

NHS Long Term Plan

Report

Healthwatch Wirral

whot

would you do?

It's your NHS. Have your say.

Wirral

Wirral is a borough of contrasts, both in its physical characteristics and demographics. Rural areas and urban and industrialised areas sit side by side in a compact peninsula of just 60 square miles and 24 miles of coastline.

The most recent population figures for Wirral show the population was 322,796 in 2017, making it one of the largest metropolitan boroughs in England.

Demographically, Wirral differs slightly to England, as it has a lower proportion of younger adults in their 20s and 30s and a higher proportion of older people.

In addition, life expectancy varies by around 10 years between wards in the East and West of Wirral, reflecting the large inequalities which are apparent in the Borough.

Wirral is one of the 20% most deprived boroughs in England and about a quarter of children live in low income families. Poorer health outcomes are present in these areas, with people more likely to smoke, have lower levels of physical activity and poor diets. This leads to lower life expectancy for both men and women, being lower than the national average in England.

Wirral also has an older population when compared to the national average, especially those over 65 - with one in three living alone. Local priorities in Wirral include a healthy older age, a positive start in life and keeping people well by reducing alcohol and tobacco use and lowering blood pressure.

Wirral does however, perform well compared to other, demographically similar areas on a range of factors such as homelessness and educational attainment. The percentage of children classed as being ready for school and attainment at GCSE are above average - and these are both hugely important for the future prosperity of Wirral residents, given that education is an established route out of poverty.¹

On the Wirral we received 320 survey responses, consisting of 257 general surveys and 63 specific condition surveys. There were also 24 attendees across two specific focus group events.

¹ Source:

<https://www.wirralintelligenceservice.org/this-is-wirral/wirral-population/>
<https://www.cheshireandmerseysidepartnership.co.uk/your-area/wirral>

Wirral

Cheshire & Merseyside
Health & Care Partnership



"Be the reason someone receives better care today"

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

35



Children are overweight or obese by year 6

16



Adults suffer from depression

10



5-16 year olds have a MH disorder

28



Will die from cancer

60



Adults are overweight or obese

3



Adults under 40 have Type 2 diabetes

57



people are living with a long term condition

11



Will die from heart disease

18



Are smokers

82



Is the average age that women will live to

19



People take less than 30 mins exercise a week

78



Is the average age that men will live to

9



People are over 75

Statistics from PHE are for the Wirral Local Authority area, pop: 321,000

Summary of Findings:

What matters most to people on the Wirral?

- When asked to consider what is most important to people to help them to lead a healthy life, **having access to the help and treatment needed** when it is wanted was deemed to be most important by people responding to the survey.
- Additionally, when asked to think of one thing that would help them to lead a healthy life, respondents primarily focused on factors relating to **health information and education**, access to health and wellbeing activity, access to community and transport support, and timely services to healthcare.
- We asked people to tell us about what they feel is important to keep independence and stay healthy in later life. **Being able to stay in their own home for as long as possible** was by far the most important factor.
- We also asked respondents to think about one more thing that would help to retain their independence and live healthily for as long as possible. Primarily factors focused upon **community and home support**, loneliness, communication and accessibility.
- When asked about managing and choosing support and treatment, respondents told us that **choosing the right treatment being a joint decision** between them and the relevant health and care professional is most important to them.
- We also asked respondents to tell us one more thing that would help them to manage and choose how the NHS supports them. Emerging themes included community care and support, finance, resources and investment, appointments and **use of technology**.
- People in the Wirral told us that **being able to talk to their doctor or other health professional** and having absolute confidence that **their personal data is managed well** and kept secure, were both the most important factors when interacting with the NHS.
- When asked to consider what respondents felt was most important when interacting with the NHS, people said that the most highly rated factor was being able to talk to the doctor or other health care professionals wherever they were.
- Respondents were then asked to think about one more thing that needs to change to help them to successfully manage health and care. These answers have been categorised under emerging themes, which included factors relating to technology, **communication and support**, GP appointments and information and self-help provision. People commented on the need for individual support for those in need to give reassurance to other family members and get more home care support.
- People with Cancer told us they were **positive about the quality of assessment, treatment and support**, as well as the time they had to wait at each stage. Although ability to access ongoing support provided a mixed response.
- People with multiple long-term conditions generally felt this made it harder to access support.
- Those with specific conditions felt that **communications could be improved**.

Survey results

The following sections now break down the results of the 320 responses across Wirral to the surveys designed by Healthwatch England. The first sections use the 257 responses to the general ‘People’s general experiences of health and care services’ survey, before breaking down the 63 survey responses from people discussing support for specific conditions.

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

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

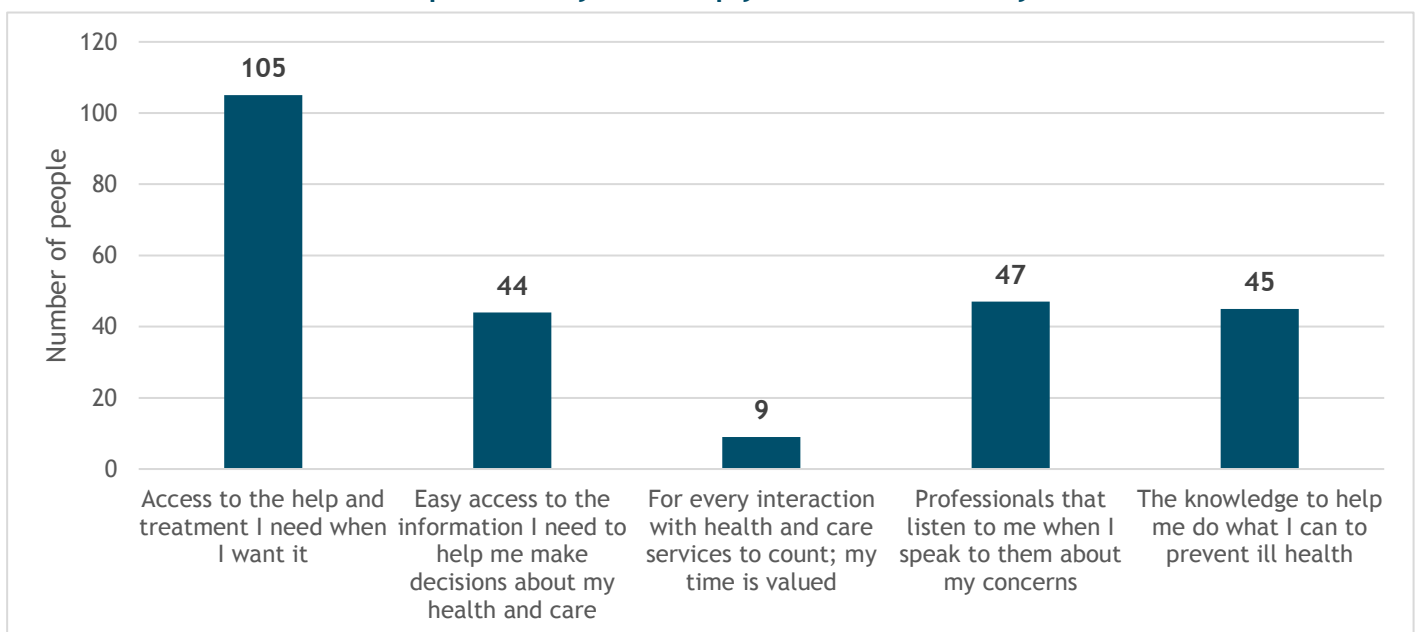
For each of these, people were asked to choose which of a number of options was most important to them. Following this, people were asked to rate each of the options on a scale of ‘very important’ to ‘not important at all’. Therefore, more than one option could be considered ‘very important’. Finally,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

What is important to people about health and care services

Living a healthy life

When considering how to live a healthy life, **Chart 1** shows that having access to the help and treatment needed when it is wanted was deemed to be most important by people responding to the survey. 250 people responded to this question.

