NHS Long Term Plan

Healthwatch Engagement
May 2019

Shaping the future of our NHS in North West London

healthwatch

“It sometimes depends on the ‘generation gap’.

Digital information is good for most people, but not all. Verbal and written communication is still essential for many of us.”

Local resident and service user

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General Services

In Focus

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What is the NHS Long Term Plan?

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

The Government is investing an extra £20 billion a year in the NHS. The NHS has produced a 'Long Term Plan' setting out the things it wants health services to do better for people across the country.

This includes making it easier to access support closer to home and via technology, doing more to help people stay well, and providing better support for people with long-term health conditions.

Feedback from Local People

Whilst the national plan has set some clear goals, it's up to local areas to decide how they're achieved – that means engaging with local people and listening to their experiences and expectations of current and future services.

Healthwatch organisations in North West London, alongside the national Healthwatch network has collected local views on the Long Term Plan through surveys, focus groups and events between April and June 2019, to give tens of thousands of people the opportunity to help local hospitals, GP surgeries and community services hear about the changes people would like to see.

The general national survey was completed by 938 people across North West London, with responses from a wide age range 11% were under 18, the next largest groups at 20% those 55-64 and 65-74. We note a few of the headlines here:

87% of respondents wanted "*professionals that listen to me when I speak to them about my concerns*" and 96% of respondents felt it very important or important that communications were timely. 89% thought it was either important or very important that any results were communicated quickly making the best use of technology.

Hosting 18 events in April, May and June 2019, local Healthwatch organisations in North West London engaged with a total of 257 local people.

Engagement Events

- Brent - 2 events (3rd and 8th May).
- Ealing - 2 events (15th and 22nd May).
- Hammersmith and Fulham - 2 events (17th April and 8th May).
- Harrow - 3 events (2nd, 16th and 20th May).
- Hillingdon - 3 events (16th April, 7th and 8th May).

- Kensington & Chelsea - 2 events (29th and 30th April).
- Hounslow - 2 events (30th May and 14th June).
- Westminster - 2 events (9th and 10th May).

Experience of Services
During the events, we asked people 'what works, what doesn't work, and what could easily be improved'?

What Matters
We then asked what matters most to them and recorded experiences around prevention and early intervention, assessment, diagnosis and treatment, and ongoing care and support.

Communication and Engagement
We also asked people how engaged they would like to be, and whether they would like to be involved in designing new services. As part of this, we asked them which aspects of communication and engagement could be improved.

This report gives an overview of findings.

What matters most to people in North West London?

Firstly, we look at services as a whole. When exploring basic service attributes, we find that local people consider communication, staffing, continuity of treatment and care, plus service access to be *most important* in current and future services.

Summary: Services in General

Communication
When talking to local people about present and future services, communication is an important topic. People tell us that good communication is vital - at both individual level (between service and patient) and for the wider community (having information about services available in and around the borough).

As well as a good level of information, people prefer use of simple, accessible language and formats, ideally suited to the needs of the recipient. This also means that the 'drive for greater use of technology' should not altogether replace traditional formats such as written letters and verbal communication.

Staffing, Training and Continuity
Many people have noticed that health and social care services are under 'full stretch', with sometimes considerable pressures on staff. It is desirable that future changes are equitable for staff and service users alike, with good levels of support available to all.

Some people feel that doctors could improve their interpersonal skills. People also say there should be better training on Mental Health and long term conditions such as Diabetes. Some suggested reinstating grants to incentivise uptake for training.

Summary: Services in General

Staffing, Training and Continuity (continued)

While many people are happy to see a different health or care professional to reduce their waiting time, a significant number, such as people with Dementia require consistency and a named contact. When looking at continuity, there is no one size fits all.

It can be difficult to see a doctor of a preferred gender – some gynecology patients have experienced delays, or wasted journeys, to see a female practitioner.

Service Access
It is clear that people would like greater access to services (particularly GPs) and better support in obtaining their appointments. Many experience poor telephone access and systems, however some have noticed improvements in online booking, and availability of out-of-hours appointments.

While patients are complimentary about telephone triage, there is concern that it should not be the only option, or prevent a personal consultation when it would be ‘the best clinical option’.

While many people anticipate delays, a large number consider punctuality to be important - complaints about waiting times are common. Experiences of waiting lists are mixed, however a large proportion of patients are waiting too long - to see their GP or for services generally.

Although there should be a choice on referral, this is not always the case. Some people feel they are excluded from the process, or have little control.

On transport, we hear that stricter eligibility criteria has left many people unsupported.

Coordination and Consistency
People would also like greater levels of co-ordination between services locally and regionally - for example one patient experienced considerable delays with hospital discharge, as the hospital and community rehabilitation service were in different boroughs. It was felt that services could also strive to be more consistent, and with it become ‘fairer and more equitable for all’.

Learning from Discussion (Checklist)

Communication – local people would like:

- Good levels of communication.
- Information that is consistent, accurate and up-to-date.
- Clear oral and written language and information in accessible formats.
- Choice of electronic, oral or written communication.
- To be aware of existing services, and advised on which to use.
- Timely information and engagement on service changes.
- Engagement between services and the 'wider community'.

Staffing, Training and Continuity – local people would like:

- Good working conditions and working environment for staff (example, employers to observe the 'Anchor Organisations' principles).
- Adequate staffing levels and well resourced specialists.
- A well trained workforce (both hard and soft skills).
- Continuity (choice of professional) if required.
- A named contact.

Service Access – local people would like:

- Good telephone access.
- Reliable and easy-to-use booking systems.
- Punctuality of services and communication from staff when this is not the case.
- Priority for those with a particular need (such as Autism).

Coordination and Consistency – local people would like:

- Consistency across services.
- Services in different localities, and of different specialities to work together.
- Staff to be aware of, and actively utilise Health Passports.

Local people would also like:

- Recognition of their disability, condition or need.
- To be included, involved and respected.
- Good levels of awareness (training for staff).

General Services: From Diagnosis to Ongoing Care

We talked about various aspects around assessment, diagnosis, treatment and ongoing care and support.

Assessment, Diagnosis and Treatment

It was felt that generally, services need to be more transparent and better coordinated.

People said that waiting times from assessment to treatment are ‘too long’, with some suggesting a cap. We heard examples of inadequate ongoing support for patients following the assessment, and a lack of joint decision making between the service user and the health professional.

Digital technology is considered to be a positive element of NHS services, although there was consensus that technologies are being under utilised in local health services and not meeting full potential (for example in research and applications for patients).

Cultural awareness was flagged as a ‘key area of concern’ and it was suggested that health professionals and service users ‘could be matched’ on the basis of experience with different groups and cultures.

Prevention and Early Intervention

To maximise prevention, we need ‘clear referral pathways’, accessible support and greater use of self-help and peer support groups. Consulting patients on the design and delivery of services can also make it work better for all.

There was much emphasis on promoting ‘healthy lifestyle’ factors such as diet and exercise – local people could be encouraged to attend groups or talks and to learn new skills (such as cooking).

Reinstating health checks in schools could be useful, plus provision of a Patient Advice & Liaison Service (PALS) for primary care.

