but there are pockets of significant disadvantage, where residents experience poorer health outcomes. There are wide inequalities between people living in areas of high levels of deprivation and those living in areas of low deprivation; more deprived populations generally have poorer outcomes in terms of health and education. Life expectancy is lower than the national average at 78.9 years for men and 81.9 years for women.[11]

In Warrington, we received 256 survey responses, consisting of 249 general surveys and 7 specific condition surveys. There were also 40 attendees across two specific focus group events.

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[11] Source: Warrington Borough Profile https://www.warrington.gov.uk/download/downloads/id/16619/warrington-borough-profile.pdf

Summary of Findings:

What matters most to people in Warrington?

- Having access to the help and treatment needed when it is wanted and having easy access to information needed to help make decisions about health and care were the most important factors people told us were needed in living a healthy life. People told us they wanted more support with healthy eating and lifestyle, and wanted improved access to services and joined-up care.
- To help keep independence and stay healthy whilst getting older, people indicated that being able to stay in their own home for as long as possible was most important to them. It was also noted that people want there to be convenient ways to travel to health and care services when needed. More effective support services and opportunities to meet other people to combat social isolation were also mentioned.
- Choosing the right treatment being a joint decision between the person and the relevant health and care professional is overwhelmingly most important to people in Warrington in managing and choosing support and treatment, alongside receiving timely communications. People discussed the need for more services to be available locally, greater levels of information and advice to be available, and greater use of online technology.
- People in Warrington told us that having absolute confidence that their personal data is managed well and kept secure, being able to make appointments using phone or computer, and the use of technology to communicate results efficiently were deemed as the most important things when interacting with the NHS.
- Comments regarding the use of technology in health and care were varied. Some people told us that they would like to see more online or accessible appointments or be able to easily access records and results, whereas others felt that face to face communication could not be replaced. The ability to access personal records was also considered important.
- General comments overwhelmingly related to the accessibility of GP appointments, but also to appointments with other healthcare professionals. Respondents, especially those in work, would like to see more out of hours GP appointments and quicker referrals.
- People with Cancer are generally positive about the assessment, treatment and support they have received, and feel the wait at each of these stages was at least 'OK'.
- Focus group attendees with learning disabilities said that they often felt that they were rushed out of their GP appointment before they had the time to process the information that was given to them.

Survey results

The following sections now break down the results of the 256 responses across Warrington to the surveys designed by Healthwatch England. The first sections use the 249 responses to the general 'People's general experiences of health and care services' survey, before breaking down the 7 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). Having easy access to information needed to help make decisions about health and care was considered the next 'very important' aspect. 246 people responded to this question.

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

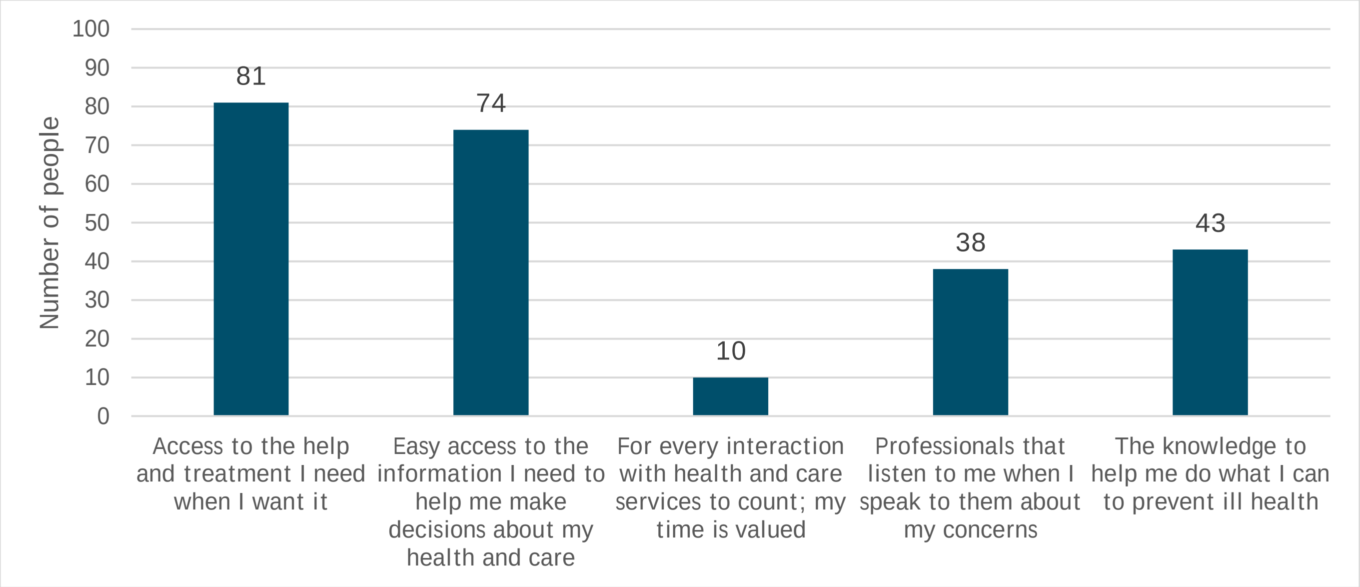


Table 1: When asked to rate on a scale of very important to not important at all respondents to the survey felt that ‘Access to the help and treatment I need when I want it’ was the most important factor, however, the option receiving the second largest ‘most important’ response was ‘Professionals that listen to me when I speak to them about my concerns’. It is also important to note that all five statements were deemed as either ‘very important’ or ‘important’, as the table below shows. 246 people responded to this question, though 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
Access to the help and treatment I need when I want it	169	69	8	0	0
Professionals that listen to me when I speak to them about my concerns	162	75	8	0	0
Easy access to the information I need to help me make decisions about my health and care	154	72	19	1	0
For every interaction with health and care services to count; my time is valued	147	83	14	1	0
Having the knowledge to help me do what I can to prevent ill health	139	91	16	0	0

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:

Healthy eating/exercise

Many people commented on the desire to eat more healthily, the importance of having access to reasonably priced nutritional food and the ability to make healthier eating choices. Increasing access to exercise (providing free or subsidised classes or activities, increasing cycle paths) and the importance of social or community activities were mentioned.

- *“I need to exercise more but it is difficult when you have a young family and work full time, free childcare in leisure centres would be great”*
- *“Lots of community classes aimed at older people like me.”*
- *“Healthy food to be more affordable.”*

- *“More healthy, active options at work. We used to have a social club offering keep fit yoga, etc.”*

Access to services

A common theme was the need for easy access to GP appointments and other medical services. There was also a requirement for regular annual checks for those with certain conditions such as a Learning Disability.

- *“Easier access to a GP.”*
- *“Hospital appointments quicker to achieve than GP appointments.”*
- *“Having services easily accessible without taking time out from work and also without having very long waiting lists.”*
- *“To be able to have more health checks at the age I am and not have to wait until I am older, to prevent illness later on in life.”*
- *“Access to the right equipment at the right time is difficult in the time from agreement and referral to a service our children grow and have different needs.”*
- *“Annual Health checks and annual reviews easy read information and for the doctor to take more time in appointments. Give professionals training to understand learning disabilities and autism more.”*

Air Quality

Concerns regarding the amount of traffic and air pollution were mentioned by many people living in this area of Cheshire.

- *“Clean, fresh air - unpolluted.”*
- *“Ensure the air in the vicinity of Runcorn and Widnes was free of toxic air pollution from the chemical works along the Mersey estuary. Not satisfied with companies like INEOS claiming they are not causing air pollution and other pollutions. Lung cancer rates in Runcorn are some of the highest in the country. It's not just down to smoking.”*
- *“Traffic and pollution measures to be urgently prioritised.”*

Integration of Services

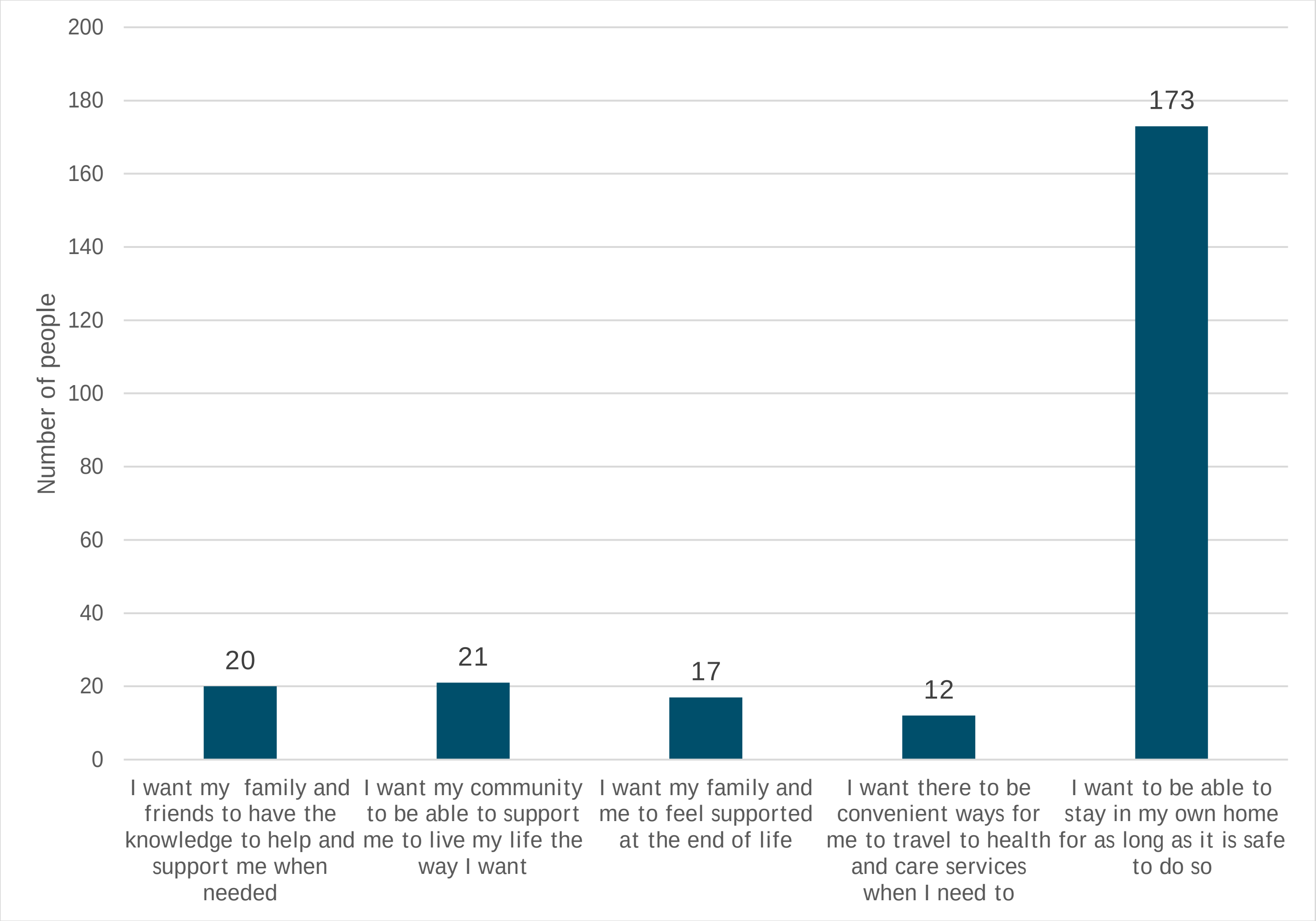
The importance of joined up care was also highlighted by some.