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



However, when asked to rate on a scale of very important to not important at all, all other options were considered either very important or important as **Table 1** below shows. Up to 247 people responded to this question, though not everyone responded to each option:

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

	Very important	Important	Neutral	Not important	Not important at all
Access to the help and treatment I need when I want it	186	53	3	0	1
Professionals that listen to me when I speak to them about my concerns	169	64	6	0	1
Having the knowledge to help me do what I can to prevent ill health	148	79	16	3	1
Easy access to the information I need to help me make decisions about my health and care	145	80	11	2	2
For every interaction with health and care services to count; my time is valued	123	82	22	5	2

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

Many respondents repeatedly asked for more affordable healthier food options, with meal plan education and information. They also thought that free access to physical exercise activities and facilities was a need for communities. Timely appointments and support were also mentioned. The comments included:

Health information and education

Respondents highlighted a good use of radio to inform people on health advice and education, whilst others mentioned the need for more education on healthy meal plans.

- *“Health advice on radio stations is very good - especially for people travelling long distances.”*
- *“More education on how to cook healthy meals on a budget - particularly through high school.”*

Accessibility to health and wellbeing activity

People mentioned the need for more access to healthier and affordable activities in their local areas. People commented on the following:

- *“Better access to facilities that could help me improve my life such as cheaper access to gyms or lifestyle classes.”*
- *“Free exercise classes and gym, especially to the community over 50 years old.”*
- *“Programs to help and encourage people to exercise and to eat healthily.”*
- *“Have local NHS sponsored keep fit/exercise facilities.”*

- *“Easier access to appointments before/after work hours (9-5).”*
- *“Free access to council gym, exercise classes and other facilities.”*
- *“More diet advice available, free diet plans and affordable healthy food.”*

Community and transport support

- *“Reduce people smoking in all public areas.”*
- *“Better transport links to local hospitals for physically frail people.”*
- *“The government to make a sincere effort to cut air pollution dramatically so the health of all our nation improves as soon as possible.”*

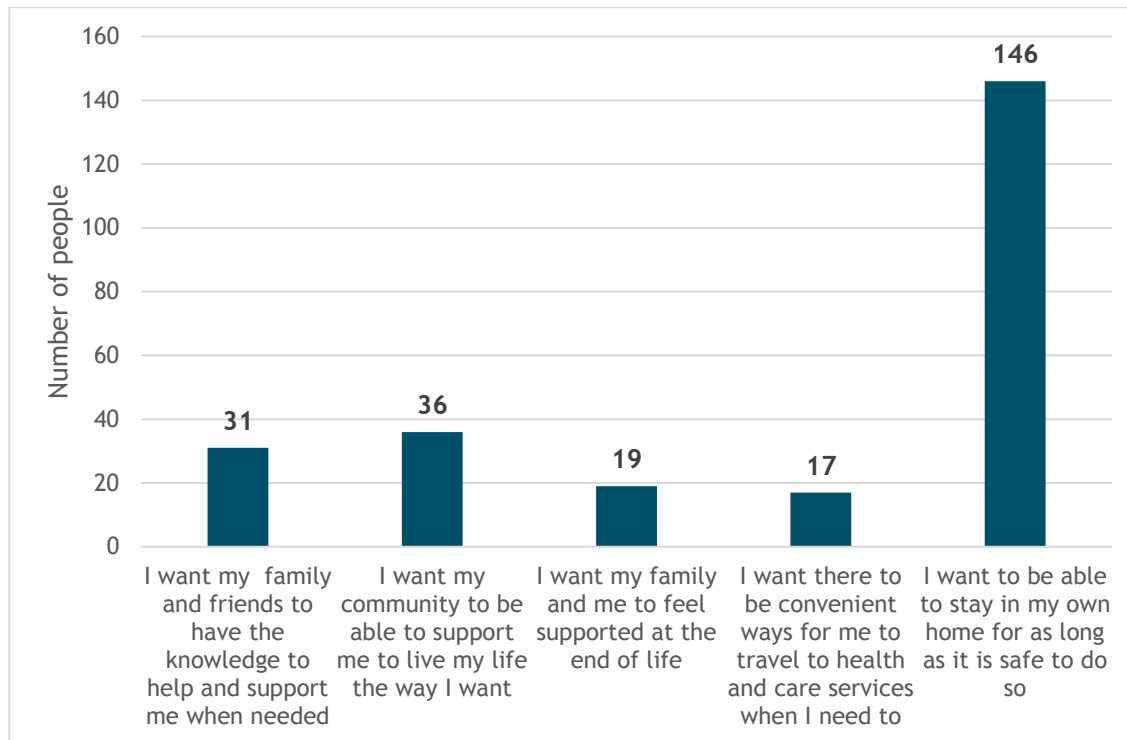
Timely services for health care

- *“Ability to speed up physiotherapy appointments, in our area we now have to wait 6 months for our first consultation. If I have problems with sciatica for instance what good is an appointment 6 months later. Why can't we go back to having physiotherapy in our own surgeries, I have been told that it costs no more and we would have been seen quicker. This is a political decision made without duty of care to people suffering great pain.”*
- *“NHS not to be privatised. Medical professionals to understand severe hearing disability and deafness. Less computers as substitute for people.”*
- *“Make it easier to get an appointment with my doctor. Currently I have to sit waiting for 8am then try and phone, often it's an engaged tone. Then you can't get an appointment same day.”*
- *“Already had to wait six months for an operation and so I had to pay for my operation as I was in severe pain.”*
- *“To be able to see a doctor sooner not wait nearly 2 weeks for an appointment.”*

Keeping independence and staying healthy in later life

We asked people to tell us about what they feel is important about keeping independence and staying healthy in later life. Being able to stay in their own home for as long as possible was by far the most important factor (see Chart 2). 249 people responded to this question.

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



In Table 2 when asked to rate this however, although being able to live independently in their own home is rated as the most important, all of the other statements identified were also rated as very important or important. Up to 243 people responded to this question, though not everyone responded to each option.