Ongoing Care and Support

Generally it was felt that greater support is needed following assessments - particularly for long term conditions. Better use of digital technology (such as remote appointments) and closer working between social prescribers and community groups could enhance personal support.

If referring, provision of a care plan detailing locations, contacts and timescales would be useful for patients, carers and services. Patients also need to ‘know about their rights’.

General Services: From Diagnosis to Ongoing Care

Ongoing Care and Support (continued)

People also said that the mental health of carers should not be overlooked and that carers could benefit from advocates - particularly when addressing inequalities and lack of support.

To assist ongoing support, discharge letters should be more informative (including named contacts) and those aged 75 plus could benefit more from social prescribing and home visits.

Learning from Discussion (Checklist)

Assessment, Diagnosis and Treatment - local people would like:

- Services that are transparent and well coordinated.
- Timely access to treatment and support following assessment (with a waiting time cap).
- To be included, involved and respected (joint decision making).
- Optimal use of digital technology - for professionals and service users.
- Good cultural awareness and inclusion.

Prevention and Early Intervention - local people would like:

- Referral pathways that are ‘clear’ and support that is ‘accessible’.
- Access to self-help and peer support.
- User engagement in service design and delivery.
- Good awareness of ‘healthy lifestyles’.
- Health checks in schools.
- A Patient Advice & Liaison Service (PALS) for primary care.

Ongoing Care and Support - local people would like:

- Good levels of support following assessment (particularly for long term conditions).
- Optimal use of digital technology - for professionals and service users.
- Partnership working – community groups and social prescribers.
- Care plans and discharge letters that are detailed and clear.
- Promotion of patients’ rights.
- Mental health and other support for carers.
- More supplementary services for older people.

How could communication and engagement be improved?

We asked people how engaged they would like to be, and whether they would like to be involved in designing new services. As part of this, we asked them which aspects of communication and engagement could be improved.

People feel they are ‘asked to do too many satisfaction surveys’, and that we need ‘more than forms’. Focus groups could be used to help design the surveys - to make them more appealing, and perhaps more relevant.

Updates on how the information is used would be useful, and most importantly, people want to see the impact of the suggestions they have made, or at least for their suggestions to be considered and to be told why/why not they have been acted on.

It was noted that focus groups are not always representative of a borough’s diverse demographic and different abilities, therefore outreach (such as school visits to talk with children and parents) would increase inclusivity.

On service related feedback, it was felt that the Friends and Family Test is ‘inadequate’.

Learning from Discussion (Checklist)

Communication and Engagement - local people would like:

- Fewer surveys (to combat ‘feedback fatigue’).
- To be included in survey and engagement design.
- Updates on how their feedback has/has not been used.
- Good representation, including at events.
- An alternative to the Friends and Family Test.

What did people tell Healthwatch?

Here, we take a more detailed look at the top themes emerging from discussion.

1. Communication

When talking to local people about present and future services, communication is an important topic.

In this section, we explore communication at a personal, service-wide and community-wide level. We also consider accessibility, inclusivity of information and complaints processes.

1.1 Personal Communication

People often complain about insufficient or inconsistent personal information from health or social care professionals.

Selected Comments, Personal Communication

Positive experiences:

"My GP explains things well – makes me feel comfortable and listened to." [Hounslow]

"Many felt when discharged from hospital, things were explained to them clearly." [Hounslow]

"My GP is brilliant, and I can always get an appointment" [Hillingdon]

"I felt respected by my GP" [Hillingdon]

"Access to my GP is quick and it's easy to fill my repeat prescription" [Hillingdon]

Negative experiences:

"Poor communication from my GP when changing my medication." [Harrow]

"People aren't often encouraged or provided with the necessary information to help themselves." [Kensington & Chelsea]

"Inconsistent information provided." [Harrow]

"Receptionist 'no good' at communicating with patients." [Westminster]

"My poor husband ended up on patient transport for hours, he is diabetic, it nearly made him ill, they just can't seem to join things up" [Hammersmith & Fulham]

"Access to my GP is not always easy" [Hillingdon]

"I needed to wait a month to see my own GP after another GP in the same practice wanted to see me quickly" [Hillingdon]

"Having to wait for 2 weeks to see a GP, even though it was a follow up appointment" [Hillingdon]

"In some cases the language used and communication is not clear and customer care skills can be better" [Hillingdon]

Suggestions:

“Participants said they received text messaging from GPs to give feedback but don’t respond to it because they receive too many.” [Hounslow]

1.2 Service-wide Communication

When looking at services as a whole, people say they are not always aware of basic service information, such as opening times.

Selected Comments, Service-wide Communication

Positive experiences:

“There is a course for informing people about avoiding diabetes – very good for prevention and awareness.” [Westminster]

Negative experiences:

“My GP doesn’t promote services, such as extended hours.” [Harrow]

“There are good NHS sites and apps, but they are hard to find; contact details aren’t always clearly displayed or they aren’t provided at all.” [Kensington & Chelsea]

“I am not accessing the right services because the systems have changed and not communicated” [Hillingdon]

“The website needs to be up-to-date.” [Harrow]

“There are problems with admin within hospitals - letters are often being sent to confirm appointments that have already taken place, this has happened to patients at Ealing hospital. Additionally, there have been examples of data breaches whereby letters containing medical information have been sent to the wrong addresses without the patient knowing.” [Ealing]

“Discharge papers are too legalistic and could be simpler” [Hillingdon]

Suggestions:

“How about getting volunteers to help draft standard letters or provide a plain language compliment”? [Hammersmith & Fulham]

1.3 Community-wide Information

People benefit from knowing what exists within and around the borough, however information is not always available borough-wide.

Selected Comments, Community-wide Information

Negative experiences:

“We need clearer information on which services are appropriate – A&E, walk-ins for example.” [Harrow]

“We need more information on service closures or changes (Alexandra Avenue Walk-In Centre, for example).” [Harrow]

“A lot more promotion of pharmacy services needed.” [Harrow]

“Care navigators - this person didn’t know they existed, it took a year to find out and get an assessment.” [Westminster]

Suggestions:

“Something like a ‘Patient’s Guide’ – what we should be looking for is a good idea.” [Harrow]

“Why not create a Citizens Panel?” [Kensington & Chelsea]

“Services need to engage with the wider community – clients and residents.” [Brent]

“Educate people to know when to go to the GP rather than A&E – includes making it easier to see the GP.” [Brent]

1.4 Accessibility of Information

As well as a good level of information, people prefer use of simple, accessible language and formats, ideally suited to the needs of the recipient.

Selected Comments, Accessibility of Information

Negative experiences:

“I need accessible information that is easier to understand.” [Harrow]

“Communications should better suit the recipient.” [Harrow]

“The use of terminology which is not explained makes accessing services difficult” [Hillingdon]

“Language, when communicating to the public, needs to be simple.” [Harrow]

“Patients need greater levels of education and understanding.” [Brent]

“Information and forms not always provided in an accessible way – complex language (jargon) used.” [Brent]

"Where English is not the first language of the doctor, it is sometimes difficult to be understood." [Brent]

Suggestions:

"Information and forms being provided in easy read. Removing complex language." [Harrow]

1.5 Inclusivity of Communication

People have a diverse range of needs, therefore the 'drive for greater use of technology' should not altogether replace traditional formats such as written letters and verbal communication.