- *“Joined up care pathways which prevent isolated GP/hospital/clinic visits.”*
- *“The specialists that we see all have such different knowledge and work that we accept that there will be travel to see experts and duplication in some areas. However, where appointments are linked to such areas as education, health and social care, there is much to do to ensure we have less repetition as services are working better together, i.e. joined up administration, single records and access for all of the agencies involved.”*
- *“Services must work together to achieve better outcomes.”*

Keeping independence and staying healthy in later life

We asked people to tell us 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). 243 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 246 people responded to this question, though 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	186	42	12	0	0

I want there to be convenient ways for me to travel to health and care services when I need to	168	66	9	2	0
I want my family and me to feel supported at the end of life	166	64	14	0	0
I want my family and friends to have the knowledge, to help and support me when needed	159	72	15	0	0
I want my community to be able to support me to live my life the way I want	144	85	13	3	0

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 question so answers were collated into themes and summarised below:

Effective Support Services and Carers

One of the most common themes with regards to what people feel would help them to live independently was related to the value of carers and support workers:

- *"Support for/consideration of people ageing without children."*
- *"Proper and sustained care in my home from a dedicated team suited to my specific needs."*
- *"If I require healthcare in my own home, it is provided by staff that are suitably trained, and provided in a timely manner."*
- *"For social workers to ensure that I have enough one to one hours so that my support workers can help."*
- *"Good quality carers who do not have to rush constantly. It would be useful if it was the same carers wherever possible."*

Social Interaction

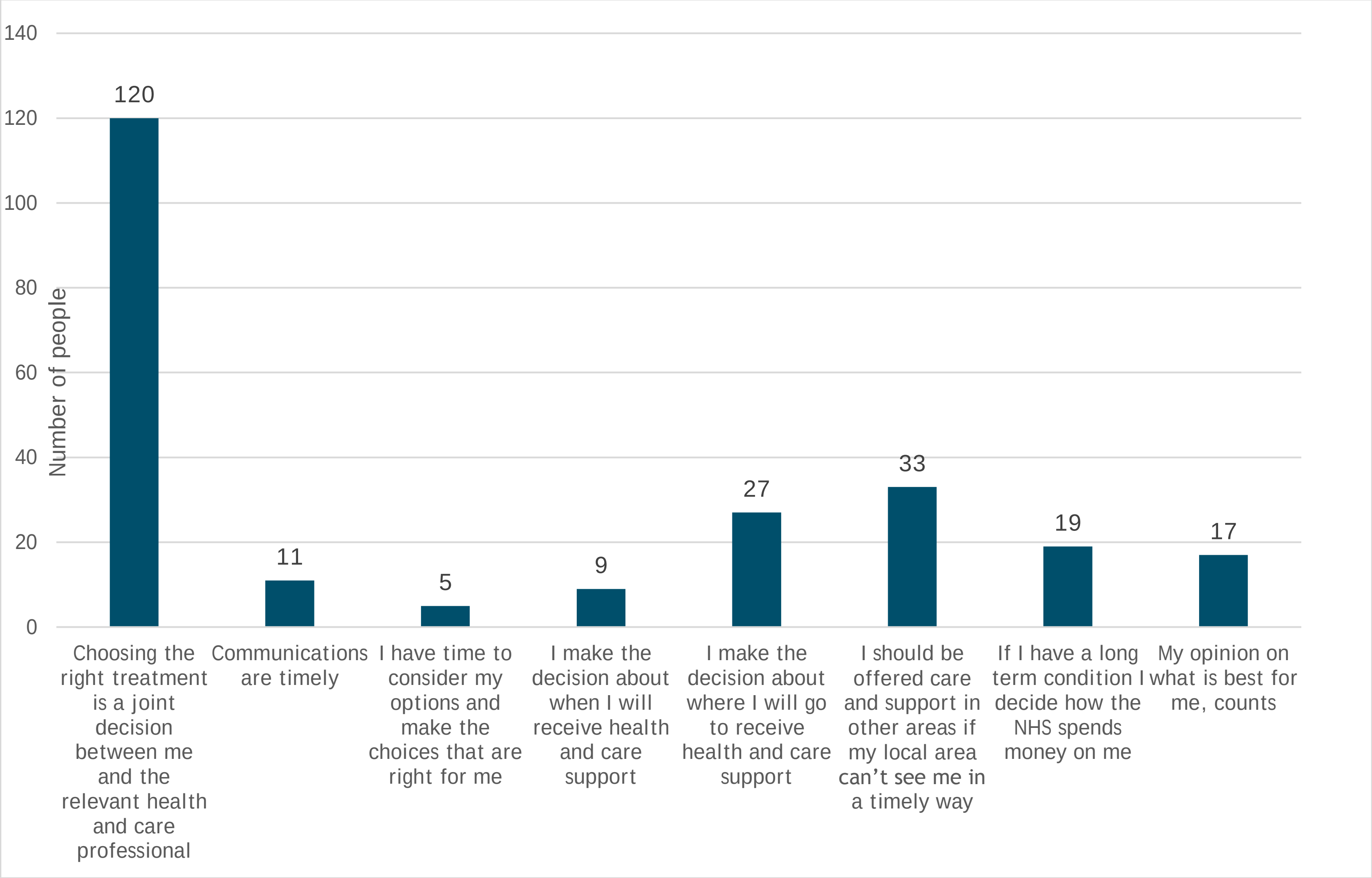
Some respondents also commented that feeling connected with others was or would be important to them.

- *"More opportunities for people to get together just to chat and maybe take part in an activity. Would reduce social isolation and improve people's mental wellbeing."*
- *"Good support and the Learning Disabilities team have good activities to take part in and going out in the community."*
- *"Social prescribing is hugely effective at reducing demands on primary provision. However, the element of transport seems to be forgotten within such programmes. Given the purchasing power of the NHS and related bodies cannot a comprehensive plan be developed to provide transportation options to increase participation in social prescribed activities. Maybe the inclusion of some evening opportunities could allow joint provision of transport with entertainment providers (domino and bingo nights etc.) to share costs of acquisition, operation and maintenance. I experience at least five clients per week who cannot be socially active due to the lack of transport availability. I'm sure we could have a huge increase in take up of social prescribing where a transport solution is offered."*
- *"Important to support each other- social interaction."*

Managing and choosing support and treatment

Chart 3 shows that people we spoke to in Warrington told us that choosing the right treatment being a joint decision between them and the relevant health and care professional was overwhelmingly 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. 241 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 deemed choosing the right treatment as a joint decision between themselves and a relevant health and care professional as the most important factor when managing and choosing the support they need, followed by a desire to receive timely communications. Up to 243 people responded to this question, though not everyone 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 the relevant health and care professional	143	89	11	0	0
Communications are timely	139	82	17	0	0
My opinion on what is best for me, counts	116	95	31	1	0
I should be offered care and support in other areas if my local area can't see me in a timely way	115	99	20	9	0
I have time to consider my options and make the choices that are right for me	114	106	13	1	0
I make the decision about where I will go to receive health and care support	107	101	30	4	0
I make the decision about when I will receive health and care support	101	110	30	1	0
If I have a long-term condition, I decide how the NHS spends money on me	73	103	53	7	0

General comments received from respondents regarding managing and choosing support are summarised below.

Information, Communication and Choice

Many respondents stated that they needed quality information and guidance to enable them to make choices. Knowledge of the available services and their locations was also a key theme. Comments included:

- *"Better information about available services and how to access them."*
- *"Good quality, timely information that provides me with everything that I need to make an informed choice."*

- *"Better communication - more timely correspondence, linked up with primary and secondary services. Make use of holistic therapies for example acupuncture and pain management - much more cost effective than medication."*
- *"Health care support directory."*
- *"Take more time with me and my learning disability, training for NHS staff."*
- *"Clear communication about options available and the benefits of each option."*

Funding for, and accessibility of services locally

People told us that they would like to see more financial investment in both infrastructure and staffing. Comments showed that respondents felt that services could also be more accessible either by being closer at hand or that transport means to get to appointments are improved. Comments included:

- *"Modern local hospital that is adequately resourced."*
- *"More investment in people/nurses."*
- *"Accountability by those who hold the budgets - too much power for the CCGs and Local Medical Councils. The balance of power needs to return to the patient and be less about the GP budget."*
- *"More support workers and advocates."*
- *"More money for healthcare."*
- *"Once EHCP plans are agreed there is never the right funding or organisations to fulfil needs and agencies argue over who has responsibility to fund. Despite this all being statutory funding and ultimately from the same taxes we pay to the government."*
- *"No long delays and a bed when I need it, then proper support.*
- *"Easier access to services - there are too many hoops to jump through."*
- *"Public transport access could be better."*
- *"Access to hospitals and clinics. I can't get the bus."*
- *"I live in Lymm. Most convenient hospital is Wythenshawe, 15 minutes by car. Have to go to Warrington, no buses within reasonable distance, or to Halton about 1 hour in a car if motorway is not blocked. Refuse to go to Halton. Thought we had a choice?"*

Use of Online Technology

Respondents also felt that better use could be made of technology for appointments and signposting:

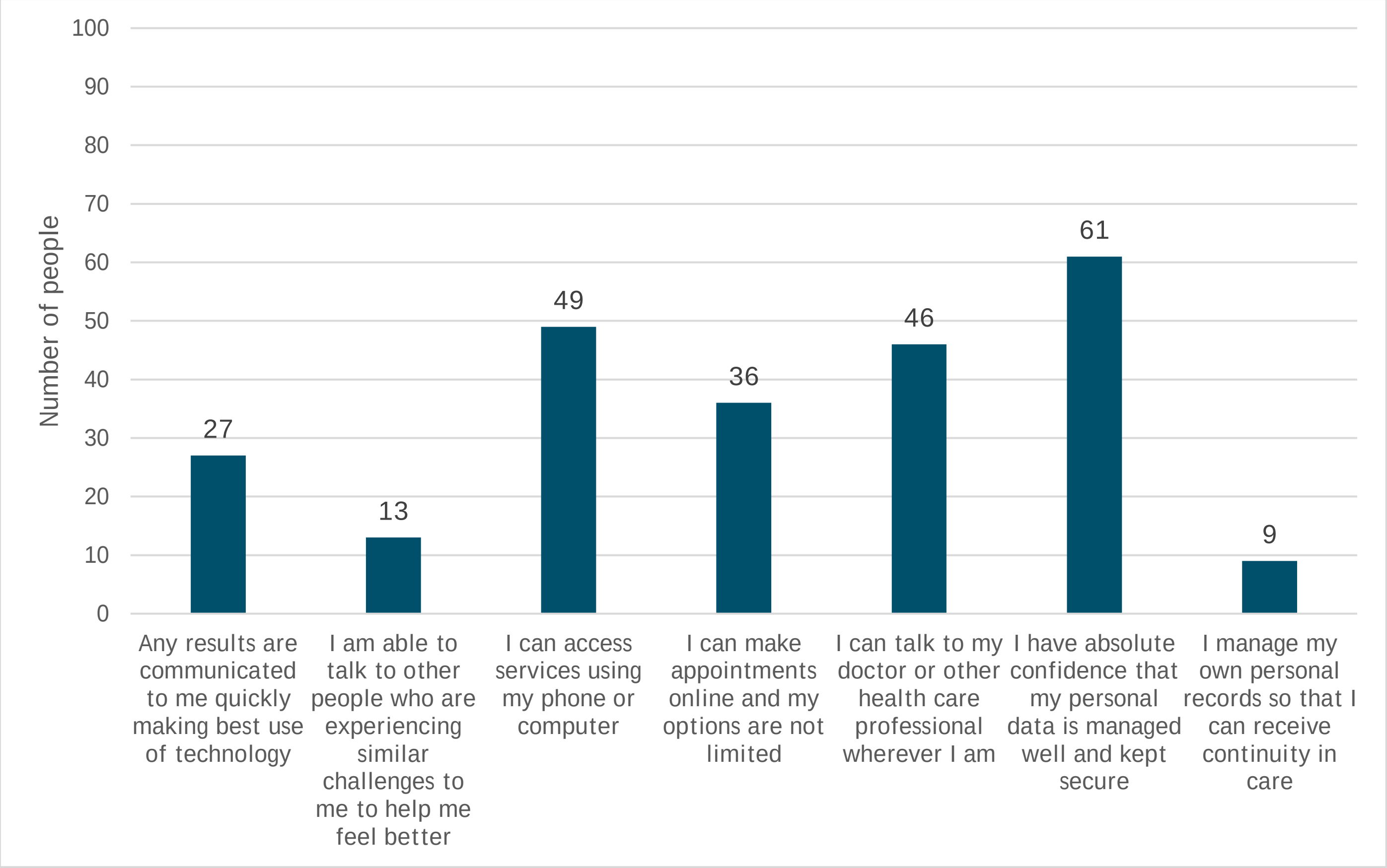
- *"Online chat doctor service."*
- *"Make use of online technology."*
- *"Booking appointments online, not having to ring up."*
- *"More online services/online booking."*
- *"Clear point of access from which we can be signposted/navigate the system so that we aren't lost in the system... the NHS app has great potential to be this for the majority of people. Those unable to use the app should be able to access someone who can use the app for them."*

