NHS Long Term Plan Report

Healthwatch Liverpool

wh●●●t
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.[1] It is the most ethnically diverse area in Merseyside.[2] 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.[3] 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.[4] 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.

Liverpool — Cheshire & Merseyside Health & Care Partnership

If Liverpool 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
64 — Adults are over-weight or obese
4 — Adults under 40 have Type 2 diabetes
55 — people are living with a long term condition
11 — Will die from heart disease
22 — Are smokers
80 — Is the average age that women will live to
25 — People take less than 30 mins exercise a week
76 — Is the average age that men will live to
6 — People are over 75

Statistics from PHE are for the Liverpool Local Authority area, pop: 467,000

---

[1] https://www.nomisweb.co.uk/reports/lmp/la/1946157104/report.aspx#tabrespop
[2] https://www.merseytravel.gov.uk/about-us/corporate-information/corporate-responsibility/Documents/Liverpool%20City%20Region%20Demographic%20Information%20March%2017.pdf
[3] https://liverpool.gov.uk/media/10001/1-imd-2015-executive-summary.pdf
[4] 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?
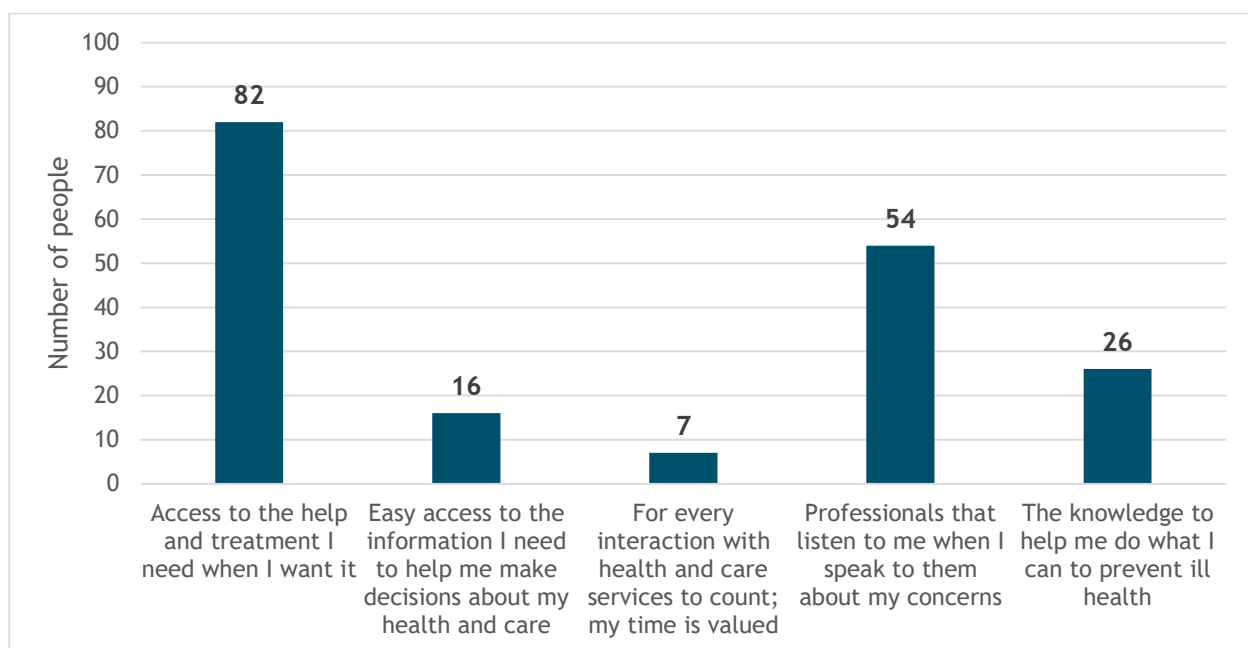
However, when asked to rate on a scale of very important to not important at all, all other options were considered either very important or important as the **Table 1** below shows. Up to 189 people responded to this question, though not everyone responded to each option:

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?
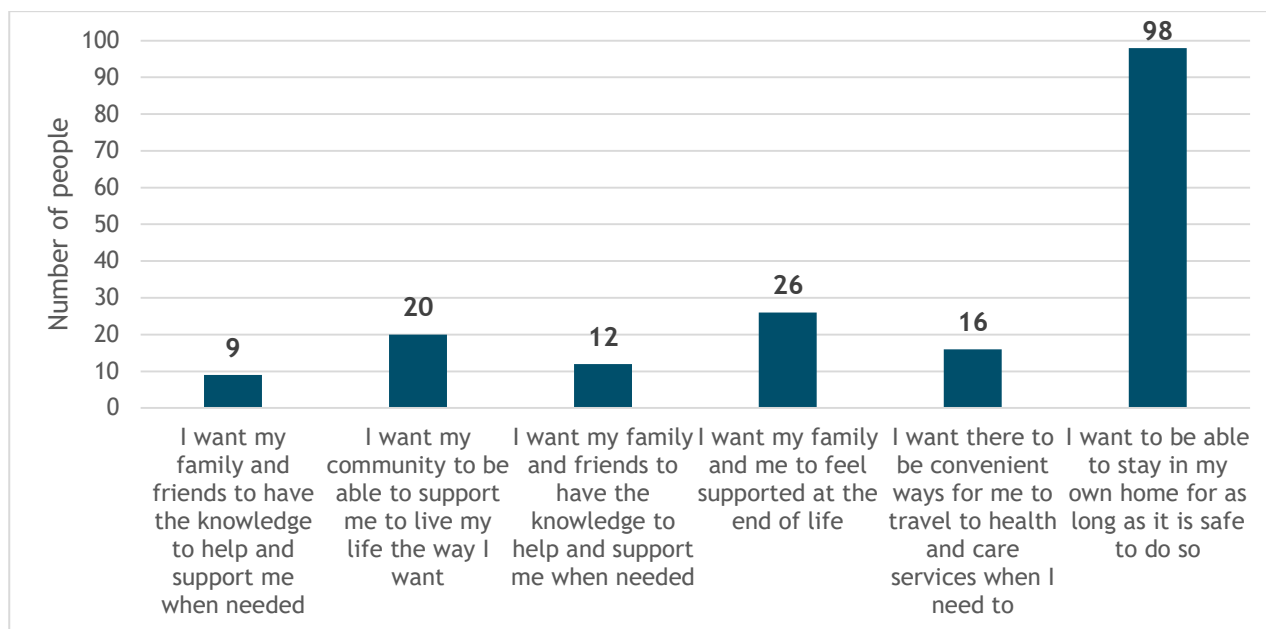
In **Table 2** when asked to rate this however, although being able to live independently in their own home is rated as the most important, all of the other statements identified were also rated as very important or important. In particular having a community who are able to support them to live their 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	99	53	22	2	0

support me to live my life the way I want					

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

What would you do?

- *"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
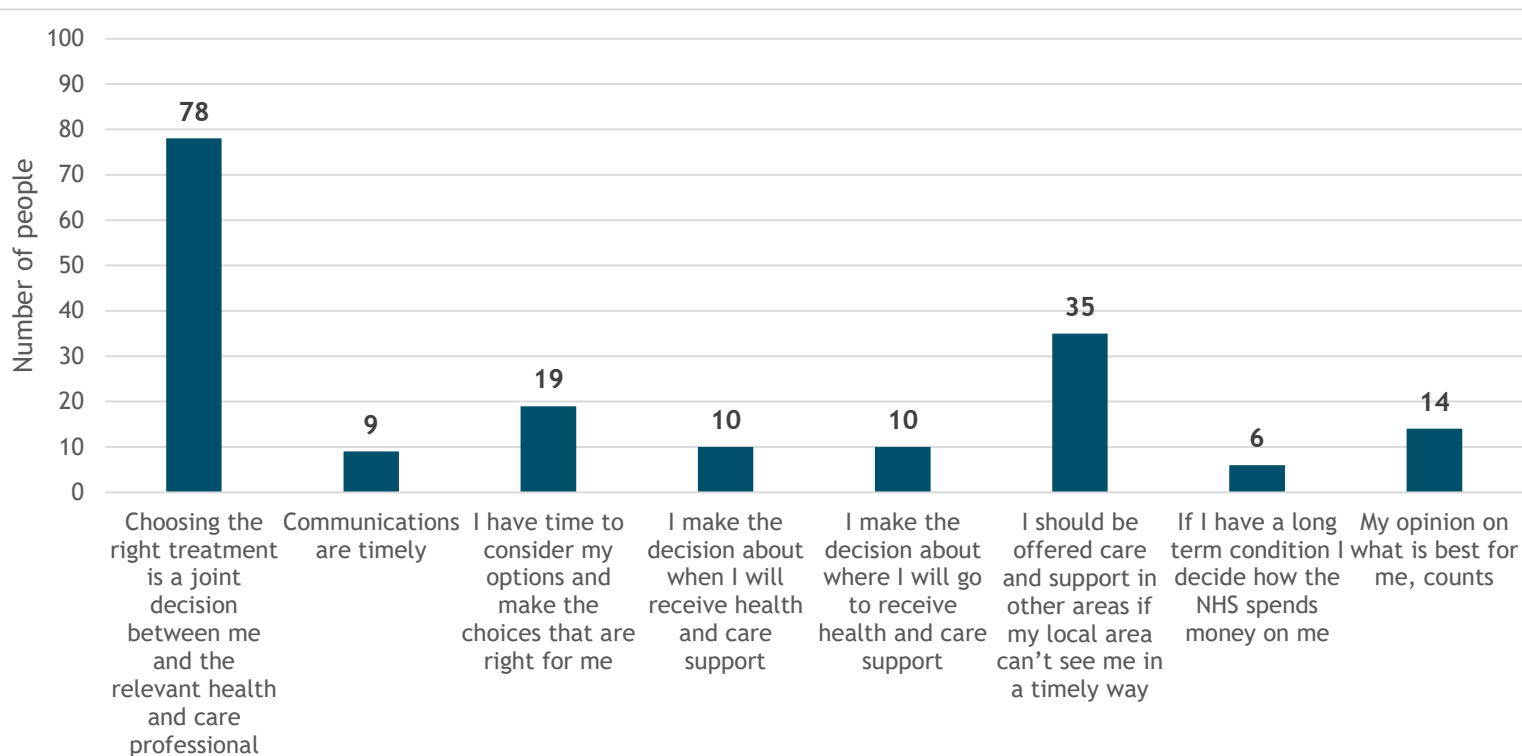
need?