Selected Comments, Inclusivity of Communication

Negative experiences:

"It sometimes depends on the 'generation gap'. Digital information is good for most people, but not all. Verbal and written communication is still essential for many of us." [Harrow]

1.6 Complaints

Experiences of complaints are mixed.

Selected Comments, Complaints

Positive experiences:

"Provided a complaint and received an excellent response." [Kensington & Chelsea]

Negative experiences:

"Been trying to give feedback to WLCCG about Grenfell-related services for two years, without having any progress; the feedback thus evolved into a complaint, which did not need to be the case." [Kensington & Chelsea]

Suggestions:

"We need to enable carers/unpaid visitors to report problems with those they are visiting." [Westminster]

2. Staffing, Training and Continuity

Many people have noticed that health and social care services are under ‘full stretch’, with sometimes considerable pressures on staff.

In a stark account, a volunteer in Ealing says “through delivering food parcels I see nurses relying on food banks and living in homeless hostels. How can they provide the best quality care when they are struggling so much themselves?”

Healthwatch Brent comments “We hear in the news that we are losing nurses and doctors every week due to stress, overwork and mental health problems. Service users and those in the industry ask ‘how and when’ will this be addressed?

We need good employers for our healthcare staff in order to retain them.
There seems to be confusion about whether bursaries for training new nurses will continue, and whether this is making a difference or not. There also seems to be a mismatch between what we hear in the news and the statements in the NHS Long Term Plan summary. Where is the workforce going to come from?”

In this section, we look at staffing and retention, training and service continuity.

2.1 Staffing and Retention

The recruitment and retention of staff is a challenge people understand and experience the consequences of.

Selected Comments, Staffing and Retention

Positive experiences:

“I felt respected by my GP” [Hillingdon]

Negative experiences:

“Recruitment is a ‘big problem’, you never see the same person. All outsourced.” [Harrow]

“There is a learning difficulties nurse that helps and supports patients – although one nurse for 3 hospitals – NPH, CMH and Ealing.” [Brent]

“We all know staff in the NHS are overworked.” [Harrow]

“Staff are leaving because of working conditions. Staffing is inadequate, leading to deficiencies in the service.” [Harrow]

“People can be reluctant to phone for assistance (for example a lady on the floor with a dislocated hip).” [Harrow]

"Nurses filling in and covering shifts due to shortages. They can only do this for so long before they get fed up. Too much is asked of them." [Ealing]

2.2 Training

Some people feel that doctors could improve their interpersonal skills. People also feel there should be better training on Mental Health and long term conditions such as Diabetes. Some suggested reinstating grants to incentivise uptake for training.

Selected Comments, Training

Positive experiences:

"One of the people in the focus group's mother had a fall. They had a breakdown and the paramedics were able to calm her down (even broke protocol to do so). They saw this a very positive experience. Turned out, they had been trained in how to sufficiently deal with those with learning disabilities." [Hounslow]

Negative experiences:

"Doctors should be better able to use their PC and listen to the patient simultaneously." [Harrow]

"Someone with Diabetes who had cut their leg - the GP 'didn't know how to dress the wound' but A&E did." [Harrow]

"Training for carers is "non-existent." [Westminster]

"Participants were concerned about who was training carers because they have seen them not follow basic rules of hygiene. There was an example given of a time a carer was working in the medical surgery (of a care home), wearing gloves, and the person went into the kitchen wearing the same gloves. However, ECIL to do run a 12 week course for carers about medical administration and hygiene etc." [Ealing]

Suggestions:

"Mandatory training in mental health services and for GP networks." [Harrow]

"Reinstate the training grant that was 'taken away' (bursary)." [Harrow]

"Training for pharmacists to have wider knowledge." [Harrow]

"Before appointing an agency, the NHS should consider how the agency trains its carers on sensitive issues like nutrition, language, Mental Health, multiple conditions, cultural sensitivities. It should then consider how the agency monitors this as well." [Westminster]

2.3 Continuity

While many people are happy to see a different health or care professional to reduce their waiting time, a significant number, such as people with Dementia require consistency and a named contact. When looking at continuity, there is no one size fits all.

It can be difficult to see a doctor of a preferred gender – some gynecology patients have experienced delays, or wasted journeys, to see a female practitioner.

Selected Comments, Continuity

Positive experiences:

“Sees the same GP - prefers this because communication is easier and it’s more comfortable. It’s ‘hard to trust people’ so this makes this easier.” [Hounslow]

Negative experiences:

“I had the same carer for over a year, she was trained and knowledgeable. Now ‘it’s a different one every week’. The service isn’t reliable.” [Harrow]

“When seeing multiple different professionals, a lot of repetition happened. Had to give mini medical histories every single time.” [Hounslow]

“I need to develop a continuous relationship with my own specific doctor.” [Harrow]

“For social care, definitely the same person. The carer on the phone ‘tries to find someone to talk to’, it often takes an hour and they get someone they don’t know. It’s not effective or efficient.” [Harrow]

“The ‘named GP’ system does not mean anything in reality. I have never seen them.” [Ealing]

Suggestions:

“Seeing the same professional reduces the time taken at appointments, therefore may be more efficient.” [Harrow]

“If you see the same person regularly the appointments are smoother and quicker – surely this saves the NHS in the long run.” [Harrow]

“Focus on prevention should be top of the agenda as this is the key to reducing pressure on services, particularly A&E” [Hillingdon]

3. Service Access

It is clear that people would like greater access to services (particularly GPs) and better support in obtaining their appointments. Here, we look at contact and booking, waiting times and punctuality, referrals and transport.

3.1 Contact and Booking

Many people experience poor telephone access and systems, however some have noticed improvements in online booking, and availability of out-of-hours appointments.

While patients are complimentary about telephone triage, there is concern that it should not be the only option, or prevent a personal consultation when it would be ‘the best option’.

Selected Comments, Contact and Booking

Positive experiences:

“Growing availability of remote/phone appointments.” [Westminster]

“GP good at offering alternative and out-of-hours appointments.” [Westminster]

“It’s easier to book online or in person (than it was).” [Westminster]

“I got a telephone triage – I phoned, described my symptoms and they were able to tell me if I needed to come in. Very good service.” [Ealing]

“GP has specific afternoon hours for urgent cases, the receptionist also has a medical experience and knowledge, so she can give you an initial assessment if you show up in urgent cases.” [Ealing]

Negative experiences:

“Poor telephone access to outpatients at Northwick Park Hospital.” [Harrow]

“I need more support to get appointments.” [Harrow]

“Can’t get an appointment – keep phoning.” [Harrow]

“Phone lines not telling callers how long they will wait is costly and stressful.” [Kensington & Chelsea]

3.2 Waiting Times and Punctuality

While many people anticipate delays, a large number consider punctuality to be important - complaints about waiting times are common. Experiences of waiting lists are mixed, however a large proportion of patients are waiting too long - to see their GP or for services generally.