Engaging people in health service delivery

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

As Chart 4 shows below, people in the Warrington area told us that having absolute confidence that personal data is managed well and kept secure was considered most important by people who answered the survey, this was followed by a desire to access services using a phone or computer. Also considered important was the ability to talk to a healthcare professional from any location. 241 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 having absolute confidence that their personal data is managed well and kept secure was very important and on a par with making good use of technology to receive test results. Other options such as people talking to a healthcare professional wherever they are, 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, were shown to be important rather than very important as can be seen in Table 4 below. Up to 243 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
I have absolute confidence that my personal data is managed well and kept secure	126	85	26	3	0
Any results are communicated to me quickly making best use of technology	126	88	25	2	1
I can talk to my doctor or other health care professional wherever I am	82	122	34	5	1
I can make appointments online and my options are not limited	77	112	34	15	6
I can access services using my phone or computer	75	111	40	12	5
I manage my own personal records so that I can receive continuity in care	62	100	63	15	3
I am able to talk to other people who are experiencing similar challenges to me to help me feel better	60	90	65	24	3

Access to appointments

General comments overwhelmingly related to the accessibility of GP appointments, but also to appointments with other healthcare professionals. Respondents, especially those in work, would like to see more out of hours GP appointments and quicker referrals. Comments included:

- *“Quicker access to Physiotherapist services, when referred.”*
- *“It is difficult for working people to make appointments to see medical professionals, particularly if it is not an urgent matter but you do need to see someone. There are limited appointments and everyone, no matter who you speak to or where they live, is having problems getting an appointment. You are told to ring 8-8.30 am for an appointment, but this is when a lot of people are travelling to work. The system does not work very well for the working population. In my experience, I received a letter for a health check. There was a limited number of places available. I phoned when I got in from work only to be informed that I was too late and all the places had been taken. I am a widowed, working single parent and am trying to be responsible about my health. I don't want to be ill or go into hospital but the system doesn't help people like me.”*
- *“It is important that I am given appointments at a time of the day that suits me.”*

- *"GPs having the time to listen - quite often appointments feel rushed - I try and avoid going to the GP if possible."*

Technology and access to personal records

Comments regarding the use of technology in health and care were varied. 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 face to face communication could not be replaced. The ability to access personal records was also considered important. Comments included:

- *"People to have full access to their own records if they choose. Person-centred care should mean the person is the centre of information."*
- *"Easier online access to past treatments/prescriptions."*
- *"Whilst access to services and support in a timely manner is important, this should not be at the expense, or instead of, face to face consultations."*
- *"Easy to transfer my health records between hospitals/GPs."*
- *"Knowledge for confident use of NHS website."*

Further Comments

- *"Quite positive about the services offered, things are much better than elsewhere in the world."*
- *"I am very thankful for the NHS - far better than elsewhere in Europe."*
- *"NHS care is the foundation of the country - regardless of vulnerability, age or location. Everyone has a right to high quality, equitable care at the point of access."*
- *"Commissioned services regulate without notification of inspection or visit, i.e. CQC at hospitals."*
- *"I would like the services to be able to communicate better so I don't have to tell my history multiple times."*
- *"Knowledge is the key."*
- *"Listen to me."*
- *"Keep cancer services in Halton for the people of Halton/Warrington and surrounding areas."*
- *"NHS is a broken system in many areas. Some of it is world class but at times the NHS seems third world. Some staff are lovely - others should not be in the profession. Lack of funding and staff is an issue - but sometimes funds are mismanaged. Spending money on art work for chief executive's offices should not be allowed. Funds are for patient care and staff costs - not massaging manager's egos. End of life care is a disgrace. Don't hide behind patient confidentiality- family need to be included in care plans for the terminally ill and palliative care should be available. Not enough GPs, hence why people turn up in A&E - easier access to GP appointments for working people - employers to allow staff time off for medical appointments."*

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 seven 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

Conditions	Number of people
Cancer	3
Dementia	1
Heart and lung diseases	1
Learning disability	1
Mental health	1

Table 6: Who are you responding on behalf of?

Conditions	Myself	Someone else
Cancer	2	1
Dementia	1	0
Heart and lung diseases	1	0
Learning disability	0	1
Mental health	1	0

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

Conditions	Yes	No
Cancer	3	0
Dementia	1	0
Heart and lung diseases	1	0
Learning disability	1	0
Mental health	1	0

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	Not applicable
Cancer	3	0	0	0
Dementia	1	0	0	0
Heart and lung diseases	0	0	1	0
Learning disability	0	0	1	0
Mental health	0	1	0	0

Cancer:

- *"I felt supported straight from my diagnosis."*
- *"It was excellent."*

Heart and lung diseases:

- *"Incompetent system, with information being lost by the hospital."*

Mental Health:

- *"Not able to get a GP appointment very easily."*

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

Conditions	Very positive	Positive	Average	Negative	Very negative	**Don't know**
Cancer	2	1	0	0	0	0
Dementia	0	1	0	0	0	0
Heart and lung diseases	0	0	0	0	1	0
Learning disability	0	0	0	1	0	0
Mental health	0	0	0	1	0	0

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

Conditions	Yes	No
Cancer	2	1
Dementia	0	1
Heart and lung diseases	0	1

Learning disability	0	1
Mental health	0	1

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

Conditions	It made getting support easier	It made getting support harder	No difference	I don't know	Not applicable
Cancer	0	0	2	0	0
Dementia	0	0	0	0	0
Heart and lung diseases	0	0	0	0	0
Learning disability	0	0	0	0	0
Mental health	0	0	0	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?

Conditions	Very slow	Slow	Ok	Fast	Very fast	**Don't know**
Cancer	0	0	3	0	0	0
Dementia	0	0	1	0	0	0
Heart and lung diseases	1	0	0	0	0	0
Learning disability	0	1	0	0	0	0
Mental health	0	1	0	0	0	0

Tell us more about the time you had to wait:

Cancer

- *"Four weeks"*

Heart and lung diseases

- *"Two months"*

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

Conditions	Very slow	Slow	Ok	Fast	Very fast	**Don't know**
Cancer	0	0	1	1	1	0
Dementia	0	0	1	0	0	0
Heart and lung diseases	1	0	0	0	0	0
Learning disability	1	0	0	0	0	0
Mental health	0	1	0	0	0	0

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

Conditions	Yes	No
Cancer	2	1
Dementia	1	0
Heart and lung diseases	1	0
Learning disability	0	1
Mental health	0	1

Cancer

- *"Having a named nurse to talk to [worked well]."*

Heart and lung diseases:

- *'Urgent' results of tests information were not arranged."*

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

Conditions	Yes	No
Cancer	3	0
Dementia	1	0
Heart and lung diseases	1	0
Learning disability	1	0
Mental health	0	1

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

Conditions	Very slow	Slow	OK	Fast	Very fast
Cancer	0	0	1	1	1
Dementia	0	0	1	0	0
Heart and lung diseases	1	0	0	0	0
Learning disability	0	1	0	0	0

Please tell us more about the length of time you waited

Heart and lung diseases

- "Over 2 months and still not arranged, even though progress meetings were organised by the hospital"

Learning disability

- *"Too long"*

Table 17: How easy did you find it to access ongoing support after you were diagnosed or assessed?

Conditions	Very easy	Easy	OK	Difficult	Very difficult	**Don't** know	Not applicable
Cancer	0	1	1	0	0	0	1
Dementia	0	0	1	0	0	0	0
Heart and lung diseases	0	0	0	0	0	0	1
Learning disability	0	0	0	1	0	0	0
Mental health	0	0	0	0	1	0	0

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

Conditions	Yes	No	Somewhat
Cancer	2	0	1
Dementia	1	0	0
Heart and lung diseases	0	1	0
Learning disability	0	1	0
Mental health	0	0	1

Please explain how the care did or did not meet your expectations and how it could have been improved.

Cancer

- *"All treatment seemed organised."*
- *"I expected to have surgery or radiotherapy but I am on chemotherapy tablets which is marvellous."*

Mental Health:

- *"I was given medication but not offered counselling."*

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?

Conditions	Yes	No	Somewhat
Cancer	2	0	1
Dementia	1	0	0
Heart and lung diseases	0	1	0
Learning disability	0	1	0
Mental health	0	1	0

Please explain how the care did or did not meet your expectations and how it could have been improved.

Mental Health

- *"Hard to get seen."*

Heart and lung diseases

- "Exceedingly long delays in receiving urgent test results which have still not been arranged."

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
Cancer	3	0	0	0	0	0	0
Dementia	0	1	0	0	0	0	0
Heart and lung diseases	1	0	0	0	0	0	0
Learning disability	1	0	0	0	0	0	0
Mental health	1	0	0	0	0	0	0

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

Conditions	Less than 30 minutes	30 minutes to 1 hour	1 - 2 hours	Over 2 hours
Cancer	0	1	2	0
Dementia	1	0	0	0
Heart and lung diseases	1	0	0	0
Learning disability	0	1	0	0
Mental health	0	0	1	0

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

Conditions	Less than 30 minutes	30 minutes to 1 hour	1-2 hours	More than 2 hours
Cancer	0	1	1	1
Dementia	0	1	0	0
Heart and lung diseases	0	1	0	0
Learning disability	0	1	0	0
Mental health	0	0	1	0

What is most important to you?

Table 23: When first seeking help

Conditions	Seeing a health professional, you normally see but you may have to wait	Seeing any medically appropriate health professional who is free immediately
Cancer	0	2
Dementia	0	1
Heart and lung diseases	1	1
Learning disability	0	0
Mental health	0	1

Table 24: When you received a diagnosis and explanation of treatment or support options

Conditions	Seeing a health professional, you normally see but you may have to wait	Seeing any medically appropriate health professional who is free immediately
Cancer	0	2
Dementia	1	0
Heart and lung diseases	1	0
Learning disability	0	1
Mental health	0	1

Table 25: During your initial treatment or support

Conditions	Seeing a health professional, you normally see but you may have to wait	Seeing any medically appropriate health professional who is free immediately
Cancer	0	2
Dementia	0	1
Heart and lung diseases	1	0
Learning disability	0	0
Mental health	0	1

Table 26: During your long-term support

Conditions	Seeing a health professional, you normally see but you may have to wait	Seeing any medically appropriate health professional who is free immediately
Cancer	0	2
Dementia	0	1
Heart and lung diseases	1	0
Learning disability	0	0
Mental health	0	1

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?