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

	Very important	Important	Neutral	Not important	Not important at all
I want to be able to stay in my own home for as long as it is safe to do so	202	30	8	2	1
I want my family and me to feel supported at the end of life	169	56	7	2	1

I want there to be convenient ways for me to travel to health and care services when I need to	152	73	13	1	0
I want my family and friends to have the knowledge, to help and support me when needed	129	83	23	5	0
I want my community to be able to support me to live my life the way I want	120	83	29	6	1

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

Community and home support

People commented on the need for individual support for those in need, to give reassurance to other family members and get more home care support. People said the following:

- *“Help for my kids. I don't want to be a burden but I don't want to go into a home. They don't either.”*
- *“I don't want to be a burden to my wife so I want care to be available if I need it.”*
- *“Knowing that my father will be looked after if I can't keep doing it.”*
- *“Support in the community for long term health conditions including back pain/chronic pain support outside of NHS services, e.g. local community centre.”*
- *“Medical staff visiting elderly patients at home.”*
- *“More care needs to be put into the community to avoid hospital admissions.”*
- *“Someone calling once a day to check I can walk to the kitchen and bathroom”*
- *“Have more supported living accommodation in Wirral to care for families as I am a carer who looks after two people.”*

Health and social care and activities

- *“Free access to activities in leisure centres.”*
- *“Local access to help and community services”*
- *“More access to social groups.”*
- *“Funding to push the elderly to exercise, eat healthily and to drink more water.”*

Loneliness

- *“Recognition (and investment and resources) from NHS and council provided services that public transport (links, accessibility, cost, frequency) is essential to older people/those with poor mobility for accessing health services/appointments. As loneliness and isolation is the biggest killer of older people who live alone, the area of public transport is grossly neglected. What is the point of telling me about a day service or group I can access if I have no way of getting there?”*

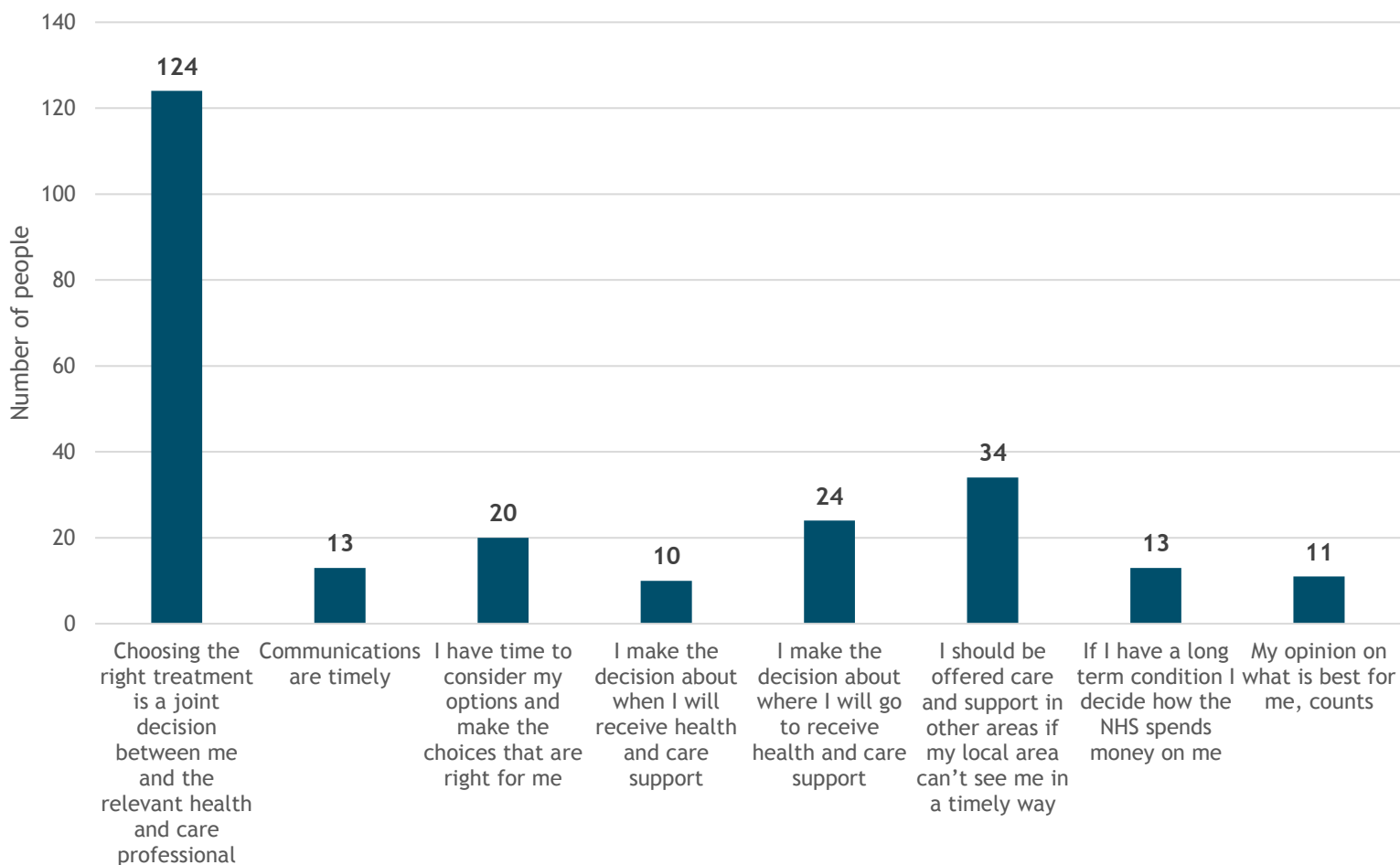
Health care communication and access

- *“The interface between council care and the NHS needs to be smoother and not be a matter for the patient to sort out. In political terms, there shouldn't be a tussle between local government and the NHS over who pays for what. Perhaps it is time to fix individual patient budgets which can be allocated to hospital/GP/council, rather than setting overall budgets.”*
- *“More care in the community for those who need to access it.”*
- *“Easy access to professional care including domiciliary care and help to keep people out of care homes or hospitals, not charities who are not always clinically trained, are run as businesses with the CEOs on mega salaries.”*

Managing and choosing support and treatment

Chart 3 shows that people we spoke to in the Wirral told us that choosing the right treatment being a joint decision between them and the relevant health and care professional is most important to them in managing and choosing support and treatment. 249 people responded to this question.

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



When asked to select how important different factors were on a scale of very important to not important at all, people mostly considered that timely communications were very important. This is detailed in Table 3 below, in order of the options that most people classed as being very important. Up to 252 people responded to 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	163	64	12	0	0
Choosing the right treatment is a joint decision between me and the relevant health and care professional	159	84	9	0	0
I have time to consider my options and make the choices that are right for me	121	102	13	4	0
I make the decision about where I will go to receive health and care support	112	83	38	3	2
I should be offered care and support in other areas if my local area can't see me in a timely way	108	106	26	3	1
My opinion on what is best for me, counts	106	102	30	0	0
I make the decision about when I will receive health and care support	92	96	43	9	0
If I have a long-term condition, I decide how the NHS spends money on me	79	92	32	13	2

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

Community and care support

People commented on their individual service experience and the support they need, covering staff training and information on getting help and support. The comments included:

- *“More timely primary care appointments and a short secondary care waiting time”*
- *“My experience of Arrowe Park is being taken towards unsuitable for my condition.”*
- *“More local authority care in my older age. Not with private, for profit only, older people's care.”*
- *“Trained health professionals that understand the latest research in regards to ME/CFS”*
- *“I need to fit appointments around my work and caring for my father so the out of hours appointments have been good for me.”*
- *“Better information on what professional help and support is available in the local area, not charities who are not always clinically trained, are run as businesses with the CEO's on mega salaries.”*