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.
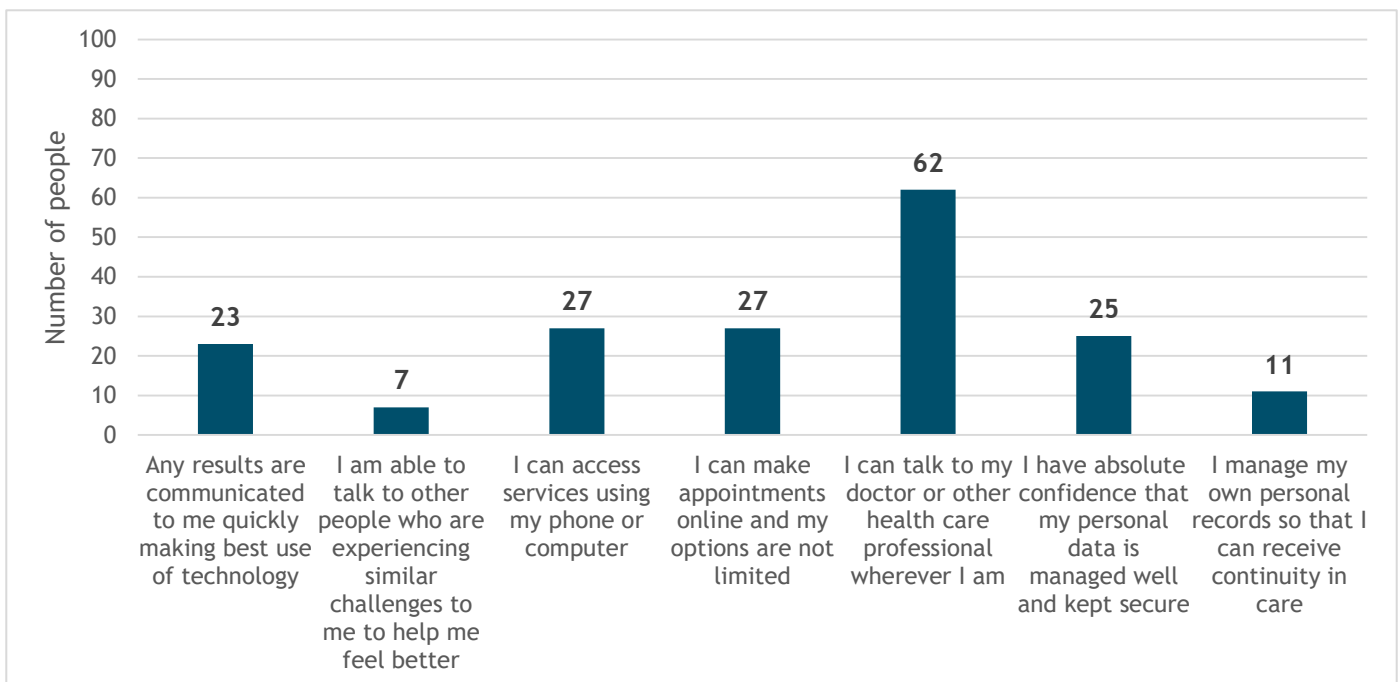

Chart 4: What is most important to you when interacting with the NHS?

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	121	49	8	4	0

of technology					
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.

<u>Technology</u>

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."*

<u>Communication</u>

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.