Conditions	A lot of support	Some support	I don't need support	**Don't** know
Cancer	1	0	2	0
Dementia	0	1	0	0
Heart and lung diseases	0	1	0	0
Learning disability	1	0	0	0
Mental health	0	0	1	0

What could the NHS do to help you stay healthy or manage any condition you have?

Heart and lung diseases:

- *"Get the managers to sort out a proper and efficient service."*
- *"Get them to follow patients through the assessment & treatment stage."*
- *"Keep promises to triage patients at A&E quickly, not just leave everyone waiting."*

Further comments

Heart and lung diseases

- *"Basically, the hospital managers are failing their staff and patients."*

In focus: what is important to families of seriously ill and disabled children about health and care services?

As part of our research activity, Healthwatch Warrington conducted a focus group in collaboration with local charity *Tree of Hope* with families of seriously ill and disabled children in order to gain specific insight into the views of people accessing services. This focus group took place on 25th April 2019, and was attended by 10 people.

The key issues were perceived to be services not linking up and working well together, access to provision once a need is identified, and funding processes not taking all factors into account. Below is a selection of views and experiences from attendees:

- *“Services must work better together to achieve outcomes.”*
- *“Once EHCP plans are agreed there is never the right funding or organisations to fulfil needs and agencies argue over who has responsibility to fund. Despite this all being statutory funding and ultimately from the same taxes we pay to the government.”*
- *“Everything is focused on the here and now, the current year’s budget and what they can/cannot spend. Never mind the fact that slightly more spent on one child in a financial year may actually save the same services a lot more money over the coming few years. Very short sighted and no long-term vision.”*
- *“Serious and complex disabilities are often very similar or have the same ‘label’, though rarely do they have the exact same needs. Clinicians and services want to put everyone into pigeon holes and treat them exactly the same. In reality, every child and situation is very different and the greater the level of need, the greater the flexibility their needs to be.”*
- *“Access to the right equipment at the right time is difficult. In the time from assessment and referral to a service, our children grow and/or their needs change, implementing the whole process has to start again and this is costly and time consuming.”*
- *“The specialists we have to see all have such different knowledge and work that we accept that there will be travel to see experts and duplication in some areas. However, where appointments are linked to areas such as education, health and social care, there is much to do to really ensure we have less repetition as services are working better together, i.e. joined up administration, single records and access for all agencies involved.”*
- *“Our child was just out of the criteria for the SDR operation being funded, despite our consultant saying that it would benefit him. We have had to fundraise for this ourselves as well as the physiotherapy afterwards to make sure the operation was as successful as it could be. The support we receive from the health and social care sector is minimal as we are means tested. We do own our house and have one of us working full time, however, once the mortgage and bills are paid, living costs associated with a disabled child as well as an older sibling to care for; we are far worse off than families we see at school and clinics where neither work and they live in social housing. If we didn’t have our personal pride, and my husband’s hard work to build his career, we would be better off if we acknowledged the stress we were under, ceased work and claimed benefits. The system doesn’t inspire confidence or encourage us to support ourselves.”*

In focus: what is important to adults with learning disabilities about health and care services?

As part of our research activity, Healthwatch Warrington conducted a focus group in collaboration with local advocacy service *Speak Up Warrington* for adults with learning disabilities in order to gain specific insight into the views of people accessing services. This focus group took place on 16th April 2019, and was attended by 30 people. The main issues raised by people included:

- Access to services - numerous people with physical disabilities talked about access to services out of area being difficult.
- Listening to people.
- Training for NHS staff to better understand issues for adults with learning disabilities - people said that at times they felt misunderstood by staff or that they didn't understand what the healthcare professional was talking about as they were using "big words".
- A lot of service users said that they often felt that they were rushed out of their GP appointment before they had the time to process the information that was given to them; "*I would like my doctor to take more time with me as sometimes, because of my LD, it takes me longer to process information*."

healthwatch

NHS Long Term Plan Report

Chapter 10 - Healthwatch Wirral

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what would you do?

It's your NHS. Have your say.

Wirral

Wirral is a borough of contrasts, both in its physical characteristics and demographics. Rural areas and urban and industrialised areas sit side by side in a compact peninsula of just 60 square miles and 24 miles of coastline.

The most recent population figures for Wirral show the population was 322,796 in 2017, making it one of the largest metropolitan boroughs in England.

Demographically, Wirral differs slightly to England, as it has a lower proportion of younger adults in their 20s and 30s and a higher proportion of older people.

In addition, life expectancy varies by around 10 years between wards in the East and West of Wirral, reflecting the large inequalities which are apparent in the Borough.

Wirral is one of the 20% most deprived boroughs in England and about a quarter of children live in low income families. Poorer health outcomes are present in these areas, with people more likely to smoke, have lower levels of physical activity and poor diets. This leads to lower life expectancy for both men and women, being lower than the national average in England.

Wirral also has an older population when compared to the national average, especially those over 65 - with one in three living alone. Local priorities in Wirral include a healthy older age, a positive start in life and keeping people well by reducing alcohol and tobacco use and lowering blood pressure.

Wirral does however, perform well compared to other, demographically similar areas on a range of factors such as homelessness and educational attainment. The percentage of children classed as being ready for school and attainment at GCSE are above average - and these are both hugely important for the future prosperity of Wirral residents, given that education is an established route out of poverty.[12]

On the Wirral we received 320 survey responses, consisting of 257 general surveys and 63 specific condition surveys. There were also 24 attendees across two specific focus group events.

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[12] Source:
https://www.wirralintelligenceservice.org/this-is-wirral/wirral-population/
https://www.cheshireandmerseysidepartnership.co.uk/your-area/wirral

Wirral

Cheshire & Merseyside
Health & Care Partnership

"Be the reason someone receives better care today"

If Wirral was a village of just 100 people...

35 Children are overweight or obese by year 6

16 Adults suffer from depression

10 5-16 year olds have a MH disorder

28 Will die from cancer

60 Adults are over-weight or obese

3 Adults under 40 have Type 2 diabetes

57 people are living with a long term condition

11 Will die from heart disease

18 Are smokers

82 Is the average age that women will live to

19 People take less than 30 mins exercise a week

78 Is the average age that men will live to

9 People are over 75

Statistics from PHE are for the Wirral Local Authority area, pop: 321,000

Summary of Findings:

What matters most to people on the Wirral?

- When asked to consider what is most important to people to help them to lead 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.
- Additionally, when asked to think of one thing that would help them to lead a healthy life, respondents primarily focused on factors relating to health information and education, access to health and wellbeing activity, access to community and transport support, and timely services to healthcare.
- We asked people to tell us about what they feel is important to keep independence and stay healthy in later life. Being able to stay in their own home for as long as possible was by far the most important factor.
- 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. Primarily factors focused upon community and home support, loneliness, communication and accessibility.
- When asked about managing and choosing support and treatment, respondents 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.
- We also asked respondents to tell us one more thing that would help them to manage and choose how the NHS supports them. Emerging themes included community care and support, finance, resources and investment, appointments and use of technology.
- People in the Wirral told us that being able to talk to their doctor or other health professional and having absolute confidence that their personal data is managed well and kept secure, were both the most important factors when interacting with the NHS.
- When asked to consider what respondents felt was most important when interacting with the NHS, people said that the most highly rated factor was being able to talk to the doctor or other health care professionals wherever they were.
- Respondents were then asked to think about one more thing that needs to change to help them to successfully manage health and care. These answers have been categorised under emerging themes, which included factors relating to technology, communication and support, GP appointments and information and self-help provision. People commented on the need for individual support for those in need to give reassurance to other family members and get more home care support.
- People with Cancer told us they were positive about the quality of assessment, treatment and support, as well as the time they had to wait at each stage. Although ability to access ongoing support provided a mixed response.
- People with multiple long-term conditions generally felt this made it harder to access support.
- Those with specific conditions felt that communications could be improved.

Survey results

The following sections now break down the results of the 320 responses across Wirral to the surveys designed by Healthwatch England. The first sections use the 257 responses to the general 'People's general experiences of health and care services' survey, before breaking down the 63 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.

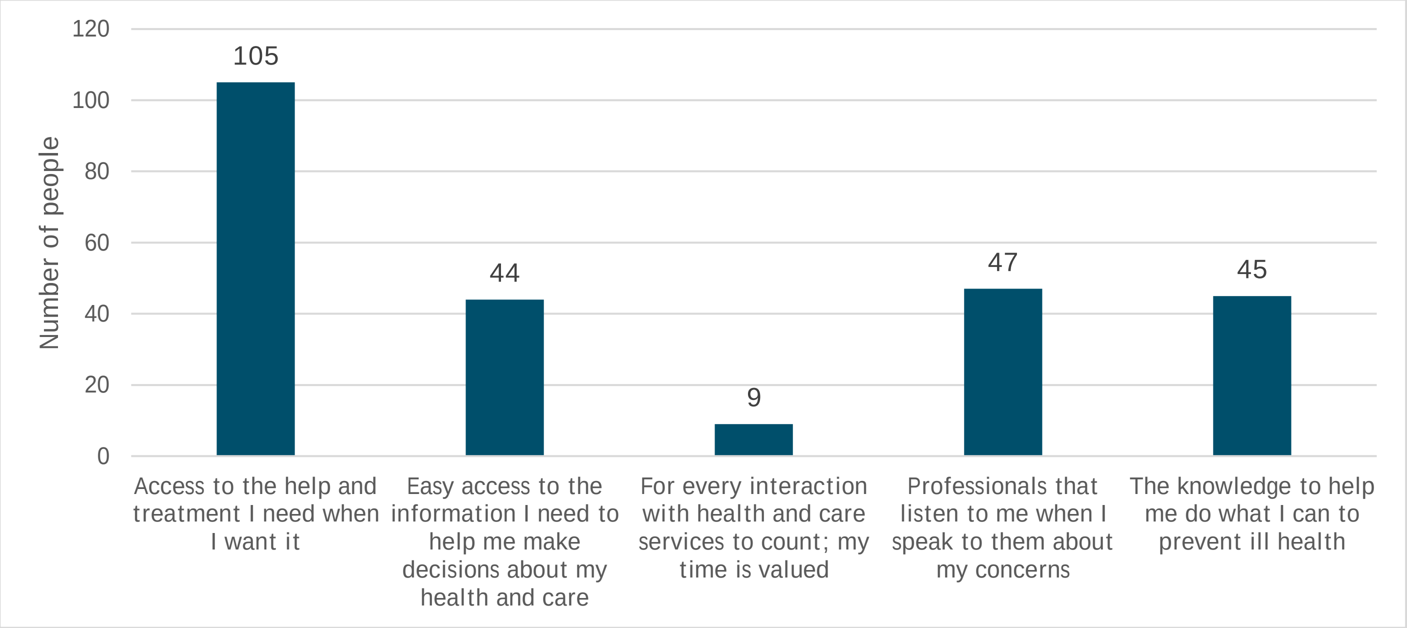
For each of these, people were asked to choose which of a number of options was most important to them. Following this, people were asked to rate each of the options on a scale of 'very important' to 'not important at all'. Therefore, more than one option could be considered 'very important'. Finally, 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, Chart 1 shows that having access to the help and treatment needed when it is wanted was deemed to be most important by people responding to the survey. 250people responded to this question.