Finance, resources and investment

People commented on the NHS investment and financial circumstances to support the community, others commented on the transport and car parking service charges. The comments included:

- *“Ability to see a consultant without having to resort to paying for a private consultation. Many people cannot afford this usually large amount; therefore, the system is unfair. If other methods of treatment have failed, then surely it is not too much to ask to see a consultant.”*
- *“Sufficient funding of the NHS to ensure local health care needs ARE met and that the best care is given. Privatisation of the NHS is dangerous as there is evidence from health professionals that some outsourced health services are poor.”*
- *“Investment and resources in health and social care services in my community as prevention and community-based services would give me freedom and genuine choice as to how I manage and choose the way in which the NHS supports me.”*
- *“Parking charges visiting hospitals either as visitor, inpatient or attending clinics. Not everybody can afford travel costs whether own or public transport and car park charges feel like a stealth tax and being penalised for somebody's illness.”*

Appointments and health care experiences

Many respondents spoke about the accessibility people have at their local GP, some felt that they should be spoken to more as an individual. Others spoke of their experience using the service and how they were treated. The comments are outlined below:

- *“Being able to see a GP without having to phone up several times to get an appointment.”*
- *“I would like the health care professionals to listen and talk to patients like normal human beings instead of imbeciles. I would like more than 5 minutes with the Doctor.”*
- *“Hospital appointment times - e.g. waited 4 months to see a specialist - had to pay privately.”*
- *“Wirral NHS do not have enough resources to meet demand.”*
- *“More accessible GP appointments with more support from the same GP.”*
- *“More clinics providing healthcare other than seeing a doctor.”*
- *“Best case scenario - in my opinion, would be if I could have treatment to alleviate pain in an old bad leg that was operated on 60 years ago, but has now been made bad by injuries incurred 2.5 years ago to other leg breaking Tibia and Fibia and leaning on this has killed old bad leg. Now have to walk with stick even though the new break 2.5 years ago has now mended. Perhaps steroid injections are the answer or perhaps another operation?”*
- *“Proper access. It is almost impossible to get an appointment same day with my GP and online booking for non-urgent appointment is weeks away. Sometimes it might be “urgent” but it could be something that needs seeing to sooner rather than later.”*
- *“I need my confidence restoring in hospitals... I’ve just watched my sister go into hospital with gall stones and within three days she had multiple organ failure and died. She led a very healthy lifestyle, I think doctors acted slowly, she was not CT scanned for 24 hours, probably because of NHS money restraints, the pancreas was in trouble and doctors didn’t scan her until the damage was setting in. I do not expect a doctor to say “we’re as baffled as you are” how on earth is that meant to reassure us? she was dying before our eyes; we don’t even know if it was sepsis. That frightens me. I would never go near Whiston Hospital again.”*

Use of Technology

- *“Appointment for doctor’s appointments to be available.”*

- *“I’m not sure to be honest - at the moment I find it good to access the NHS - online resources especially.”*

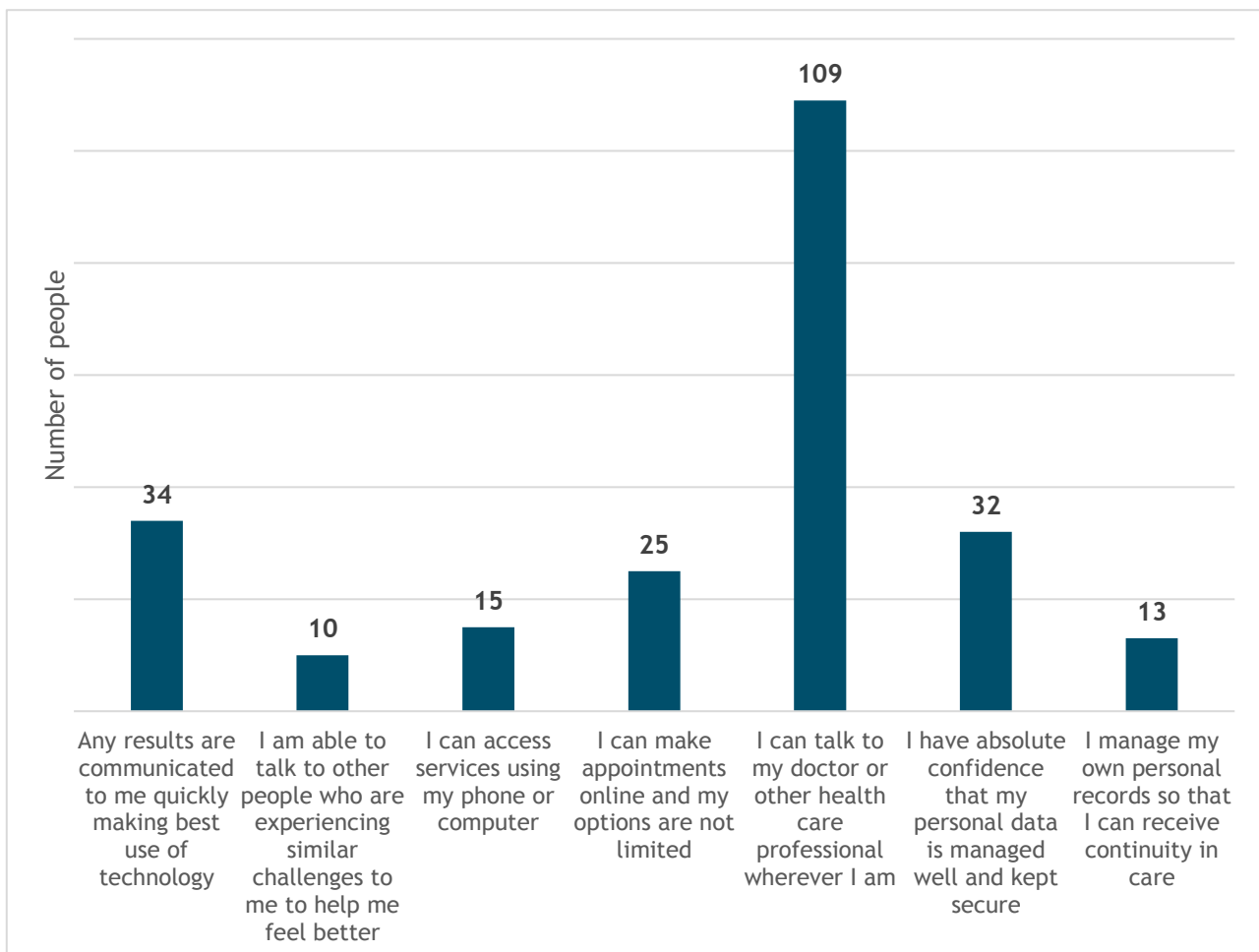
Engaging people in health service delivery

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

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

People in the Wirral told us that being able to talk to their doctor or other health professional and having absolute confidence that their personal data is managed well and kept secure, were both deemed as the most important when interacting with the NHS (see Chart 4 below). 238 people responded to this question.

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



When asked to select how important different factors were on a scale of very important to not important at all (Table 4), people said that the most highly rated factor was being able to talk to the doctor or other health care professionals where ever they may be. Up to 244 people responded to this question, though not everyone responded to each option.