Selected Comments, Waiting Times and Punctuality

Positive experiences:

"GP did a good initial assessment and sent to the hospital, where I was diagnosed with a serious condition the next day and operated on." [Kensington & Chelsea]

"GP has a walk in service three days a week, you arrive in the morning on the day and you get seen." [Kensington & Chelsea]

"GP did a good initial assessment and sent to the hospital, where I was diagnosed with a serious condition the next day and operated on." [Kensington & Chelsea]

"My GP is brilliant, and I can always get an appointment." [Hillingdon]

"It's more accessible when signing in with technology at appointments." [Harrow]

Negative experiences:

"We need better communication between departments to line up appointments" [Hillingdon]

"There needs to be better accessibility to deal with appointments" [Hillingdon]

"Appointments always running late – you can be waiting for a long time." [Brent]

"There should be no waiting time for patients if they have Autism. Carers find it very stressful to manage the patient when they become restless and start to get aggressive or anxious and worried." [Brent]

"The whole dementia pathway didn't work, it was hard to get an appointment and the wait took two years to get anything." [Westminster]

"3 week delay for GP appointment, 2 week delay for physiotherapy." [Westminster]

"Called for a consultation and advised to 'call in 14 days' this is too long." [Westminster]

"Had to go to hospital for blood test as the GP had a 3 week wait." [Hillingdon]

"I have to wait 2 months to see my preferred GP." [Ealing]

"There is a lack of community services. I asked for physio after a broken arm. The wait is approx. 19 weeks. Effectively physio is not available. It has to be immediate to be effective." [Ealing]

"Delayed operation - cancelled last minute as they didn't have the drugs needed to do the procedure." [Hillingdon]

" A&E has a massive waiting time" "Long waiting time in A&E" [Hillingdon]

3.3 Referrals

Although there should be a choice on referral, this is not always the case. Some people feel they are excluded from the process, including when things go wrong (such as referral to the wrong service) or that services do not connect to support progress of referral, treatment and follow up.

Selected Comments, Referrals

Positive experiences:

"I received a text about my referral – made it easier to remember." [Brent]

Negative experiences:

"I asked my GP for a referral to Guys and St Thomas. I got a letter with an appointment for Charing Cross. I logged on and cancelled it and then received another letter for a new appointment at Charing Cross. I called the number and was told I can't actually cancel it myself, only they can. Eventually I got my appointment at Guys." [Ealing]

"I asked for referral to another hospital and got the same thing, an appointment letter listing a different hospital. Choice does not exist. The systems automatically decide which hospital you go to." [Ealing]

"Audiology: My GP said she could refer me to a local Specsavers but if patient flow reduced to Charing Cross then we could lose the Charing Cross ENT department which would mean there was nowhere to go for more complex patients." [Ealing]

3.4 Travel and Transport

When engaging with older people in particular, we hear accounts of long journeys, a lack of basic support and poor timing of transport. It is also reported that stricter eligibility criteria leaves many people unsupported.

Transport links from borough to hospital are not always convenient, particularly when ill. Parking was cited as an issue for both patients and staff.

Selected Comments, Travel and Transport

Positive experiences:

"One person a travel buddy which helped them become more independent. In fact, this person could now come to the community access service by themselves." [Hounslow]

Negative experiences:

"Multiple pickups, long journey for first passenger." [Kensington & Chelsea]

"The Department for Health is restricting access to transport for appointments." [Westminster]

"Experiences of older, chronically ill and diabetic patients deteriorating due to long wait times, long journeys and long periods without food or drink." [Kensington & Chelsea]

"Transport starts at 9am, even when some appointments start at 10, meaning some are missed." [Kensington & Chelsea]

"Poor public transport links between Ealing and Northwick Park Hospital – which is not ideal if you are ill'. [Ealing]

"Parking problems - all the parking metres were closed near the surgery, making it difficult for disabled people to access the service. General parking issues means that people must use taxis and these costs build up, especially if you have a long term condition." Staff also have to pay sometimes. [Ealing]

Suggestions:

"A local community project is successful - providing rehabilitation support including treatment in the community and buses to the hospital." [Harrow]

4. Coordination and Consistency

People would like good levels of co-ordination between services locally and regionally, and greater consistency in general.
Healthwatch Brent comments "Only 10 to 15% of our health needs require health service input. So [the LTP] needs to recognise the rest of what keeps us well. Record keeping and integration of data across the whole sector seems essential if this is to work, from hospital to GP to community, to any service area we use. What needs to be integrated so that it suits [works for] people? Social Care needs to be part of this new system – but so do lots of other services that we use in our lives – all these things need to work together to keep us well."

4.1 Co-ordination

People comment on a lack of coordination, and say that services in different localities and of different specialisms ‘could work better together’.

Selected Comments, Co-ordination between services

Positive experiences:

“My pharmacist gave me a ‘My Medication Passport’ – excellent idea!” [Ealing]

“GP shared a ‘Health Passport’ with the patient, meaning she was able to easily share information with the hospital when she had to go to A&E - useful as an older person.” [Ealing]

Negative experiences:

“NHS boundaries and discharge – mother who has had hip replacement ‘still in hospital after 3 weeks’ because the hospital is in a different borough to the rehabilitation service.” [Harrow]

“Lack of communication between health professionals puts the onus on carers to connect different members of a care support network.” [Hammersmith & Fulham]

“Different health professionals ‘all ignore each other’ and ‘no one follows the plan’.” [Hammersmith & Fulham]

“Some processes should be better connected; interconnected between Citizens Advice Bureau and the extended care network” [Hammersmith & Fulham]

“Patient waiting too long for an operation due to lack of communication between care navigators.” [Westminster]

“Hard to get a consistent dentist on the NHS.” [Hillingdon]

“UCL wouldn’t give me treatment because I was being seen by another hospital (cancer).” [Westminster]

“Poor communication between departments/companies: Featherstone Clinic out of hours - couldn’t do the x-ray because they are privately run and so couldn’t share the x-ray results. They went to urgent care for the x-ray and then had to get tested elsewhere, due to a lack of communication between the different areas/companies running the departments. This is also the case in hospitals.” [Ealing]

Suggestions:
“Health Passports work well- when a person has them and the medical professional uses them.” [Harrow]

4.2 Consistency

It was felt that services could also strive to be more consistent, and with it become ‘fairer and more equitable for all’.

Selected Comments, Consistency

Negative experiences:

“Inconsistency across GP surgeries, some it is easy to get an appointment in others extremely difficult – why is there such inconsistency?” [Harrow]

“Access to GP surgeries mixed - not consistent across the borough.” [Harrow]

“Computers that don’t talk to each other.” [Harrow]

Suggestions:

“Integrate services so you tell your story once only”.” [Hillingdon]

“Digitise care to support integrated services so you tell your story once only.” [Hillingdon]

From Diagnosis to Ongoing Care

We talked about various aspects around assessment, diagnosis, treatment, early intervention and ongoing care and support.

5. Assessment, Diagnosis and Treatment

It was felt that generally, services need to be more transparent and better coordinated.

People said that waiting times from assessment to treatment are ‘too long’, with some suggesting a cap. We heard examples of inadequate ongoing support for patients following the assessment, and a lack of joint decision making between the service user and the health professional.

Digital technology is considered to be a positive element of NHS services, although there was consensus that technologies are being ‘under utilised’ in local health services and ‘not meeting full’ potential (for example in research and applications for patients).