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



However, when asked to rate on a scale of very important to not important at all, all other options were considered either very important or important as Table 1 below shows. Up to 247 people responded to this question, though 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
Access to the help and treatment I need when I want it	186	53	3	0	1
Professionals that listen to me when I speak to them about my concerns	169	64	6	0	1
Having the knowledge to help me do what I can to prevent ill health	148	79	16	3	1
Easy access to the information I need to help me make decisions about my health and care	145	80	11	2	2
For every interaction with health and care services to count; my time is valued	123	82	22	5	2

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, so, answers were collated into themes and summarised below:

Many respondents repeatedly asked for more affordable healthier food options, with meal plan education and information. They also thought that free access to physical exercise activities and facilities was a need for communities. Timely appointments and support were also mentioned. The comments included:

Health information and education

Respondents highlighted a good use of radio to inform people on health advice and education, whilst others mentioned the need for more education on healthy meal plans.

- *“Health advice on radio stations is very good - especially for people travelling long distances.”*
- *“More education on how to cook healthy meals on a budget - particularly through high school.”*

Accessibility to health and wellbeing activity

People mentioned the need for more access to healthier and affordable activities in their local areas. People commented on the following:

- *“Better access to facilities that could help me improve my life such as cheaper access to gyms or lifestyle classes.”*
- *“Free exercise classes and gym, especially to the community over 50 years old.”*
- *“Programs to help and encourage people to exercise and to eat healthily.”*
- *“Have local NHS sponsored keep fit/exercise facilities.”*

- *"Easier access to appointments before/after work hours (9-5)."*
- *"Free access to council gym, exercise classes and other facilities."*
- *"More diet advice available, free diet plans and affordable healthy food."*

Community and transport support

- *"Reduce people smoking in all public areas."*
- *"Better transport links to local hospitals for physically frail people."*
- *"The government to make a sincere effort to cut air pollution dramatically so the health of all our nation improves as soon as possible."*

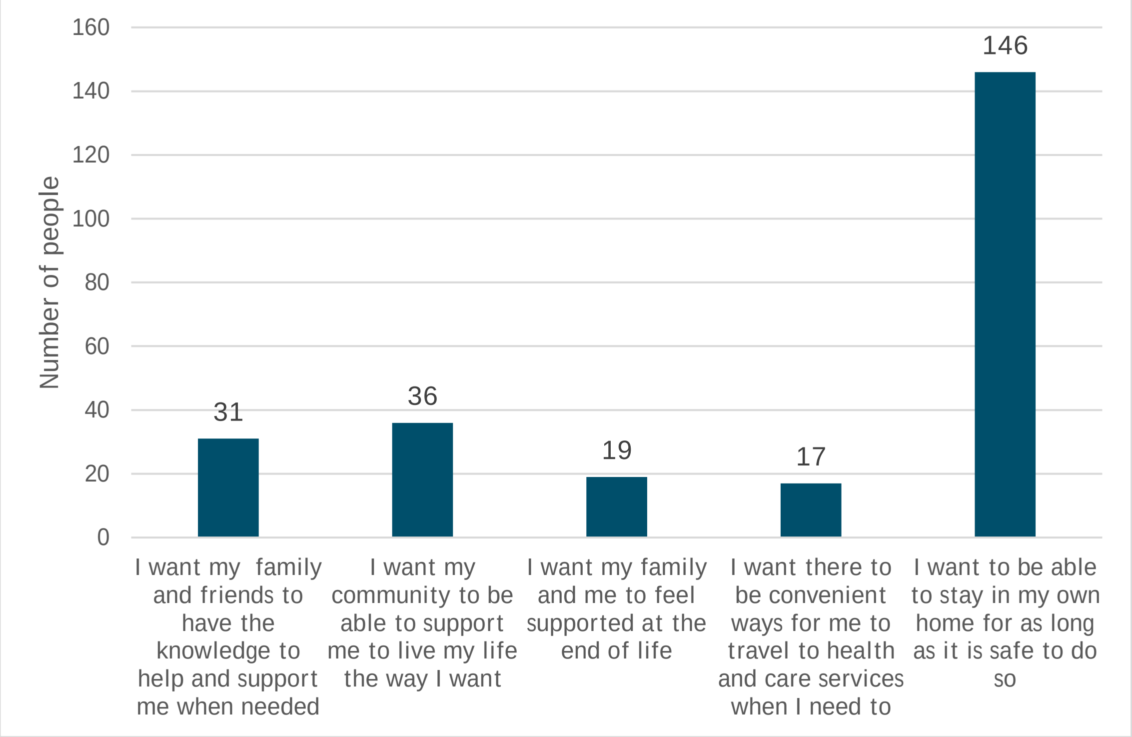
Timely services for health care

- *"Ability to speed up physiotherapy appointments, in our area we now have to wait 6 months for our first consultation. If I have problems with sciatica for instance what good is an appointment 6 months later. Why can't we go back to having physiotherapy in our own surgeries, I have been told that it costs no more and we would have been seen quicker. This is a political decision made without duty of care to people suffering great pain."*
- *"NHS not to be privatised. Medical professionals to understand severe hearing disability and deafness. Less computers as substitute for people."*
- *"Make it easier to get an appointment with my doctor. Currently I have to sit waiting for 8am then try and phone, often it's an engaged tone. Then you can't get an appointment same day."*
- *"Already had to wait six months for an operation and so I had to pay for my operation as I was in severe pain."*
- *"To be able to see a doctor sooner not wait nearly 2 weeks for an appointment."*

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). 249 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 243 people responded to this question, though 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	202	30	8	2	1
I want my family and me to feel supported at the end of life	169	56	7	2	1

I want there to be convenient ways for me to travel to health and care services when I need to	152	73	13	1	0
I want my family and friends to have the knowledge, to help and support me when needed	129	83	23	5	0
I want my community to be able to support me to live my life the way I want	120	83	29	6	1

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 question so answers were collated into themes and summarised below:

Community and home support

People commented on the need for individual support for those in need, to give reassurance to other family members and get more home care support. People said the following:

- *“Help for my kids. I don't want to be a burden but I don't want to go into a home. They don't either.”*
- *“I don't want to be a burden to my wife so I want care to be available if I need it.”*
- *“Knowing that my father will be looked after if I can't keep doing it.”*
- *“Support in the community for long term health conditions including back pain/chronic pain support outside of NHS services, e.g. local community centre.”*
- *“Medical staff visiting elderly patients at home.”*
- *“More care needs to be put into the community to avoid hospital admissions.”*
- *“Someone calling once a day to check I can walk to the kitchen and bathroom”*
- *“Have more supported living accommodation in Wirral to care for families as I am a carer who looks after two people.”*

Health and social care and activities

- *“Free access to activities in leisure centres.”*
- *“Local access to help and community services”*
- *“More access to social groups.”*
- *“Funding to push the elderly to exercise, eat healthily and to drink more water."*

Loneliness

- *“Recognition (and investment and resources) from NHS and council provided services that public transport (links, accessibility, cost, frequency) is essential to older people/those with poor mobility for accessing health services/appointments. As loneliness and isolation is the biggest killer of older people who live alone, the area of public transport is grossly neglected. What is the point of telling me about a day service or group I can access if I have no way of getting there?”*

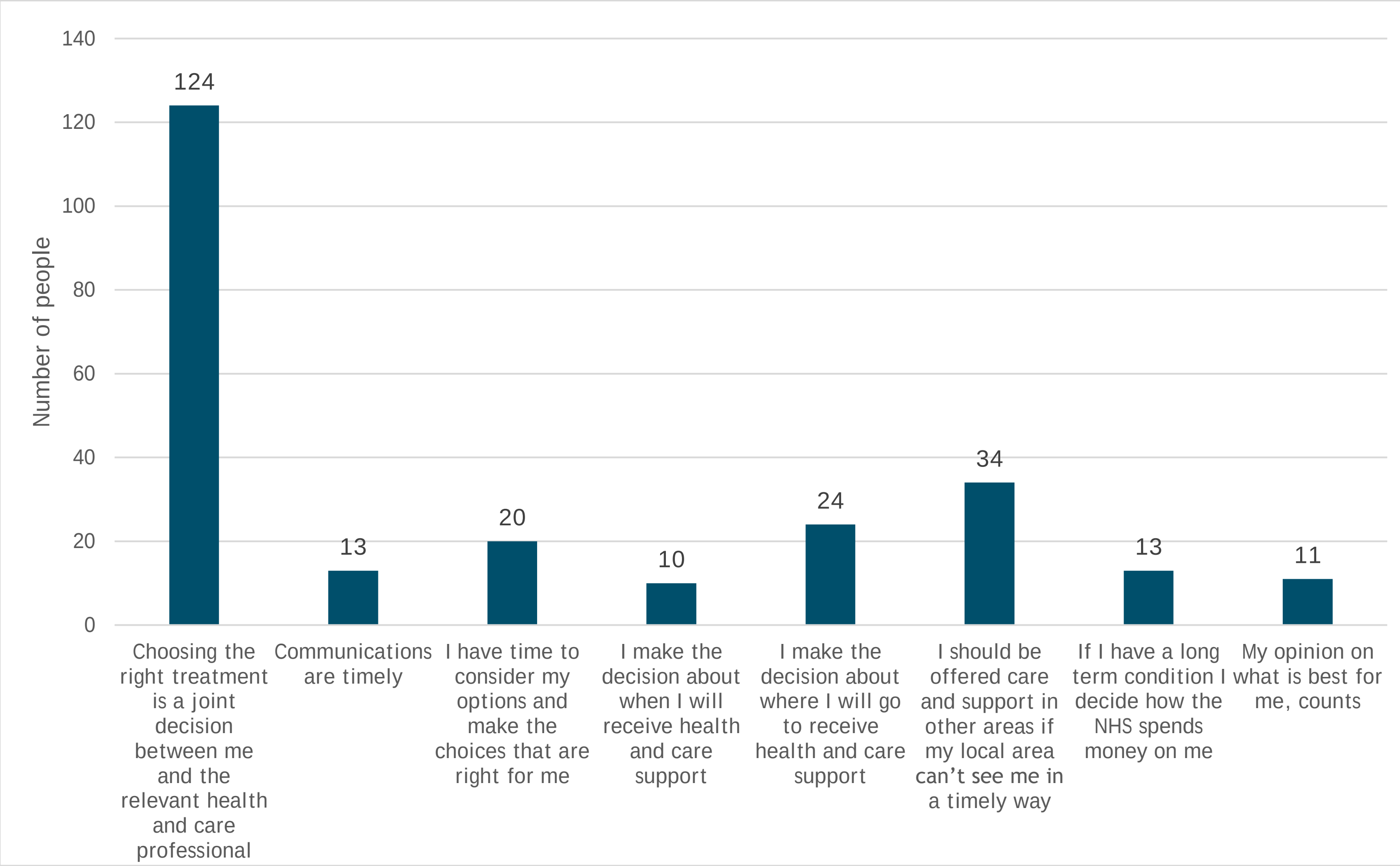
Health care communication and access

- *"The interface between council care and the NHS needs to be smoother and not be a matter for the patient to sort out. In political terms, there shouldn't be a tussle between local government and the NHS over who pays for what. Perhaps it is time to fix individual patient budgets which can be allocated to hospital/GP/council, rather than setting overall budgets."*
- *"More care in the community for those who need to access it."*
- *"Easy access to professional care including domiciliary care and help to keep people out of care homes or hospitals, not charities who are not always clinically trained, are run as businesses with the CEOs on mega salaries."*

Managing and choosing support and treatment

Chart 3 shows that people we spoke to in the Wirral 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. 249 people responded to this question.