Table 4: Rate how important the following things are to you when it comes to keeping your independence and ageing healthily.

	Very important	Important	Neutral	Not important	Not important at all
I can talk to my doctor or other health care professional wherever I am	141	81	17	1	0
Any results are communicated to me quickly making best use of technology	131	78	22	4	1
I have absolute confidence that my personal data is managed well and kept secure	130	83	28	2	1
I can access services using my phone or computer	95	102	33	5	2
I can make appointments online and my options are not limited	94	95	26	13	3
I manage my own personal records so that I can receive continuity in care	72	80	65	18	3
I am able to talk to other people who are experiencing similar challenges to me to help me feel better	67	68	60	31	10

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

Technology

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

- *“Still have to appreciate that some of the ageing population do not use the internet/are not smart phone savvy so provision has to be made for them for next 10-20 years.”*
- *“Having an online repository of medical history/test results/treatment programs would be a great boon. For families, this should be accessible by carers, partners, parents etc - subject to agreed access requests and restrictions.”*
- *“Online access to my health records.”*
- *“Please don't expect everyone to be I.T. literate and do everything online, we need access to human beings.”*

Communication and support

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

- *“Better communication & less waiting times for results.”*
- *“Not having to repeat things.”*
- *“Easy access to local services and more consistent approach to providing services. There are too many changes which are not communicated well to the local public.”*
- *“Reliable and prompt communication from hospital/doctor/nurse etc. after having had procedures/treatments at hospitals or in surgeries. Notifications by phone/text or email/letter.”*
- *“Live in Extra Care Supported Living Accommodation which is sadly lacking on the Wirral.”*

GP Appointments

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

- *“GP Practices and appointments need to be more accessible for people who work”*
- *“Easier access to GP appointments or nursing staff who can help me when needed.”*
- *“Not to feel anxious about contacting health care professionals. It is easy to think they are too pressured to deal with your problem.”*
- *“To be able to have continuity with my own doctor.”*
- *“Apps to manage appointments and access repeat prescriptions.”*
- *“Face to face contact with health professionals where I have time to discuss my health concern, am listened to and feel confident that I am receiving the best care available for me in relation to my diagnosis/problem and not due to cost or doing it on the cheap.”*
- *“To see a GP at my practice when I need to and not be asked if it's an emergency when I ask for an appointment. All the days appointments have been taken in 10 minutes from 8am opening.”*

Information, self-help provision and community

A number of people mentioned the importance of information, training and self-help mechanisms through holistic community approaches:

- *“More advice and education available face-to-face closer to home.”*
- *“Understanding of my hearing disability and limited use of technology.”*
- *“Access to self-help groups and alternative therapies. Also, free access to gyms and swimming.”*
- *“Meeting other patients with my concerns, Fibro, Sjögren’s, DDD, COPD, chronic Neuropathy, etc.”*
- *“Regular updates on what is available to me via email or text.”*
- *“Knowing where to go and who provides what. There is no uniformity in help across the Wirral.”*
- *“Preventative focus in primary care with an approach which is holistic and about women's health and wellbeing not just the health of individual body parts, e.g. breasts, cervix, which is what's on offer at the moment.”*

People's experiences of NHS support for specific conditions

People with specific conditions were asked to complete a separate survey on their experiences of the NHS support they had received in relation to that condition. This included discussion on the three stages of the care journey; assessment, diagnosis and treatment; the provision of ongoing care and support; and prevention and/or early intervention. We received 63 responses in total to this survey. This section breaks down the responses we received in terms of number of people by specific condition:

Table 5: Respondents with specific conditions

Condition	Number of people
Autism	2
Cancer	30
Dementia	4
Heart and lung diseases	6
Learning disability	0
Long-term condition e.g. diabetes, arthritis	14
Mental Health	7

Table 6: Who are you responding on behalf of?

Condition	Myself	Someone else
Autism	0	2
Cancer	26	4
Dementia	1	3
Heart and lung diseases	3	3
Learning disability	0	0
Long-term condition e.g. diabetes, arthritis	11	3
Mental Health	6	1

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

Condition	Yes	No
Autism	1	1
Cancer	27	3
Dementia	3	1
Heart and lung diseases	3	3
Learning disability	0	0
Long-term condition e.g. diabetes, arthritis	11	3
Mental Health	6	1

Experience of getting help and support

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

Condition	Yes	No	Somewhat	Not applicable
Autism	1	1	0	0
Cancer	23	3	4	0
Dementia	1	0	3	0
Heart and lung diseases	2	0	3	0
Learning disability	0	0	0	0
Long-term condition e.g. diabetes, arthritis	5	3	5	0
Mental Health	2	3	2	0

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

Autism:

- *“We realised the issues but no-one would listen - four years getting a diagnosis.”*

Cancer:

- *“I was diagnosed with early stage breast cancer (DCIS) and needed a lumpectomy, 2 lymph nodes removed and follow-up radiotherapy. Whilst it was detected early, for which I was very grateful, I was refused a reassurance scan afterwards. Regardless of the stage of detection, from a mental health perspective, all patients with any kind of ‘cancer’ diagnosis, should be offered the choice.”*
- *“Further options for treatment were not explored. Only treatment offered was a surgical intervention but on pushing the consultant a different treatment was reluctantly informed.”*
- *“Saw GP who made a referral quickly.”*

- *"It took a long time before I was told I had an adeno cystic cancer at the back of my nose, I had a polyp which was removed and a biopsy taken. I do not think I received any support. I did not seek any support."*
- *"I did not know who to ask."*
- *"MacMillan were only sort of helpful."*
- *"Met my needs 100%."*
- *"Lack of support when not accessing cancer services (i.e. basic NHS)."*
- *"The support met my needs although it took three years to identify and diagnose fibromyalgia."*
- *"Multi-disciplinary team has provided excellent support."*
- *"Quick diagnosis, relevant referrals and good treatment so far."*
- *"So far I've been happy."*
- *"Communication between consultants at the different hospitals could have been better on the time of initial diagnosis."*
- *"Went to Countess of Chester for 3.5 years before GIST tumour was found - they initially thought it was Pancreatic but diagnosed as GIST at Royal Liverpool."*

Dementia:

- *"Quicker appointments. Less time in between appointments."*
- *"Having a regular carer would have been good. Different ones each time was not good for my husband and tiresome for me telling them over and over what we needed."*

Heart and lung diseases:

- *"No support really apart from my GP."*
- *"No support for COPD sufferers."*
- *"I couldn't get a home visit and my daughter had to get me to the surgery."*

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

- *"Visit to GP, sent for x-ray, prescribed meds, was told I had 'wear and tear'. That was it, no info given."*
- *"Basically, felt like I had painkillers given me and left to plod on. Was scary having no info on the condition. No info on impact on health, or what to expect, no advice on how best to help ease the condition or to slow down the degeneration."*
- *"More info at diagnosis would be good, along with other options such as being told a referral to MSK is possible."*
- *"No coordination in care between primary and secondary care, no continuity of care, no looking at the whole picture."*
- *"Not really. There was no continuity in a large practice. Balancing treatment with five long term conditions is not achievable in an eight-minute consultation unless the GP understands that the easiest option is likely to upset the other four conditions."*
- *"Pain relief could have been provided earlier."*
- *"It met my needs as I was sent for blood tests and found out I needed B12 injections."*
- *"It did in the end but after many appointments. Still not fully sorted."*

Mental Health:

- *"GP just put me on tablets with no follow up."*
- *"I was in a mental health crisis and eventually taken to A&E at Arrowe Park. Having waited for more than half an hour in a large and busy waiting area my distress increased. Eventually seen by a nurse and given medication."*

- “Not enough mental health services and support for people on the Wirral.”
- “Doctor met my needs and offered me the right support & was very helpful.”