Cultural awareness was flagged as a 'key area of concern' and it was suggested that health professionals and service users 'could be matched' on the basis of experience with different groups and cultures.

General Services: Assessment, Diagnosis and Treatment

Common themes include:

Communication
Any interactions between the health professional and the service user should be transparent, informative and respectful, without rushing the service user (the current limited time for appointments makes this difficult). GPs need to be better coordinated with one another and with specialists; service users also need to know their pathways to the specialist.

Waiting Times
Patients wait 'too long' from assessment to treatment - people say the wait can go from a 4-week minimum to as long as a year, allowing conditions to worsen. One group suggested a cap on waiting times.

Support (Appointment Duration)
Many people agree that the 10-minute time limit on appointments, and the restriction of only talking about one condition, disadvantages people with multiple conditions, as well as people with communication difficulties i.e. language barriers or speaking tangentially as part of an existing disorder.

Optimising Technology
Digital technology is considered to be a positive element of NHS services, although there was consensus that technologies are being 'under utilised' in local health services and 'not meeting' full potential (for example in research and applications for patients).

Cultural Awareness
This was a 'key area of concern' for the Kensington and Chelsea group, with some stressing the importance of understanding that anything that could be considered 'minor' or 'routine' might not be so for the patient, particularly those from BAME groups; the group also pointed out that assessment, diagnosis and treatment can all be problematic for BAME groups with Mental Health conditions. Some suggested more matching health professionals and service users on the basis of experience with different groups and cultures.

General Services: Assessment, Diagnosis and Treatment

Summary of other popular themes:

- **Alternative locations and services:** GPs should find a service that suits the patient, even when they can't provide it. The question of travel to that alternative service would be a question of what the doctor would do

to support the patient in the event that this happens. Suggestion that a patient does not always need to attend a non-physical appointment.
- **Ongoing care and support:** Health professionals should offer support while waiting for diagnosis, then treatment. The group said that there needs to be long-term follow up as well (consultant follow up after one year).
- **Care Plan:** These need to be implemented for everyone. There are many cases when plans do not exist or haven't been agreed with the patient (specifically in Mental Health cases). These too need to be maintained efficiently and clearly followed up.
- **Upskilling GPs:** Primary care professionals should be coached to interpret or read X-rays.
- **Improving feedback and complaints services:** It should be easier to report and provide feedback; PALS should be more widely available; NHS staff should have a system for following up with patients for feedback; a dedicated, independent complaint service.
- **Signposting:** There should be more information provided at GP surgeries; better signposting and training for frontline staff.
- **Continuity of Care:** Patient information should be kept in one place, shared with and read by different doctors; Option to see the same doctor.
- **Training and Staffing:** Invest in radiographers; problem with manpower; more nurse practitioners in surgeries, give them more responsibility; Podiatrist needs to be seen frequently for diabetes patients.

6. Prevention and Early Intervention

To maximise prevention we need 'clear referral pathways', accessible support and greater use of self-help and peer support groups. Consulting patients on the design and delivery of services can also make it work better for all.

There was much emphasis on promoting 'healthy lifestyle' factors such as diet and exercise - local people could be encouraged to attend groups or talks and to learn new skills (such as cooking).

Reinstating health checks in schools could be useful, plus provision of a Patient Advice & Liaison Service (PALS) for primary care.

General Services: Prevention and Early Intervention

Common themes include:

Clarity and Accessibility
Referral pathways should be 'clear' and support services 'accessible'. Out of area services could be utilised, to avoid long waiting times locally.

Support Groups and Self Care

It was suggested that increased referrals to patient self-help and support groups could benefit patients – social prescribers and volunteer 'community champions' could play an important role in signposting. Expert Patient Programmes are also shown to be effective.

Co-Produced/Designed Services
Consult patients and carers on planning, with monitoring services to track the service's progress and identify issues (could be patient-led).

Diet, Exercise and Healthy Lifestyle
Preventative solutions through diet and exercise are important. We need to provide exercise classes and community activity that can draw people in - combining this with talks about improving health; Inter-generational pro health activities; cooking lessons; walking groups for adults.

School Nursing
Reinstate health checks in school to support early intervention.

Patient Advice & Liaison Service (PALS)
There is no current equivalent to PALS in primary care (except one Nottingham scheme); this could be explored as a means of support.

General Services: Prevention and Early Intervention

Summary of other popular themes:

- **Breast feeding:** This should be encouraged and supported among more new parents.
- **Awareness of Mental Health conditions:** More education for the public on signs of mental health deterioration, and on knowing how to provide support or signposting if required.
- **Using Technology:** 'Gamified' apps that would encourage people to change unhealthy behaviours and prevent chronic lifestyle illnesses; Show people how to use the NHS websites; OpenAge to give talks in local areas/games and apps; Need info on available online services
- **Community Outreach and Signposting:** Library/café/Community centre for volunteer listeners/signposters; Network of community neighbours to signpost and link a person to the health and social care services they need; Informative booklets
- **Information in Health Centres:** Videos in surgeries to explain options to patients; Embedded community clinics
- **Education and Training**: Regular training on prevention in the community. **BAME Outreach:** Need more outreach with different ethnic groups that are not taking up certain screenings
- **Specialist Practitioners:** Able to follow up people who have been "flagged" (might need more frequent tests and referrals).
- **Wellwoman and wellmen clinics:** Greater provision.

7. Ongoing Care and Support

Generally it was felt that greater support is needed following assessments - particularly for long term conditions. Better use of digital technology (such as remote appointments) and closer working between social prescribers and community groups could enhance personal support.

If referring, provision of a care plan detailing locations, contacts and timescales would be useful for patients, carers and services. Patients also need to 'know about their rights'.

People also said that the mental health of carers should not be overlooked and that carers could benefit from advocates - particularly when addressing inequalities and lack of support.

To assist ongoing support, discharge letters should be more informative (including named contacts) and those aged 75 plus could benefit more from social prescribing and home visits.

General Services: Ongoing Care and Support

Common themes include:

Using Digital Technology:
Better use of app development; offering remote appointments; using personal data proactively to improve continuity of care; offering remote synergy between mental and physical information. Put technology into people's homes (digital care assistance).

Social Prescribing
Could work with local volunteer and community groups, remaining mindful that the work of these groups can sometimes obscure the gaps within local health and social care services, without getting the necessary support themselves.

Referral Information and Communications
The health professional should provide the patient with a plan at the beginning with location, contact and timescale in an introductory info pack; this would be to support the patient, but would also be useful to the referral unit. There should be a directory of support, and surgeries should have the details updated and available to patients.

Information about Patient Rights
The patient should know what to expect, especially in terms of what they are entitled to.

Carers
More messaging and recognition around mental health is needed - rather than being seen as 'too complex' we need to treat it as essential support. We need more carer-patient advocacy, and advocacy on behalf of carers; need to

recognise inequalities in care (single parents receiving less home support after being discharged), and inequalities of need.

After-Care
Better support for when you leave hospital - a discharge letter should include details of who will support you (a named doctor, district nurse etc). Home visits should be available for people aged over 75.