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



When asked to select how important different factors were on a scale of very important to not important at all, people mostly considered that timely communications were very important. This is detailed in Table 3 below, in order of the options that most people classed as being very important. Up to 252 people responded to tis question, though not everyone responded to eavh 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
Communications are timely	163	64	12	0	0
Choosing the right treatment is a joint decision between me and the relevant health and care professional	159	84	9	0	0
I have time to consider my options and make the choices that are right for me	121	102	13	4	0
I make the decision about where I will go to receive health and care support	112	83	38	3	2
I should be offered care and support in other areas if my local area can't see me in a timely way	108	106	26	3	1
My opinion on what is best for me, counts	106	102	30	0	0
I make the decision about when I will receive health and care support	92	96	43	9	0
If I have a long-term condition, I decide how the NHS spends money on me	79	92	32	13	2

We also asked respondents to tell us one more thing that would help them to manage and choose how the NHS supports them. Answers have been collated and categorised under emerging themes.

Community and care support

People commented on their individual service experience and the support they need, covering staff training and information on getting help and support. The comments included:

- *"More timely primary care appointments and a short secondary care waiting time"*
- *"My experience of Arrowe Park is being taken towards unsuitable for my condition."*
- *"More local authority care in my older age. Not with private, for profit only, older people's care."*
- *"Trained health professionals that understand the latest research in regards to ME/CFS"*
- *"I need to fit appointments around my work and caring for my father so the out of hours appointments have been good for me."*
- *"Better information on what professional help and support is available in the local area, not charities who are not always clinically trained, are run as businesses with the CEO's on mega salaries."*

Finance, resources and investment

People commented on the NHS investment and financial circumstances to support the community, others commented on the transport and car parking service charges. The comments included:

- *“Ability to see a consultant without having to resort to paying for a private consultation. Many people cannot afford this usually large amount; therefore, the system is unfair. If other methods of treatment have failed, then surely it is not too much to ask to see a consultant.”*
- *“Sufficient funding of the NHS to ensure local health care needs ARE met and that the best care is given. Privatisation of the NHS is dangerous as there is evidence from health professionals that some outsourced health services are poor.”*
- *“Investment and resources in health and social care services in my community as prevention and community-based services would give me freedom and genuine choice as to how I manage and choose the way in which the NHS supports me.”*
- *“Parking charges visiting hospitals either as visitor, inpatient or attending clinics. Not everybody can afford travel costs whether own or public transport and car park charges feel like a stealth tax and being penalised for somebody's illness.”*

Appointments and health care experiences

Many respondents spoke about the accessibility people have at their local GP, some felt that they should be spoken to more as an individual. Others spoke of their experience using the service and how they were treated. The comments are outlined below:

- *“Being able to see a GP without having to phone up several times to get an appointment.”*
- *“I would like the health care professionals to listen and talk to patients like normal human beings instead of imbeciles. I would like more than 5 minutes with the Doctor.”*
- *“Hospital appointment times - e.g. waited 4 months to see a specialist - had to pay privately.”*
- *“Wirral NHS do not have enough resources to meet demand.”*
- *“More accessible GP appointments with more support from the same GP.”*
- *“More clinics providing healthcare other than seeing a doctor.”*
- *“Best case scenario - in my opinion, would be if I could have treatment to alleviate pain in an old bad leg that was operated on 60 years ago, but has now been made bad by injuries incurred 2.5 years ago to other leg breaking Tibia and Fibia and leaning on this has killed old bad leg. Now have to walk with stick even though the new break 2.5 years ago has now mended. Perhaps steroid injections are the answer or perhaps another operation?”*
- *“Proper access. It is almost impossible to get an appointment same day with my GP and online booking for non-urgent appointment is weeks away. Sometimes it might be "urgent" but it could be something that needs seeing to sooner rather than later.”*
- *“I need my confidence restoring in hospitals... I’ve just watched my sister go into hospital with gall stones and within three days she had multiple organ failure and died. She led a very healthy lifestyle, I think doctors acted slowly, she was not CT scanned for 24 hours, probably because of NHS money restraints, the pancreas was in trouble and doctors didn’t scan her until the damage was setting in. I do not expect a doctor to say “we’re as baffled as you are” how on earth is that meant to reassure us? she was dying before our eyes; we don’t even know if it was sepsis. That frightens me. I would never go near Whiston Hospital again.”*

Use of Technology

- *“Appointment for doctor’s appointments to be available.”*

- *“I'm not sure to be honest - at the moment I find it good to access the NHS - online resources especially.”*

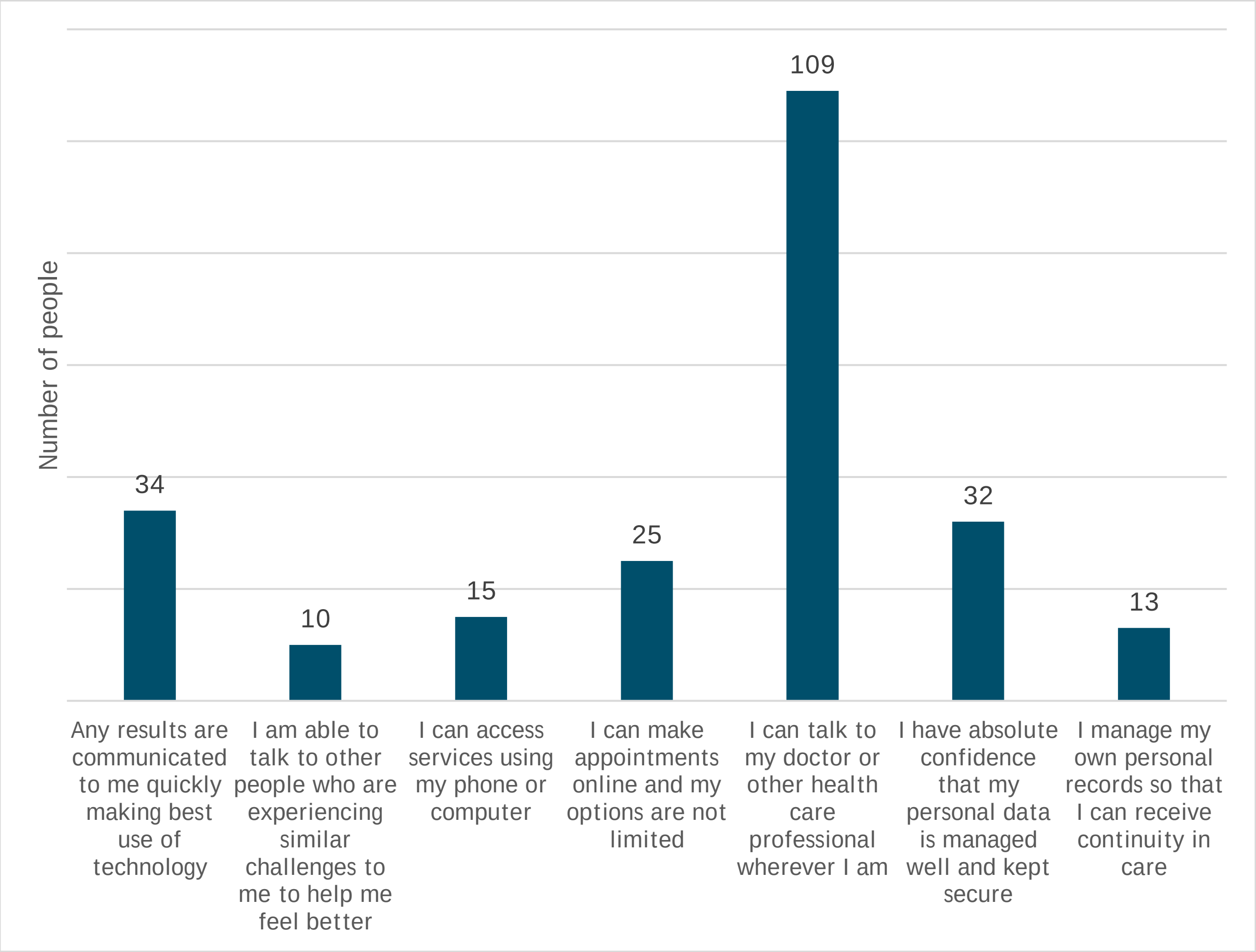
Engaging people in health service delivery

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.

People in the Wirral told us that being able to talk to their doctor or other health professional and having absolute confidence that their personal data is managed well and kept secure, were both deemed as the most important when interacting with the NHS (see Chart 4 below). 238 people responded to this question.

Chart 4: What is most important to you 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 (Table 4), people said that the most highly rated factor was being able to talk to the doctor or other health care professionals where ever they may be. Up to 244 people responded to this question, though not everyone responded to each option.

Table 4: 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 can talk to my doctor or other health care professional wherever I am	141	81	17	1	0
Any results are communicated to me quickly making best use of technology	131	78	22	4	1
I have absolute confidence that my personal data is managed well and kept secure	130	83	28	2	1
I can access services using my phone or computer	95	102	33	5	2
I can make appointments online and my options are not limited	94	95	26	13	3
I manage my own personal records so that I can receive continuity in care	72	80	65	18	3
I am able to talk to other people who are experiencing similar challenges to me to help me feel better	67	68	60	31	10

Respondents were then asked to think about one more thing that needs to change to help them to successfully manage health and care. These answers have been categorised under emerging themes.

Technology

A number of people talked about not only the continued use of technology for a more accessible service and recording their medical records online, but also an awareness that not everybody is able to use technology:

- *“Still have to appreciate that some of the ageing population do not use the internet/are not smart phone savvy so provision has to be made for them for next 10-20 years.”*
- *“Having an online repository of medical history/test results/treatment programs would be a great boon. For families, this should be accessible by carers, partners, parents etc - subject to agreed access requests and restrictions.”*
- *“Online access to my health records.”*
- *“Please don't expect everyone to be I.T. literate and do everything online, we need access to human beings.”*

Communication and support

Communication was also an emerging theme amongst respondents and in particular, how they are communicated to:

- *"Better communication & less waiting times for results."*
- *"Not having to repeat things."*
- *"Easy access to local services and more consistent approach to providing services. There are too many changes which are not communicated well to the local public."*
- *"Reliable and prompt communication from hospital/doctor/nurse etc. after having had procedures/treatments at hospitals or in surgeries. Notifications by phone/text or email/letter."*
- *"Live in Extra Care Supported Living Accommodation which is sadly lacking on the Wirral."*

GP Appointments

GP appointments were also mentioned by respondents, and for a number of reasons, including accessibility, i.e. ease of making an appointment, to quality of appointment, including how much time people get to spend with their GP:

- *"GP Practices and appointments need to be more accessible for people who work"*
- *"Easier access to GP appointments or nursing staff who can help me when needed."*
- *"Not to feel anxious about contacting health care professionals. It is easy to think they are too pressured to deal with your problem."*
- *"To be able to have continuity with my own doctor."*
- *"Apps to manage appointments and access repeat prescriptions."*
- *"Face to face contact with health professionals where I have time to discuss my health concern, am listened to and feel confident that I am receiving the best care available for me in relation to my diagnosis/problem and not due to cost or doing it on the cheap."*
- *"To see a GP at my practice when I need to and not be asked if it's an emergency when I ask for an appointment. All the days appointments have been taken in 10 minutes from 8am opening."*

Information, self-help provision and community

A number of people mentioned the importance of information, training and self-help mechanisms through holistic community approaches:

- *"More advice and education available face-to-face closer to home."*
- *"Understanding of my hearing disability and limited use of technology."*
- *"Access to self-help groups and alternative therapies. Also, free access to gyms and swimming."*
- *"Meeting other patients with my concerns, Fibro, Sjögren's, DDD, COPD, chronic Neuropathy, etc."*
- *"Regular updates on what is available to me via email or text."*
- *"Knowing where to go and who provides what. There is no uniformity in help across the Wirral."*
- *"Preventative focus in primary care with an approach which is holistic and about women's health and wellbeing not just the health of individual body parts, e.g. breasts, cervix, which is what's on offer at the moment."*

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 63 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	2
Cancer	30
Dementia	4
Heart and lung diseases	6
Learning disability	0
Long-term condition e.g. diabetes, arthritis	14
Mental Health	7

Table 6: Who are you responding on behalf of?