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

Condition	Very Positive	Positive	Average	Negative	Very Negative	Don't know
Autism	0	1	0	1	0	0
Cancer	10	11	5	2	1	1
Dementia	0	3	1	0	0	0
Heart and lung diseases	0	0	3	1	0	2
Learning disability	0	0	0	0	0	0
Long-term condition e.g. diabetes, arthritis	0	7	1	4	0	2
Mental Health	0	2	1	3	1	0

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

Condition	Yes	No
Autism	0	2
Cancer	15	15
Dementia	3	1
Heart and lung diseases	4	2
Learning disability	0	0
Long-term condition e.g. diabetes, arthritis	7	6
Mental Health	2	4

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

Condition	It made getting support easier	No difference	It made getting support harder	I don't know	Not applicable
Autism	0	0	0	0	0
Cancer	2	9	0	2	2
Dementia	0	1	1	1	0
Heart and lung diseases	0	0	4	0	0
Learning disability	0	0	0	0	0

Long-term condition e.g. diabetes, arthritis	0	1	5	1	0
Mental Health	0	1	1	0	0

The health and care support received after initially seeking help

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

Condition	Very slow	Slow	Ok	Fast	Very fast	Don't know
Autism	0	1	0	0	0	1
Cancer	1	4	8	10	7	0
Dementia	0	2	2	0	0	0
Heart and lung diseases	0	4	2	0	0	0
Learning disability	0	0	0	0	0	0
Long-term condition e.g. diabetes, arthritis	2	4	6	1	0	1
Mental health	0	5	1	1	0	0

Autism:

- *“Four years to see a consultant.”*

Cancer:

- *“Diagnosed July, operated August & radiotherapy during November.”*
- *“After I had my polypectomy, I waited a long time and did not realise I should have had someone with me or that I would have been told of my diagnosis.”*
- *“Two weeks.”*
- *“Three months.”*
- *“Difficult at first, taken ill whilst travelling and spent time in a hospital out of area and then referred as an outpatient.”*
- *“From initial referral to MDT progress was rapid.”*
- *“Sent for repeated X-Rays of wrong area of my body.”*
- *“I was diagnosed within hours of attending hospital.”*
- *“Long wait for results after surgery.”*
- *“When called back to hospital for diagnosis, given 3pm appointment but left to 5:30pm before being told that you have Pancreatic Cancer.”*
- *“Two weeks for surgery - chemotherapy commenced when appropriate.”*

Dementia:

- *“The initial diagnosis took time, as expected really but getting care and respite break was good.”*

Heart and lung diseases:

- *“Couldn't get diagnosis.”*
- *“Waited more than six months to see a consultant, this only happened when I was admitted to hospital.”*
- *“Two weeks for doctor and nearly a month for follow ups.”*

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

- *“The x-ray and diagnosis were very quick.”*
- *“Was dismissed frequently by the GP despite the fact the previous visits had been rare.”*
- *“I have a number of rare conditions. I had to wait a long time to get diagnosed and unfortunately my health had to deteriorate a great deal before diagnosis was possible. Better coordination is needed for earlier diagnosis and treatment and to prevent long term damage.”*
- *“Only due to needing repeating blood tests and needing to await results each time.”*
- *“Accessing the GP took over a week but I had a few visits before being referred on in the system.”*
- *“I am waiting to see a physio and was initially told this would be within two weeks. It has been almost six months and the condition has worsened.”*

Mental Health:

- *“12 months or more.”*
- *“Ten weeks eventually to see 'change' for CBT.”*

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

Condition	Very slow	Slow	OK	Fast	Very fast	Don't know
Autism	0	1	0	0	0	1
Cancer	1	3	4	13	8	1
Dementia	0	1	3	0	0	0
Heart and lung diseases	0	6	0	0	0	0
Learning disability	0	0	0	0	0	0
Long-term condition e.g. diabetes, arthritis	3	6	2	2	0	1
Mental health	0	5	1	1	0	0

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

Condition	Yes	No
Autism	2	0
Cancer	20	8

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

If you accessed support what aspect could be improved?

Cancer:

- *“More counselling offered.”*
- *“Computerised systems should be interlinked.”*

Dementia:

- *“More practical support.”*
- *“Speed of funding, the cost was worrying me.”*

Heart and lung diseases:

- *“More info on C.O.P.D.”*
- *“Same nurses not different ones.”*

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

- *“Different medical experts didn't work together, care fragmented, no one coordinating care, communication between primary care and out of borough specialist hospitals/medics very poor.”*
- *“More medical staff.”*
- *“Due to my condition (arthritis) I had to cancel some appointments due to pain and waiting for the next one to come took some time.”*

Mental Health:

- *“Mental health access other than tablets. Counselling and mindfulness.”*
- *“More respite.”*
- *“I think maybe bring told to get another appointment to check up on you.”*

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

Condition	Yes	No
Autism	0	2
Cancer	3	27
Dementia	0	4
Heart and lung diseases	0	6
Learning disability	0	0

Long-term condition e.g. diabetes, arthritis	8	6
Mental health	5	2

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

Condition	Very slow	Slow	OK	Fast	Very fast	Don't know
Autism	1	0	0	0	0	1
Cancer	0	10	5	2	7	2
Dementia	0	0	3	1	0	0
Heart and lung diseases	0	0	1	5	0	0
Learning disability	0	0	0	0	0	0
Long-term condition e.g. diabetes, arthritis	1	1	1	1	1	1
Mental health	0	1	1	0	0	0

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

Cancer:

- *“Three weeks.”*
- *“One week.”*
- *“Difficulty arose as referred from hospital away from home.”*
- *“Within two weeks of GP referring me to Aintree with lump in neck.”*
- *“Had to wait until femur actually snapped before things actually happened.”*

Dementia:

- *“Around six weeks was suggested but it turned out to be nearer to eight.”*

Heart and lung diseases:

- *“Only when I came into hospital and saw a consultant.”*
- *“Long-term condition e.g. diabetes, arthritis.”*

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

- *“I attended physio through NHS but now fund my own physio it helps but I can only afford monthly sessions except if the pain is too intense.”*
- *“When eventually diagnosis occurred (in A&E) the hospital dealt with it quickly.”*

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

Condition	Very easy	Easy	OK	Difficult	Very difficult	Don't know	Not applicable
Autism	0	0	1	0	0	1	0
Cancer	9	3	2	8	0	3	5
Dementia	0	1	1	2	0	0	0
Heart and lung diseases	0	0	4	1	0	1	0
Learning disability	0	0	0	0	0	0	0
Long-term condition e.g. diabetes, arthritis	0	1	1	5	1	2	4
Mental health	0	1	3	3	0	0	0

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

Condition	Yes	No	Somewhat
Autism	1	1	0
Cancer	17	2	4
Dementia	1	1	2
Heart and lung diseases	1	4	1
Learning disability	0	0	0
Long-term condition e.g. diabetes, arthritis	1	4	8
Mental health	4	3	0

Please explain how the care did or did not meet your expectations and how could it be improved?