General Services: Ongoing Care and Support

Summary of other popular themes:

- **User-friendly communications:** communicating in an accessible way (minimising clinician language, using translators, mini com, Easy Read etc.) would be an improvement.
- **Continuity of Care:** health professionals should communicate with other specialists and keep information safe. Keep track of patients with long appointment waits with regular reminders.
- **Monitoring and Scrutiny:** individual volunteers could provide scrutiny on care and communication throughout the referral journey, as some people do not feel they can complain and need support (Expert Patient Programme).
- **Transport:** coordination is ‘poor’ – communication and logistics need to be improved. More people need to be supported to access transport.
- **Self-Care:** needs to be taken seriously and supported; diabetes a particular area of need.
- **“Pensioner MOT” or “Health Passport”:** Newborn booklet model for over 65s; Health passport to give patients control.
- **Transport:** Taxi service for people travelling for care; Travel needs to be improved: you want to be as close to the service you receive as possible, you should be supported with access if this isn’t possible.

8. How could communication and engagement be improved?

Finally, we asked people how engaged they would like to be, and whether they would like to be involved in designing new services. As part of this, we asked them which aspects of communication and engagement could be improved.

People feel they are ‘asked to do too many satisfaction surveys’, and that we need ‘more than forms’. Focus groups could be used to help design the surveys - to make them more appealing, and perhaps more relevant.

Updates on how the information is used would be useful, and most importantly, people want to see the impact of the suggestions they have made, or at least for their suggestions to be considered and to be told why/why not they have been acted on.

It was noted that focus groups are not always representative of a borough's diverse demographic and different abilities, therefore outreach (such as school visits to talk with children and parents) would increase inclusivity.

On service related feedback, it was felt that the Friends and Family Test is 'inadequate'.

General Services: How could communication and engagement be improved?

Common themes include:

Co-Design of Engagement
It was felt that 'people are asked to do too many satisfaction surveys', and that we need 'more than forms'. Focus groups could be used to help design the surveys beforehand, so that they can comment and test.

Closing the 'Feedback Loop'
Most importantly, people want to see the impact of the suggestions they have made, or at least for their suggestions to be considered and to be told why/why not they have been acted on.

Representation
Focus groups are not always representative of a borough's diverse demographic and different abilities; discussed the need to capture views from across the population.

Local Engagement
We need to go into schools and speak to parents, who remain an underrepresented group in feedback on local health and social care.

Friends and Family Test
The culture of how the NHS listens to patients 'needs to change'. It is felt that the Friends and Family Test is 'inadequate'.

General Services: How could communication and engagement be improved?

Summary of other popular themes:

- **PPGs:** Are useful avenues for providing feedback, but they are not considered to be well-publicised. We also need better links between Patient Participation Groups (PPGs) and Patient Reference Groups (PRGs).
- **Citizenship Panel:** Important to note that some people do not want to be involved in the way this meeting's attendees want to be involved; need for a citizenship structure with a panel that can be used to engage local service users and provide feedback.
- **Using Skills:** Healthwatch should utilise skills of the Discussion Group and members, capturing their expertise and using them as expert contributors in future groups and discussions.

9. In Focus - Mental Health

Engaging with 46 people, we received feedback about services including GPs, Community Mental Health services, Hospitals, SPA (Single Point of Access) and the Recovery Team. Findings are summarised below – see Appendix 1 for the full report.

Mental Health Services

GP Services
When talking about local GP services, people cite good levels of empathy from GPs, however treatment is not always effective. Some patients comment on feeling unsupported, with GPs showing 'little interest' in their personal or social circumstances – this can affect ongoing care and early intervention. One patient had to 'persuade' the doctor that he was ill, while others say that assistance is only offered in potentially suicidal cases.

Generally it is felt that mental health specialists at GPs 'are not best equipped' to help and it was also agreed that the ten minute consultation period was not sufficient. Long waiting lists are a common theme, with people receiving little or no support in the interim. Digital technology was seen as a good way to make online appointments but there is not enough direct marketing of the service.

Community Mental Health Services
We heard reports of attentive and thoughtful psychiatrists at the Child and Adolescent Mental Health Services (CAMHS). People were also complimentary about community services and hubs.

Some people comment on a lack of personalisation, in some cases leading to social isolation. For counseling, it is reported that the number of sessions on offer is not always effective, particularly for those with 'complex needs'. Waiting times are also cited as an issue, with some services not responsive following referrals.

Hospitals
People commented on good levels of empathy and support, and timely services. However, we heard experiences of poor staff attitude, a lack of quiet space or privacy on wards and an environment not conducive to recovery.

It was also suggested that cuts to community services have increased demand on hospital beds. Waiting times are also cited as an issue, particularly for Psychiatric Liaison.

Being accompanied by a partner, family member or carer can make the experience more comfortable for all. Views about mixed-sex wards differ – some people prefer them while others do not, therefore a choice would be equitable.

SPA (Single Point of Access)

Many people commented that the service is ‘not empathetic’ and offers advice of little value - such as ‘make a cup of tea, listen to music or go for a walk’. Telephone access and waiting times for callbacks are also noted as issues.

To improve understanding and empathy, it was suggested that staffing should include people who have had similar mental health illnesses.

Recovery Team
We heard accounts of compassionate staff, however people note the service is ‘over stretched’. Many experience poor telephone access, with one person trying to make contact for one week. It is also reported that communication and liaison between services and GPs is poor.

We talked about various aspects around assessment, diagnosis, treatment, early intervention and ongoing care and support:

Mental Health: From Diagnosis to Ongoing Care

Assessment, Diagnosis and Treatment
It was felt that assessments should include a ‘risk assessment’, and that only Mental Health professionals should be authorised to diagnose. A good level of training was emphasised across the board – from school staff to GPs. People also stressed the importance of contact with peer workers who have recovered from similar conditions.

Follow-up treatment and support should be tailored and personal, and alternatives (such as laughter therapy, music therapy and exercise) included in the mix of options, as appropriate.

At one event, a number of people felt the ‘only way to access emergency treatment’ was through the police and that this was inappropriate.

Prevention and Early Intervention
Discussions emphasised the importance of education for new mums, children and young people, and school staff. People said that GPs should have a ‘broader understanding’ of mental health issues. There is also a need to educate the wider community so that people with mental health issues do not feel any different and can seek support (break down the taboo factor about mental health).

It was felt that good levels of specialist support are vital, including for continued access, and people should not be discharged prematurely. Lack of community based projects, poor levels of information & signposting and use of ‘jargon’ were also cited as challenges.

Ongoing Care and Support
The ability to build relationships is considered important - a named, consistent contact (such as a care navigator) would be useful for both patients and families

and volunteers could be trained to befriend and offer peer support. Carers also need greater levels of support – suggestions include drop-in centres and peer support groups.

People would also like subsidised travel, greater choice of treatment and therapies and practical support – such as assistance in applying for benefits or completing forms. It was felt that medication 'should not always be the go to approach'.

At one event, young people use the word 'frustrating' as it is felt that help 'simply isn't there' for them.

We asked people how engaged they would like to be, and whether they would like to be involved in designing new services. As part of this, we asked them which aspects of communication and engagement could be improved:

Mental Health: Communication and Engagement

It was felt that public meetings should be well communicated, to maximise turnout. Consideration should be given to having meetings at different times in the day, including evenings, so that people can attend.