Condition	Myself	Someone else
Autism	0	2
Cancer	26	4
Dementia	1	3
Heart and lung diseases	3	3
Learning disability	0	0
Long-term condition e.g. diabetes, arthritis	11	3
Mental Health	6	1

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

Condition	Yes	No
Autism	1	1
Cancer	27	3

Dementia	3	1
Heart and lung diseases	3	3
Learning disability	0	0
Long-term condition e.g. diabetes, arthritis	11	3
Mental Health	6	1

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	Not applicable
Autism	1	1	0	0
Cancer	23	3	4	0
Dementia	1	0	3	0
Heart and lung diseases	2	0	3	0
Learning disability	0	0	0	0
Long-term condition e.g. diabetes, arthritis	5	3	5	0
Mental Health	2	3	2	0

Tell us whether the support met your needs and how it could have been improved.

Autism:

- *“We realised the issues but no-one would listen - four years getting a diagnosis.”*

Cancer:

- *“I was diagnosed with early stage breast cancer (DCIS) and needed a lumpectomy, 2 lymph nodes removed and follow-up radiotherapy. Whilst it was detected early, for which I was very grateful, I was refused a reassurance scan afterwards. Regardless of the stage of detection, from a mental health perspective, all patients with any kind of ‘cancer’ diagnosis, should be offered the choice.”*
- *“Further options for treatment were not explored. Only treatment offered was a surgical intervention but on pushing the consultant a different treatment was reluctantly informed.”*
- *“Saw GP who made a referral quickly.”*
- *“It took a long time before I was told I had an adeno cystic cancer at the back of my nose, I had a polyp which was removed and a biopsy taken. I do not think I received any support. I did not seek any support.”*
- *"I did not know who to ask.”*
- *“MacMillan were only sort of helpful."*
- *“Met my needs 100%.”*
- *“Lack of support when not accessing cancer services (i.e. basic NHS).”*

- *"The support met my needs although it took three years to identify and diagnose fibromyalgia."*
- *"Multi-disciplinary team has provided excellent support."*
- *"Quick diagnosis, relevant referrals and good treatment so far."*
- *"So far I've been happy."*
- *"Communication between consultants at the different hospitals could have been better on the time of initial diagnosis."*
- *"Went to Countess of Chester for 3.5 years before GIST tumour was found - they initially thought it was Pancreatic but diagnosed as GIST at Royal Liverpool."*

Dementia:

- *"Quicker appointments. Less time in between appointments."*
- *"Having a regular carer would have been good. Different ones each time was not good for my husband and tiresome for me telling them over and over what we needed."*

Heart and lung diseases:

- *"No support really apart from my GP."*
- *"No support for COPD sufferers."*
- *"I couldn't get a home visit and my daughter had to get me to the surgery."*

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

- *"Visit to GP, sent for x-ray, prescribed meds, was told I had 'wear and tear'. That was it, no info given."*
- *"Basically, felt like I had painkillers given me and left to plod on. Was scary having no info on the condition. No info on impact on health, or what to expect, no advice on how best to help ease the condition or to slow down the degeneration."*
- *"More info at diagnosis would be good, along with other options such as being told a referral to MSK is possible."*
- *"No coordination in care between primary and secondary care, no continuity of care, no looking at the whole picture."*
- *"Not really. There was no continuity in a large practice. Balancing treatment with five long term conditions is not achievable in an eight-minute consultation unless the GP understands that the easiest option is likely to upset the other four conditions."*
- *"Pain relief could have been provided earlier."*
- *"It met my needs as I was sent for blood tests and found out I needed B12 injections."*
- *"It did in the end but after many appointments. Still not fully sorted."*

Mental Health:

- *"GP just put me on tablets with no follow up."*
- *"I was in a mental health crisis and eventually taken to A&E at Arrowe Park. Having waited for more than half an hour in a large and busy waiting area my distress increased. Eventually seen by a nurse and given medication."*
- *"Not enough mental health services and support for people on the Wirral."*
- *"Doctor met my needs and offered me the right support & was very helpful."*

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	1	0	1	0	0
Cancer	10	11	5	2	1	1
Dementia	0	3	1	0	0	0
Heart and lung diseases	0	0	3	1	0	2
Learning disability	0	0	0	0	0	0
Long-term condition e.g. diabetes, arthritis	0	7	1	4	0	2
Mental Health	0	2	1	3	1	0

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

Condition	Yes	No
Autism	0	2
Cancer	15	15
Dementia	3	1
Heart and lung diseases	4	2
Learning disability	0	0
Long-term condition e.g. diabetes, arthritis	7	6
Mental Health	2	4

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	0	0	0
Cancer	2	9	0	2	2
Dementia	0	1	1	1	0
Heart and lung diseases	0	0	4	0	0
Learning disability	0	0	0	0	0
Long-term condition e.g. diabetes, arthritis	0	1	5	1	0

Mental Health	0	1	1	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	0	1	0	0	0	1
Cancer	1	4	8	10	7	0
Dementia	0	2	2	0	0	0
Heart and lung diseases	0	4	2	0	0	0
Learning disability	0	0	0	0	0	0
Long-term condition e.g. diabetes, arthritis	2	4	6	1	0	1
Mental health	0	5	1	1	0	0

Autism:

- *"Four years to see a consultant."*

Cancer:

- "Diagnosed July, operated August & radiotherapy during November."
- "After I had my polypectomy, I waited a long time and did not realise I should have had someone with me or that I would have been told of my diagnosis."
- "Two weeks."
- "Three months."
- "Difficult at first, taken ill whilst travelling and spent time in a hospital out of area and then referred as an outpatient."
- "From initial referral to MDT progress was rapid."
- "Sent for repeated X-Rays of wrong area of my body."
- "I was diagnosed within hours of attending hospital."
- "Long wait for results after surgery."
- "When called back to hospital for diagnosis, given 3pm appointment but left to 5:30pm before being told that you have Pancreatic Cancer."
- "Two weeks for surgery - chemotherapy commenced when appropriate."

Dementia:

- *"The initial diagnosis took time, as expected really but getting care and respite break was good."*

Heart and lung diseases:

- *"Couldn't get diagnosis."*
- *"Waited more than six months to see a consultant, this only happened when I was admitted to hospital."*

- *"Two weeks for doctor and nearly a month for follow ups."*

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

- *"The x-ray and diagnosis were very quick."*
- *"Was dismissed frequently by the GP despite the fact the previous visits had been rare."*
- *"I have a number of rare conditions. I had to wait a long time to get diagnosed and unfortunately my health had to deteriorate a great deal before diagnosis was possible. Better coordination is needed for earlier diagnosis and treatment and to prevent long term damage."*
- *"Only due to needing repeating blood tests and needing to await results each time."*
- *"Accessing the GP took over a week but I had a few visits before being referred on in the system."*
- *"I am waiting to see a physio and was initially told this would be within two weeks. It has been almost six months and the condition has worsened."*

Mental Health:

- *"12 months or more."*
- *"Ten weeks eventually to see 'change' for CBT."*

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	0	1	0	0	0	1
Cancer	1	3	4	13	8	1
Dementia	0	1	3	0	0	0
Heart and lung diseases	0	6	0	0	0	0
Learning disability	0	0	0	0	0	0
Long-term condition e.g. diabetes, arthritis	3	6	2	2	0	1
Mental health	0	5	1	1	0	0

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

Condition	Yes	No
Autism	2	0
Cancer	20	8
Dementia	4	0
Heart and lung diseases	2	4
Learning disability	0	0

Long-term condition e.g. diabetes, arthritis	8	6
Mental health	5	2

If you accessed support what aspect could be improved?

Cancer:

- *"More counselling offered."*
- *"Computerised systems should be interlinked."*

Dementia:

- *"More practical support."*
- *"Speed of funding, the cost was worrying me."*

Heart and lung diseases:

- *"More info on C.O.P.D."*
- *"Same nurses not different ones."*

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

- *"Different medical experts didn't work together, care fragmented, no one coordinating care, communication between primary care and out of borough specialist hospitals/medics very poor."*
- *"More medical staff."*
- *"Due to my condition (arthritis) I had to cancel some appointments due to pain and waiting for the next one to come took some time."*

Mental Health:

- *"Mental health access other than tablets. Counselling and mindfulness."*
- *"More respite."*
- *"I think maybe bring told to get another appointment to check up on you."*

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

Condition	Yes	No
Autism	0	2
Cancer	3	27
Dementia	0	4
Heart and lung diseases	0	6
Learning disability	0	0
Long-term condition e.g. diabetes, arthritis	8	6
Mental health	5	2

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	0	0	0	0	1
Cancer	0	10	5	2	7	2
Dementia	0	0	3	1	0	0
Heart and lung diseases	0	0	1	5	0	0
Learning disability	0	0	0	0	0	0
Long-term condition e.g. diabetes, arthritis	1	1	1	1	1	1
Mental health	0	1	1	0	0	0

Please tell us more about the length of time you waited.

Cancer:

- *"Three weeks."*
- *"One week."*
- *"Difficulty arose as referred from hospital away from home."*
- *"Within two weeks of GP referring me to Aintree with lump in neck."*
- *"Had to wait until femur actually snapped before things actually happened."*

Dementia:

- *"Around six weeks was suggested but it turned out to be nearer to eight."*

Heart and lung diseases:

- *"Only when I came into hospital and saw a consultant."*
- *"Long-term condition e.g. diabetes, arthritis."*

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

- *"I attended physio through NHS but now fund my own physio it helps but I can only afford monthly sessions except if the pain is too intense."*
- *"When eventually diagnosis occurred (in A&E) the hospital dealt with it quickly."*

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	1	0	0	1	0
Cancer	9	3	2	8	0	3	5
Dementia	0	1	1	2	0	0	0

Heart and lung diseases	0	0	4	1	0	1	0
Learning disability	0	0	0	0	0	0	0
Long-term condition e.g. diabetes, arthritis	0	1	1	5	1	2	4
Mental health	0	1	3	3	0	0	0

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

Condition	Yes	No	Somewhat
Autism	1	1	0
Cancer	17	2	4
Dementia	1	1	2
Heart and lung diseases	1	4	1
Learning disability	0	0	0
Long-term condition e.g. diabetes, arthritis	1	4	8
Mental health	4	3	0

Please explain how the care did or did not meet your expectations and how could it be improved?

Cancer:

- *“Only found out about local cancer support charities after accessing a psychology referral.”*
- *“I did not know what to expect and felt a little lost. I do not feel I got any support.”*
- *“Better financial and emotional support.”*
- *“It did meet expectations.”*

Dementia:

- *“Only one service from Age Concern. I'm not old. Where's the choice?”*
- *“I felt supported and relieved to be listened to.”*

Heart and lung diseases:

- *“Podiatry have to wait at least three months for an appointment. Had to get in touch with Consultants PA to notify the doctor about change of medication, otherwise the doctor would not write a prescription. The doctor has still not been notified about tests done six weeks ago.”*
- *“Care needs met/treatment good.”*
- *“No ongoing support for COPD, I could have exercise classes.”*
- *“Only found out about exercise classes from Healthwatch.”*
- *“I need things written because I can't explain to my family what has been said.”*

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

- *“I wasn't given any information on other options.”*
- *“Better coordination is required for better outcomes for people with multi-system conditions, especially those that are rare and require input from multiple hospitals/specialists across different boroughs.”*
- *“I have symptoms that indicate Myeloma. They started in November. A repeat test was refused as the results indicated no further action.”*
- *“Felt I was left to manage the condition on my own.”*
- *“It did meet expectations.”*
- *“Made some conditions manageable, follow up appointments would help more.”*
- *“Getting to hospital and the waiting around often felt like too much on the days my pain was worst.”*

Mental Health:

- *“Too long to wait and not easy to access.”*
- *“I was given medication to help me and also offered further support.”*

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	1	1	0
Cancer	18	2	4
Dementia	2	0	2
Heart and lung diseases	1	4	1
Learning disability	0	0	0
Long-term condition e.g. diabetes, arthritis	2	5	7
Mental health	2	5	0

Please explain how the care did or did not meet your expectations and how could it be improved?