Cancer:

- “Only found out about local cancer support charities after accessing a psychology referral.”
- “I did not know what to expect and felt a little lost. I do not feel I got any support.”
- “Better financial and emotional support.”
- “It did meet expectations.”

Dementia:

- “Only one service from Age Concern. I'm not old. Where's the choice?”
- “I felt supported and relieved to be listened to.”

Heart and lung diseases:

- *“Podiatry have to wait at least three months for an appointment. Had to get in touch with Consultants PA to notify the doctor about change of medication, otherwise the doctor would not write a prescription. The doctor has still not been notified about tests done six weeks ago.”*
- *“Care needs met/treatment good.”*
- *“No ongoing support for COPD, I could have exercise classes.”*
- *“Only found out about exercise classes from Healthwatch.”*
- *“I need things written because I can't explain to my family what has been said.”*

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

- *“I wasn't given any information on other options.”*
- *“Better coordination is required for better outcomes for people with multi-system conditions, especially those that are rare and require input from multiple hospitals/specialists across different boroughs.”*
- *“I have symptoms that indicate Myeloma. They started in November. A repeat test was refused as the results indicated no further action.”*
- *“Felt I was left to manage the condition on my own.”*
- *“It did meet expectations.”*
- *“Made some conditions manageable, follow up appointments would help more.”*
- *“Getting to hospital and the waiting around often felt like too much on the days my pain was worst.”*

Mental Health:

- *“Too long to wait and not easy to access.”*
- *“I was given medication to help me and also offered further support.”*

Table 19: During your whole experience of getting support did you receive timely and consistent communication from all of the services that you came into contact with?

Condition	Yes	No	Somewhat
Autism	1	1	0
Cancer	18	2	4
Dementia	2	0	2
Heart and lung diseases	1	4	1
Learning disability	0	0	0
Long-term condition e.g. diabetes, arthritis	2	5	7
Mental health	2	5	0

Please explain how the care did or did not meet your expectations and how could it be improved?

Cancer:

- *“It would have helped if I was given a point of contact, a MacMillan Nurse as I was with my breast cancer diagnosis.”*

Heart and lung diseases:

- *“Not much support when I left hospital.”*
- *“Very poor communication.”*
- *“Have to do everything myself.”*

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

- *“To be told you have a degenerative condition and no information given on it whatsoever left me feeling I was on my own and that there were no other options for support or monitoring.”*
- *“Communication to me, the patient, was ok, but it was not ok from medic to medic especially across different specialties/hospitals/boroughs.”*
- *“I don’t get consistent communication at all; I just make my own appointments.”*
- *“Flexible appointment system to help with the pain when it’s bad or maybe a “drop-in” set up so I could access on my better days.”*
- *“I have had no follow-up and as this is now in the hands of a so-called specialist, the GPs feel that their job is done.”*

Mental Health:

- *“Communication could be improved.”*

Time spent travelling to access support and care

Table 20: What is your main means of transport?

Condition	Own car	Another person's car	Bus	Train	Bicycle	Taxi	Other
Autism	1	1	0	0	0	0	0
Cancer	18	6	0	1	0	2	2
Dementia	0	2	2	0	0	0	0
Heart and lung diseases	3	1	1	0	0	0	1
Learning disability	0	0	0	0	0	0	0
Long-term condition e.g. diabetes, arthritis	3	3	2	1	0	2	3
Mental health	2	1	3	0	0	0	1

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

Condition	Less than 30 minutes	30 minutes to 1 hour	1 - 2 hours	Over 2 hours
Autism	0	1	1	0
Cancer	1	17	1	8
Dementia	0	2	2	0
Heart and lung diseases	1	2	2	1
Learning disability	0	0	0	0
Long-term condition e.g. diabetes, arthritis	4	9	0	1
Mental health	0	4	2	0

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

Condition	Less than 30 minutes	30 minutes to 1 hour	1-2 hours	More than 2 hours
Autism	1	1	0	0
Cancer	5	11	0	11
Dementia	3	1	0	0
Heart and lung diseases	2	3	0	1
Learning disability	0	0	0	0
Long-term condition e.g. diabetes, arthritis	4	9	0	1
Mental health	1	4	1	1

Your expectations at each stage of your care

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

Condition	Seeing a health professional you normally see but you may have to wait	Seeing any medically appropriate health professional who is free immediately	Don't mind
Autism	0	1	0
Cancer	10	15	1
Dementia	0	4	0
Heart and lung diseases	1	3	2
Learning disability	0	0	0
Long-term condition e.g. diabetes, arthritis	1	8	3
Mental health	3	3	0

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

Condition	Seeing a health professional you normally see but you may have to wait	Seeing any medically appropriate health professional who is free immediately	Don't mind
Autism	1	0	0
Cancer	9	15	1
Dementia	0	4	0
Heart and lung diseases	0	3	3
Learning disability	0	0	0
Long-term condition e.g. diabetes, arthritis	5	5	3
Mental health	2	1	3

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

Condition	Seeing a health professional you normally see but you may have to wait	Seeing any medically appropriate health professional who is free immediately	Don't mind
Autism	1	0	0
Cancer	13	10	1
Dementia	0	4	0
Heart and lung diseases	0	4	2
Learning disability	0	0	0
Long-term condition e.g. diabetes, arthritis	5	4	3
Mental health	2	2	2

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

Condition	Seeing a health professional you normally see but you may have to wait	Seeing any medically appropriate health professional who is free immediately	Don't mind
Autism	1	0	0
Cancer	14	10	1
Dementia	4	0	0
Heart and lung diseases	3	1	2
Learning disability	0	0	0
Long-term condition e.g. diabetes, arthritis	7	3	2
Mental health	3	2	1

Supporting you to have more control over your own care

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

Condition	A lot of support	Some support	I don't need support	Don't know
Autism	0	2	0	0
Cancer	4	14	7	2
Dementia	1	3	0	0
Heart and lung diseases	0	6	0	0
Learning disability	0	0	0	0
Long-term condition e.g. diabetes, arthritis	3	9	0	2
Mental health	1	6	0	0

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

Cancer:

- *“Look at a person more ‘holistically’, taking into account other health problems. Earlier detection of other health conditions e.g., screening for skin cancers etc.”*
- *“Make doctors surgeries work full time and not do only 3 days a week with one admin Doctor's receptionist telling you there are no appointments for 3 weeks.”*
- *“Increase funding & staffing levels to all areas of NHS.”*
- *“I would like easy access to the services I need.”*
- *“Provide specific information regarding illness and treatments available, including side effects.”*
- *“Explain my options.”*
- *“Increase frequency of physio treatment to the individual.”*
- *“Continue to provide relevant treatment and access to services.”*
- *“I would love to see more information on living with cancer, including lifestyle - i.e. how I can help myself... diet, exercise etc.”*
- *It's important to feel in control and that I am doing all that I can, not just medical/drugs.”*
- *“Current treatment good. Went to clinic at Chester every 6 months but I felt they were not interested - 3.5 years for diagnosis is not good enough.”*

