

NHS Long Term Plan Report

Healthwatch Halton

whot
would you do?
It's your NHS. Have your say.

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.¹

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.



¹ 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.

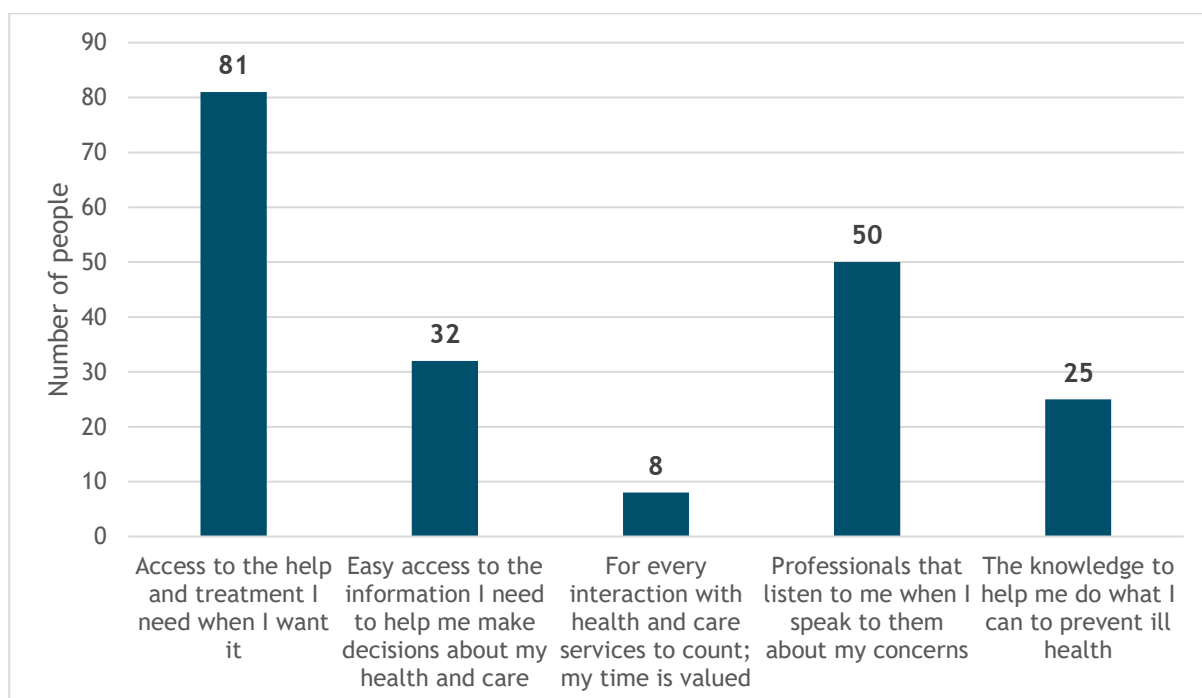
For each of these, people were asked to choose which of a number of options was most important to them. Following this, people were asked to rate each of the options on a scale of ‘very important’ to ‘not important at all’. Therefore, more than one option could be considered ‘very important’. Finally,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

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:

- *“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 dependence 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