Cancer:

- *“It would have helped if I was given a point of contact, a MacMillan Nurse as I was with my breast cancer diagnosis.”*

Heart and lung diseases:

- *“Not much support when I left hospital.”*
- *“Very poor communication.”*
- *“Have to do everything myself.”*

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

- *“To be told you have a degenerative condition and no information given on it whatsoever left me feeling I was on my own and that there were no other options for support or monitoring.”*
- *“Communication to me, the patient, was ok, but it was not ok from medic to medic especially across different specialties/hospitals/boroughs.”*
- *“I don't get consistent communication at all; I just make my own appointments.”*
- *“Flexible appointment system to help with the pain when it's bad or maybe a "drop-in" set up so I could access on my better days.”*
- *“I have had no follow-up and as this is now in the hands of a so-called specialist, the GPs feel that their job is done.”*

Mental Health:

- *“Communication could be improved.”*

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	1	0	0	0	0	0
Cancer	18	6	0	1	0	2	2
Dementia	0	2	2	0	0	0	0
Heart and lung diseases	3	1	1	0	0	0	1
Learning disability	0	0	0	0	0	0	0
Long-term condition e.g. diabetes, arthritis	3	3	2	1	0	2	3
Mental health	2	1	3	0	0	0	1

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	1	0
Cancer	1	17	1	8
Dementia	0	2	2	0
Heart and lung diseases	1	2	2	1
Learning disability	0	0	0	0

Long-term condition e.g. diabetes, arthritis	4	9	0	1
Mental health	0	4	2	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	1	1	0	0
Cancer	5	11	0	11
Dementia	3	1	0	0
Heart and lung diseases	2	3	0	1
Learning disability	0	0	0	0
Long-term condition e.g. diabetes, arthritis	4	9	0	1
Mental health	1	4	1	1

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	0
Cancer	10	15	1
Dementia	0	4	0
Heart and lung diseases	1	3	2
Learning disability	0	0	0
Long-term condition e.g. diabetes, arthritis	1	8	3
Mental health	3	3	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	1	0	0
Cancer	9	15	1
Dementia	0	4	0
Heart and lung diseases	0	3	3
Learning disability	0	0	0
Long-term condition e.g. diabetes, arthritis	5	5	3
Mental health	2	1	3

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	1	0	0
Cancer	13	10	1
Dementia	0	4	0
Heart and lung diseases	0	4	2
Learning disability	0	0	0
Long-term condition e.g. diabetes, arthritis	5	4	3
Mental health	2	2	2

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	0
Cancer	14	10	1
Dementia	4	0	0
Heart and lung diseases	3	1	2
Learning disability	0	0	0
Long-term condition e.g. diabetes, arthritis	7	3	2
Mental health	3	2	1

Supporting you to have more control over your own care

Table 27: What level of support of 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	0	2	0	0
Cancer	4	14	7	2
Dementia	1	3	0	0
Heart and lung diseases	0	6	0	0
Learning disability	0	0	0	0
Long-term condition e.g. diabetes, arthritis	3	9	0	2
Mental health	1	6	0	0

What could the NHS do to help you stay healthy or manage any condition you have?

Cancer:

- *“Look at a person more ‘holistically’, taking into account other health problems. Earlier detection of other health conditions e.g., screening for skin cancers etc.”*
- *“Make doctors surgeries work full time and not do only 3 days a week with one admin Doctor's receptionist telling you there are no appointments for 3 weeks.”*
- *“Increase funding & staffing levels to all areas of NHS.”*
- *“I would like easy access to the services I need.”*
- *“Provide specific information regarding illness and treatments available, including side effects.”*
- *“Explain my options.”*
- *“Increase frequency of physio treatment to the individual.”*
- *“Continue to provide relevant treatment and access to services.”*
- *"I would love to see more information on living with cancer, including lifestyle - i.e. how I can help myself… diet, exercise etc.”*
- *It's important to feel in control and that I am doing all that I can, not just medical/drugs."*
- *"Current treatment good. Went to clinic at Chester every 6 months but I felt they were not interested - 3.5 years for diagnosis is not good enough.”*

Dementia:

- *“Offer more support for family/respite.”*
- *“Quicker doctor's appointments.”*

Heart and Lung Diseases:

- *“Be able to see the doctor when needed.”*
- *“Give consistent information.”*
- *“More information/advice on how to stay healthy.”*
- *“More proactively give people incentives i.e. gym membership/free classes.”*
- *“Someone to ring when I am struggling.”*

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

- *“More information on self-care as well, such as referral options available if needed.”*
- *“The GP is usually the first line, there need to be more GPs and their level of training needs to be up to date and consistent. All too often when you see a different GP within the same surgery. The outcome of the consultation is radically different, often leaning towards a bias of what that particular GP understands best.”*
- *“Reviews more often than 12 months.”*
- *“I'd like to be checked regularly about blood tests, to see how my B12 is doing and get reminders when they are due next.”*
- *"Follow up appointments.”*
- *“Home visits."*
- *“Free prescriptions.”*
- *“Easier access to follow up physio."*

Mental Health:

- *“Make it easy and quick to access support services.”*
- *“Have more routine check-ups.”*

Further comments

Cancer:

- *“Overall the NHS is the best in the world. It just needs more investment. Care that I received outside the special cancer areas was sadly lacking.”*
- *"I am completing this questionnaire as a cancer patient. However, I am also a nurse and before I became ill, I was directly experiencing lack of equipment, short staffing (very often dangerous) and the feeling of not being able to care for my patients as well as I would have wished.”*
- *“The service I have received at Clatterbridge has been excellent. I often wait a long time but I feel it's worth it.”*
- *“It is now seven years since my initial diagnosis and operation. The tumour reoccurred, 18 months ago for which I am currently having treatment at Clatterbridge. Care after diagnosis much better than before.”*

Heart and Lung Diseases:

- *“The National Health Service is getting worse.”*

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

- *“I have had wonderful help from doctors and Walton centre over the years and do my best to remain as healthy as possible. It is more than upsetting to have more hurdles put in place. Hearing loss is not adequately catered for in health services, despite constant reminders.”*
- *"My most pressing request would be for continuity with assured access to a doctor I know when I need it. Mostly I look after myself, I haven't had an antibiotic for 44 years which was after the last back surgery.”*
- *“My parents in law, both in good health, had a three-monthly review appointment with the same GP even though they were generally fit and well. It usually took five minutes or so, issued repeat prescriptions for the three months and reassured us all.”*
- *“My GP practice is very good and it is not their fault when forms go missing, appointments are delayed, etc. A proper health care plan would help both the GPs and me to work together to keep me out of their surgery.”*

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

This focus group took place on the 30th of April at Lonsdale Trust Wallasey, and was attended by 7 people.

Carers outlined much around the increased levels of depression and anxiety and that they can often be overlooked themselves by professionals when caring for people, feelings of isolation were also mentioned due to the restrictions of not being able to socialise. The following main issues that arose from the focus group were:

- Carers having to give up work to care for their loved ones leads to debt problems.
- Many carers experience mental health problems such as depression and anxiety.
- Carers feel isolated due to not being able to socialise.
- GPs not acknowledging carers health needs.
- Not enough support for Parent Carers.
- No real chance of a break unless they pay for this.
- No Carers Assessment offered by anyone.
- The Mental Health of carers is often overlooked by professionals when treating the cared for.
- Not enough support in the community.
- Carers providing front end care and don’t feel supported.

More detailed responses were outlined into themes based on the responses the facilitators highlighted from the participants:

Finance and Carers Allowance:

- Carers will have debt problems as the only benefit available to them is Carers Allowance - which not all carers will be eligible for and this is not enough to live on. So many carers have to work or leave work or experience interruptions with work - No real advice on what to do. Parent Carers often experience having to be called out of work if their child is ill, so end up more stressed as this impacts on their job.

Mental Health:

- Many carers become depressed or suffer anxiety or panic attacks due to the responsibility of caring for someone with no real experience such as medication administration or general care giving, carers suffer physical health problems due to lifting in heavy end care with no training or specialised equipment.
- Many carers cannot socialise due to caring responsibilities and need to rely on family or friends to help care, therefore socialising becomes more difficult and they feel more isolated, impacting on their Mental Health.
- Carers of people with Mental Health issues are often overlooked by professionals and the care plans not shared with them even though they provide most of the care.

Accessing services and assessment:

- Many carers are not recognised by GPs or offered a carers assessment, also, there is no offer of respite unless they pay privately.
- Only private services are available to many, unless they go down the financial assessment route from Social Services, who seem reluctant to offer support from the experiences talked about here.
- Of the Carers attending, no carers had been offered a carers assessment by anyone and didn’t know about it at all.

- Many carers providing 24/7 care with no real support from anyone, not treated the same as professionals with training or equipment.

A second focus group was undertaken focusing on the Deaf community and what they thought about their experiences with health and care services.

In focus: what is important to the deaf community about health and care services?

This focus group took place on 25th April 2019 at Birkenhead Park Visitor Centre, and was attended by 17 people. Below is a summary of the themes and issues they raised:

Community support:

People commented on the deaf community and how much representation there is available.

- There is not enough consultation with the deaf Community when planning or designing services and the impact on them.
- No deaf expert representing the deaf community.
- Deaf people not accessing holistic support such as alcohol/ substance misuse due to no interpreters.

Care service and support:

- Poor quality translating services at hospitals and Primary Care.
- Organisation currently used in Wirral provide a poor service with no continuity or thought of the individual's needs, e.g. male interpreter provided for female patient during a mammogram, interpreter arrives late or doesn't show up at all.
- No deaf counsellors available for talking therapies.

Information and awareness:

- Lack of awareness from ambulance teams in communication with deaf people.
- Lack of awareness with health professionals in general in communication with deaf people.
- More technology needs to be used in urgent care for communication with deaf people.
- Patient experience questionnaire not available in the right format, so deaf people excluded.
- Deaf people need information and advice in the right format to prevent health issues escalating. Understanding the impacts of Diabetes for example should be available to the more vulnerable of our community, such as the deaf. There are inequalities re: the information to the hearing community compared to the deaf.

Consultations and notice:

- After consultations there needs to be actions made with real outcomes and meaningful consultation.
- Deaf people given referrals to support in the community with no interpreters available.

Interpreters and support:

- No choice when booking an interpreter- poor quality service - no list/directory available.
- Small charity underfunded not enough staff to represent the deaf community to explain the issues affecting them.
- No choice of interpreters- no list or directory, so no choice for the patient.

- Deaf people need deaf counsellors, it's inappropriate to have someone signing for someone receiving counselling when emotional issues are being discussed.
- Deaf people need more time to arrange interpreters etc., if consultation is to be meaningful.
- Examples of GP's referring to Slimming World with no interpreters available to explain this - excludes the deaf person and they disengage.

Training and communication:

- Deaf people are more at risk of long-term illness due to information not being in a suitable format for deaf people.
- Examples of personal experience of ambulance service staff asking children of the deaf patient to interpret for them - inappropriateness of medical terms and even sharing of personal sensitive symptoms with children.
- Examples of hospital/primary care staff having no awareness of deaf people in communicating admissions or appointments etc. All staff need awareness training at induction and refreshed annually.