Dementia:

- *“Offer more support for family/respite.”*
- *“Quicker doctor's appointments.”*

Heart and Lung Diseases:

- *“Be able to see the doctor when needed.”*
- *“Give consistent information.”*
- *“More information/advice on how to stay healthy.”*
- *“More proactively give people incentives i.e. gym membership/free classes.”*
- *“Someone to ring when I am struggling.”*

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

- *“More information on self-care as well, such as referral options available if needed.”*
- *“The GP is usually the first line, there need to be more GPs and their level of training needs to be up to date and consistent. All too often when you see a different GP within the same surgery. The outcome of the consultation is radically different, often leaning towards a bias of what that particular GP understands best.”*
- *“Reviews more often than 12 months.”*
- *“I'd like to be checked regularly about blood tests, to see how my B12 is doing and get reminders when they are due next.”*
- *“Follow up appointments.”*
- *“Home visits.”*
- *“Free prescriptions.”*
- *“Easier access to follow up physio.”*

Mental Health:

- *“Make it easy and quick to access support services.”*
- *“Have more routine check-ups.”*

Further comments**Cancer:**

- *“Overall the NHS is the best in the world. It just needs more investment. Care that I received outside the special cancer areas was sadly lacking.”*
- *“I am completing this questionnaire as a cancer patient. However, I am also a nurse and before I became ill, I was directly experiencing lack of equipment, short staffing (very often dangerous) and the feeling of not being able to care for my patients as well as I would have wished.”*
- *“The service I have received at Clatterbridge has been excellent. I often wait a long time but I feel it's worth it.”*
- *“It is now seven years since my initial diagnosis and operation. The tumour reoccurred, 18 months ago for which I am currently having treatment at Clatterbridge. Care after diagnosis much better than before.”*

Heart and Lung Diseases:

- *“The National Health Service is getting worse.”*

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

- *“I have had wonderful help from doctors and Walton centre over the years and do my best to remain as healthy as possible. It is more than upsetting to have more hurdles put in place. Hearing loss is not adequately catered for in health services, despite constant reminders.”*
- *“My most pressing request would be for continuity with assured access to a doctor I know when I need it. Mostly I look after myself, I haven't had an antibiotic for 44 years which was after the last back surgery.”*
- *“My parents in law, both in good health, had a three-monthly review appointment with the same GP even though they were generally fit and well. It usually took five minutes or so, issued repeat prescriptions for the three months and reassured us all.”*

- *“My GP practice is very good and it is not their fault when forms go missing, appointments are delayed, etc. A proper health care plan would help both the GPs and me to work together to keep me out of their surgery.”*

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

This focus group took place on the 30th of April at Lonsdale Trust Wallasey, and was attended by 7 people.

Carers outlined much around the increased levels of depression and anxiety and that they can often be overlooked themselves by professionals when caring for people, feelings of isolation were also mentioned due to the restrictions of not being able to socialise. The following main issues that arose from the focus group were:

- Carers having to give up work to care for their loved ones leads to debt problems.
- Many carers experience mental health problems such as depression and anxiety.
- Carers feel isolated due to not being able to socialise.
- GPs not acknowledging carers health needs.
- Not enough support for Parent Carers.
- No real chance of a break unless they pay for this.
- No Carers Assessment offered by anyone.
- The Mental Health of carers is often overlooked by professionals when treating the cared for.
- Not enough support in the community.
- Carers providing front end care and don't feel supported.

More detailed responses were outlined into themes based on the responses the facilitators highlighted from the participants:

Finance and Carers Allowance:

- Carers will have debt problems as the only benefit available to them is Carers Allowance - which not all carers will be eligible for and this is not enough to live on. So many carers have to work or leave work or experience interruptions with work - No real advice on what to do. Parent Carers often experience having to be called out of work if their child is ill, so end up more stressed as this impacts on their job.

Mental Health:

- Many carers become depressed or suffer anxiety or panic attacks due to the responsibility of caring for someone with no real experience such as medication administration or general care giving, carers suffer physical health problems due to lifting in heavy end care with no training or specialised equipment.
- Many carers cannot socialise due to caring responsibilities and need to rely on family or friends to help care, therefore socialising becomes more difficult and they feel more isolated, impacting on their Mental Health.
- Carers of people with Mental Health issues are often overlooked by professionals and the care plans not shared with them even though they provide most of the care.

Accessing services and assessment:

- Many carers are not recognised by GPs or offered a carers assessment, also, there is no offer of respite unless they pay privately.
- Only private services are available to many, unless they go down the financial assessment route from Social Services, who seem reluctant to offer support from the experiences talked about here.
- Of the Carers attending, no carers had been offered a carers assessment by anyone and didn't know about it at all.

- Many carers providing 24/7 care with no real support from anyone, not treated the same as professionals with training or equipment.

A second focus group was undertaken focusing on the Deaf community and what they thought about their experiences with health and care services.

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

This focus group took place on 25th April 2019 at Birkenhead Park Visitor Centre, and was attended by 17 people. Below is a summary of the themes and issues they raised:

Community support:

People commented on the deaf community and how much representation there is available.

- There is not enough consultation with the deaf Community when planning or designing services and the impact on them.
- No deaf expert representing the deaf community.
- Deaf people not accessing holistic support such as alcohol/ substance misuse due to no interpreters.

Care service and support:

- Poor quality translating services at hospitals and Primary Care.
- Organisation currently used in Wirral provide a poor service with no continuity or thought of the individual's needs, e.g. male interpreter provided for female patient during a mammogram, interpreter arrives late or doesn't show up at all.
- No deaf counsellors available for talking therapies.

Information and awareness:

- Lack of awareness from ambulance teams in communication with deaf people.
- Lack of awareness with health professionals in general in communication with deaf people.
- More technology needs to be used in urgent care for communication with deaf people.
- Patient experience questionnaire not available in the right format, so deaf people excluded.
- Deaf people need information and advice in the right format to prevent health issues escalating. Understanding the impacts of Diabetes for example should be available to the more vulnerable of our community, such as the deaf. There are inequalities re: the information to the hearing community compared to the deaf.

Consultations and notice:

- After consultations there needs to be actions made with real outcomes and meaningful consultation.
- Deaf people given referrals to support in the community with no interpreters available.

Interpreters and support:

- No choice when booking an interpreter- poor quality service - no list/directory available.
- Small charity underfunded not enough staff to represent the deaf community to explain the issues affecting them.
- No choice of interpreters- no list or directory, so no choice for the patient.

- Deaf people need deaf counsellors, it's inappropriate to have someone signing for someone receiving counselling when emotional issues are being discussed.
- Deaf people need more time to arrange interpreters etc., if consultation is to be meaningful.
- Examples of GP's referring to Slimming World with no interpreters available to explain this - excludes the deaf person and they disengage.

Training and communication:

- Deaf people are more at risk of long-term illness due to information not being in a suitable format for deaf people.
- Examples of personal experience of ambulance service staff asking children of the deaf patient to interpret for them - inappropriateness of medical terms and even sharing of personal sensitive symptoms with children.
- Examples of hospital/primary care staff having no awareness of deaf people in communicating admissions or appointments etc. All staff need awareness training at induction and refreshed annually.