Patients also need encouragement and support to get involved in engagement – Healthwatch could be useful, particularly in raising awareness, harnessing skills and building networks. Outcomes of meetings should be widely communicated and actions reported back – to keep people engaged.

10. In Focus - Learning Disabilities

Engaging with 75 people, we received feedback about services including GPs, Hospitals and Clinics. Findings are summarised below – see Appendix 2 for the full report.

Learning Disability Services

GP Services
When talking about local GP services, people comment on feeling excluded or ignored, and not being able to understand written or spoken information. It was suggested that increased training and awareness could do much to address this.

Some people also said that levels of support could be greater, for example longer appointments and shorter waiting times for people with a learning disability.
It was suggested that the system could 'flag' disabilities so staff know when to make reasonable adjustments.

Hospitals and Clinics
We heard accounts of good levels of involvement, communication and support from hospital doctors, nurses and other staff. Levels of expertise and knowledge are also particularly appreciated.

However, lengthy waits can be uncomfortable and problematic for patients, families and carers. It was suggested that use of Health Passports could help staff to prioritise. Some patients would also like more information in easy read. People were appreciative of specialist nurses and doctors, but question staffing levels (one particular nurse has a catchment of three major hospitals).

We talked about various aspects around assessment, diagnosis, treatment and ongoing care and support:

Learning Disabilities: From Diagnosis to Ongoing Care

Assessment, Diagnosis and Treatment
People felt that assessment, diagnosis and treatment at the right time is very important. Most people agreed that it was more important to see a medical person who was qualified who was free immediately if it was urgent. However, if less urgent it helps if ‘someone knows you and your history’.

Ongoing Care and Support
We heard accounts of good levels of support and communication. When asking what could work better, people are quick to comment on long waiting lists and lack of support overall. Some people suggested more emotional support for patients and carers, plus practical assistance (such as help to fill in a form). We also asked people to consider what could be ‘easily’ improved. Suggestions included enhanced training and awareness, and clearer communication to patients, and professionals.

11. In Focus - Children & Young People

Engaging with 10 people, we received feedback about services including Schools, GPs, Pharmacies and Hospitals. Findings are summarised below - see Appendix 3 for the full report.

Children & Young People’s Services

Schools
Students have opportunities to volunteer in the community (for example supporting elderly people in care homes) and this is seen as good way to ‘learn how to communicate with individuals who have health problems’.

Some students feel that care in school is not focused enough and there is not enough empathy from staff - the perception is that young people’s health complaints are not taken seriously. It was also suggested that school nurses are 'not trained properly' and 'offer ice packs for everything'.

Communication is also noted as a problem – teachers will often send an email to the nurse about a student's health concern that is not picked up until the end of the day. Mental health issues are addressed at assemblies, however students cite a shortage of named teacher contacts, and lack of follow up.

It was felt that schools could be more inclusive by appointing health prefects and monitors who are trained in Mental Health First Aid, so young people have someone to talk to of their own age.

Primary Care Services

Young people cite good support from NHS 111 and GPs, and a 'good atmosphere' at the pharmacy. However, it is obsereved that 'staff are overworked' and this impacts on quality.

Some people comment on a lack of information from their GP and poor liaison between GPs and Pharmacists.

Emergency and Acute Services

An example was given of 'a clear and supportive' service from 999, however some young people feel they 'won't be taken seriously' and this can be a disincentive.

We talked about various aspects around prevention and support:

Children and Young People: From Prevention to Support

Key themes emerging from a Westminster workshop include how to successfully promote healthy eating, how to utilise technology to engage young people, how to highlight the adverse health outcomes of smoking and how to create an inclusive and nurturing environment for open conversations about mental health.

We asked people how engaged they would like to be, and whether they would like to be involved in designing new services. As part of this, we asked them which aspects of communication and engagement could be improved:

Children and Young People: Communication and Engagement

People said…

- There was a preference for group forums over other types of engagement.
- Volunteering should be flexible, young people have different interests and ideas so some room for manoeuvre would be helpful.
- The desire to be involved in the co-design and production of solutions for problems with NHS healthcare.

12. Supplementary Topics

In this section, we look at IT systems and digital communication, the voluntary and community sector, getting the ‘best start in life’ and helping people to ‘age well’.

12.1 IT Systems and Digital Communication

The general consensus is that data sharing does not work consistently. Systems are not joined up, not always user friendly and there ‘real fears’ about security and confidentiality.

IT Systems and Digital Communication

Challenges and Barriers:

- People want personal records to be shared across district nurses etc, but there are reservations about private parties being involved and having access to patient’s information - concern that they ‘might sell their data’, or outsource to foreign countries.
- Concerns that NHS record systems are not secure, as they were broken into last year. General lack of trust in security.
- People thought there was definitely a place for IT systems but, especially the older ones, thought that it ‘just added to all the extra passwords’ that they had to remember, and as they were accessed infrequently they often forgot them or the whole system had changed yet again.
- People were concerned about too much focus on digital health care and reiterated the need for both digital and seeing people in real life.

Suggestions:

- The general consensus is that people should be allowed to opt out of data being shared.
- We need secure IT systems.
- GDPR compliance is important to patients.
- IT systems must be compatible - between GPs Hospitals (within the NHS).

12.2 Voluntary and Community Sector

The role of the voluntary and community sector is vital for health and wellbeing and supporting communities to stay well. Despite their known value, in terms of reducing social isolation plus use of services, many are not adequately supported. These organisations ‘should not be taken for granted’.

Voluntary and Community Sector

Challenges and Barriers:

- Charities and voluntary groups need to be supported. Many of these services provide something for people to do which helps to combat social isolation and keep mental health issues as a result at bay. People are often stuck at home with no reason to leave the house, and these organisations give them something to do, and leave the house. Aging people need a safe space to come out and interact with other people. Mental health services closing down will be detrimental to those who use them. People who are also less-able often access these organisations too.
- The Strength and Balance classes by the council had really positive reviews by service users, when it was first introduced it had a number of free weeks. However, over time the number of free weeks was reduced incrementally to the point where users now have to pay for classes, which resulted in people not being able to afford it and they had to stop going.
- Services must be aware of key voluntary sector agencies and refer where they can help. Eg ECIL, day hospice could be referred to
- Shop mobility: was a service where you could get a free cart to take you around, but it has been defunded and no longer exists

Suggestions:

- Community organisations need to be encouraged, funded, and supported by the council instead of constantly being inundated with higher rents and bills. These charities could also be supplied by other services with food etc - such as when supermarkets are have to throw out food which will be wasted, it can be diverted to these spaces instead.
- Community classes which are often put on by voluntary and charity groups are very important. Combating social isolation and keeping people active is a form of preventative care and they should be supported by the NHS as well as the council as they save healthcare services from having to provide further care.
- There are other things that could be useful to combat social isolation such as a free travelcard, so that people aren’t hindered by financial stress in order to leave the house for outings - it will help to encourage people to get out and see others. Additionally, libraries are being shut down by council cuts but they often double up as community centres for groups and social interactions, they also employ local people. Free gym membership for certain people could be useful to keep them active and therefore foster good mental health.