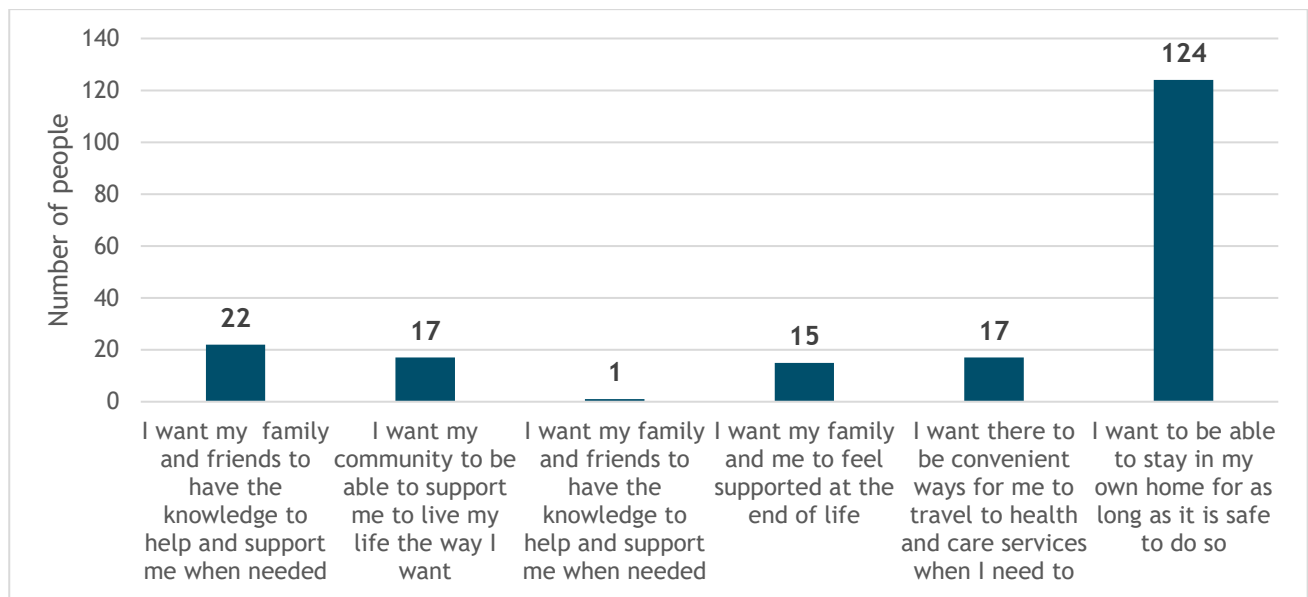
Respondents also told us that information should be more readily accessible regarding any self-help and educational health information with support services available and earlier interventions for people:

- *“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 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
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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:

- *“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 to 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

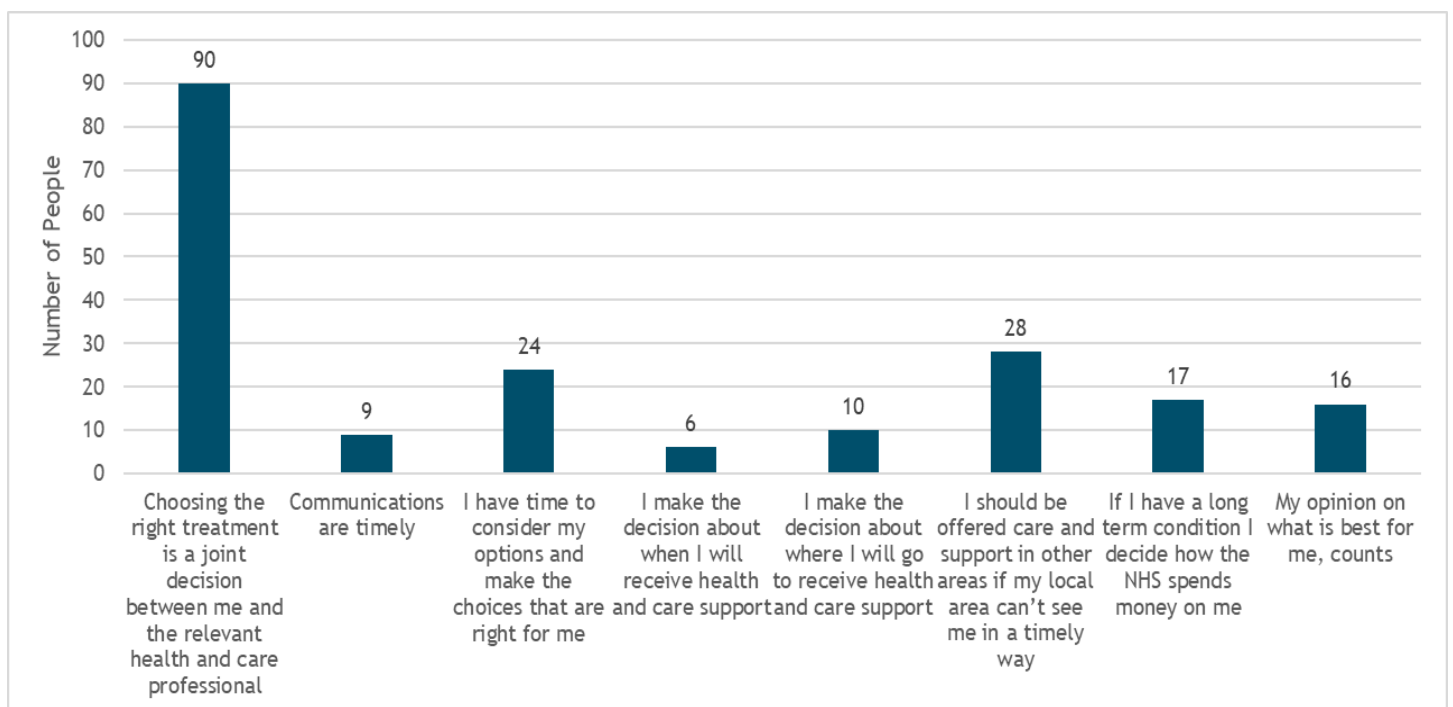
A number of respondents commented on the need for community support to enable them to stay healthy as they get older:

- “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 for 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 is much preferable to everything being online.”*

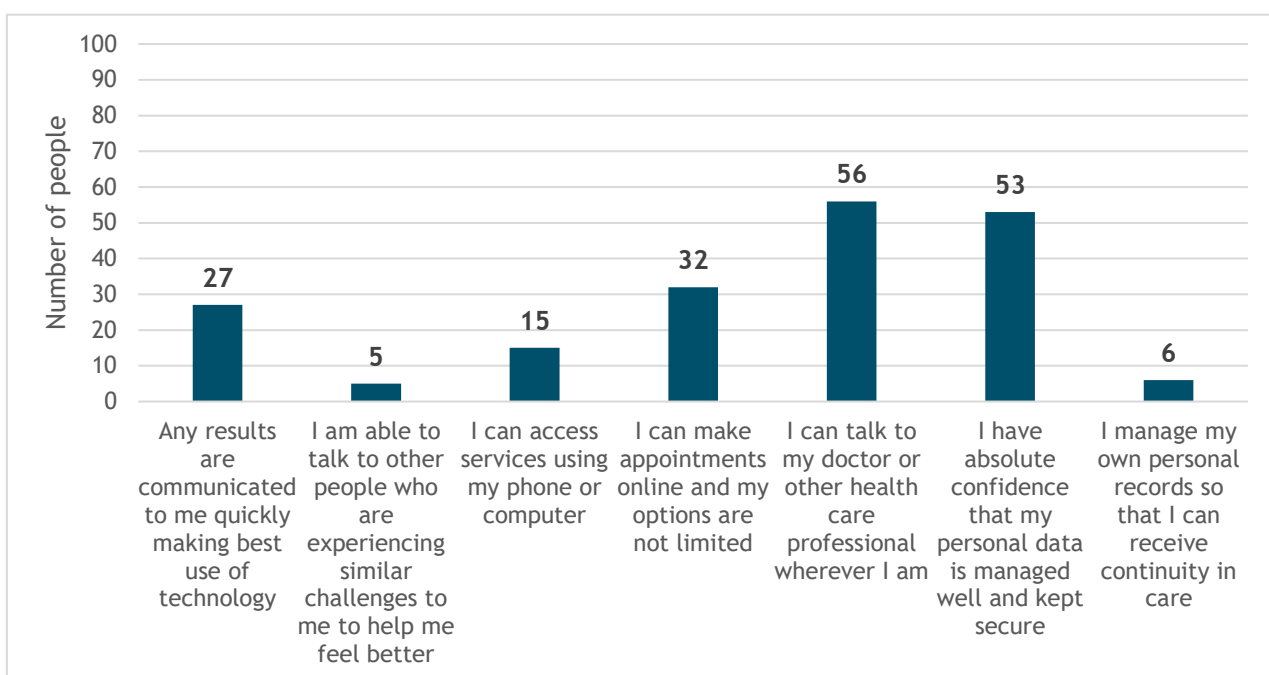
Engaging people in health service delivery

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 by 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 Woodview 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 deal 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 condition:

- *“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.”*
- *“Service 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 do 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. Patients 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.”*

Further comments:**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 of 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 gives 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 is 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; emotionally, practically and for 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 4.00pm 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 an IT system set up with a front page bullet pointing where they are at regards diagnosis and treatment it would 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.