At Healthwatch Hillingdon, particular workshops focused on ‘making sure everyone gets the best start in life’ and ‘supporting people to age well’.

12.3 Making Sure Everyone Gets the Best Start in Life

When looking at 'the best start in life', there was a high level of frustration about the difficulty of accessing services and the time it takes to find the right pathways to these services.

Making Sure Everyone Gets the Best Start in Life

Challenges and Barriers:

In the current climate of staff numbers and user demand on the NHS, it was felt that ensuring that everyone gets the best start in life was crucial but difficult to achieve without changes in peoples lifestyles and increased knowledge of healthy living.

Suggestions:

- Better education about vaccinating your child.
- More education regarding vaccinations.
- Educating new mums in how to look after a baby best - and as they grown up.
- Parent education.
- Wider family support so education for older parents.
- Better breastfeed advice and services for new and expectant mother.
- Best advice possible on contraception - avoid unwanted pregnancies.
- Good diets and exercises/
- Keeping well in pregnancy - perils of smoking and alcohol to an unborn child.

The other key challenge related to greater youth participation and genuinely listening to young people about what they need. Schools play an important role - staff need awareness of services and there should be 'better and easier' education in school about emotional wellbeing and healthy lifestyle.

12.4 Supporting People to Age Well

It was felt that prevention should be 'top of the agenda' as this is the key for reducing pressure on services, particularly A&E.

Supporting People to Age Well

Challenges and Barriers:

It was felt that 'more needs to be done' for the elderly under the following key headings:

- Education and Training

- Provision
- Communication
- Policy

Suggestions:

- **Education/Training:** To help people to be self-responsible. Free training needed for the end of life care (compassion, care, respect). Education should be used to encourage wider family support.
- **Provision:** Lunch clubs should be provided to encourage greater social activity. More creative activities are needed for those who suffer from dementia. Increase befriending groups by providing additional funding. Additional funding should be made available to increase the number of support groups in the community. There should be more activities/sport provision for older people.
- **Communication:** There needs to be better advertising services so that people know where to access services/activities. There is a significant need for raising awareness that you can be fit and healthy at any age.
- **Policy:** The following are needed: early identification of people who might need support; people's independence should not be taken away. They should be supported in the community, primarily at home, so that they can live longer in their homes; carers should be paid more and trained so that they stay in the job; social care should not be dependent on personal budgets; dementia provision should be funded through the NHS and euthanasia should be a choice for the individual.

12.5 Comments on the Long Term Plan

Finally, Healthwatch colleagues offer this advice – to those designing and implementing the Long Term Plan.

Comments on the Long Term Plan

In summary - Healthwatch says:

- If the plan is to work it needs to be co-produced with patients/service users.
- The users' voice needs to be heard from the beginning and service users must be consulted in planning.
- Hold regular 'big events' to inform and engage, and give participants timely feedback.
- Engage with Healthwatch.

Glossary of Terms

BAME	Black, Asian and Minority Ethnic
LTP	Long Term Plan
NHS	National Health Service
PALS	Patient Advice & Liaison Service
PPG	Patient Participation Group
SPA	Single Point of Access
WLCCG	West London Clinical Commissioning Group

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Distribution and Comment

This report is available to the general public, and is shared with our statutory and community partners. Accessible formats are available.

If you have any comments on this report or wish to share your views and experiences, please contact us.

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> “There’s a culture of blame around using A&E services, an assumption that people go because it’s free.
>
> It's not always the case that people want the prescriptions...”

Local resident and service user

NHS Long Term Plan Engagement

A focus on Mental Health

Shaping the future of our NHS in North West London

> “I was able to access the Crisis Team very quickly.
>
> Staff were knowledgeable and offered constructive help.”

Local resident and service user

Contents

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What is the NHS Long Term Plan?

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

The Government is investing an extra £20 billion a year in the NHS. The NHS has produced a 'Long Term Plan' setting out the things it wants health services to do better for people across the country.

This includes making it easier to access support closer to home and via technology, doing more to help people stay well, and providing better support for people with long-term health conditions.

Engaging Local People

Whilst the national plan has set some clear goals, it's up to local areas to decide how they're achieved – that means engaging with local people and listening to their experiences and expectations of current and future services.

Healthwatch organisations in North West London, alongside the national Healthwatch network has collected local views on the Long Term Plan through surveys, focus groups and events between April and June 2019, to give tens of thousands of people the opportunity to help local hospitals, GP surgeries and community services hear about the changes people would like to see.

In this report, we look at experiences and expectations associated with Mental Health.

What matters most to people in North West London?

Engaging with 46 people – service users, families and carers we found that:

Summary: Mental Health Services

GP Services
When talking about local GP services, people cite good levels of empathy from GPs, however treatment is not always effective. Some patients comment on feeling unsupported, with GPs showing 'little interest' in their personal or social circumstances – this can affect ongoing care and early intervention. One patient had to 'persuade' the doctor that he was ill, while others say that assistance is only offered in potentially suicidal cases.

Generally it is felt that mental health specialists at GPs 'are not best equipped' to help and it was also agreed that the ten minute consultation period was not sufficient. Long waiting lists are a common theme, with people receiving little or no support in the interim.

Digital technology was seen as a good way to make online appointments but there is not enough direct marketing of the service.

Community Mental Health Services
We heard reports of attentive and thoughtful psychiatrists at the Child and Adolescent Mental Health Services (CAMHS). People were also complimentary about community services and hubs.

Some people comment on a lack of personalisation, in some cases leading to social isolation. For counseling, it is reported that the number of sessions on offer is not always effective, particularly for those with 'complex needs'. Waiting times are also cited as an issue, with some services not responsive following referrals.

Hospitals
People commented on good levels of empathy and support, and timely services. However, we heard experiences of poor staff attitude, a lack of quiet space or privacy on wards and an environment not conducive to recovery.

It was also suggested that cuts to community services have increased demand on hospital beds. Waiting times are also cited as an issue, particularly for Psychiatric Liaison.

Being accompanied by a partner, family member or carer can make the experience more comfortable for all. Views about mixed-sex wards differ – some people prefer them while others do not, therefore a choice would be equitable.

Summary: Mental Health Services

SPA (Single Point of Access)
Many people commented that the service is 'not empathetic' and offers advice of little value - such as 'make a cup of tea, listen to music or go for a walk'. Telephone access and waiting times for callbacks are also noted as issues.

To improve understanding and empathy, it was suggested that staffing should include people who have had similar mental health illnesses.

Recovery Team
We heard accounts of compassionate staff, however people note the service is 'over stretched'.

Many people experience poor telephone access, with one person trying to make contact for one week. It is also reported that communication and liaison between services and GPs is poor.

Coordination between services
People commented on administrative problems, poor communication and liaison between services plus a 'postcode lottery' across boroughs. The complexity of referral pathways can also delay treatment.

Travel and Transport
In one experience, a journey to visit a partner involved 3 buses – each way. Other people cited financial cost and waiting times as issues. By one person, the Freedom Pass was regarded as 'a lifeline'.

Co-morbidities
When talking about co-morbidities we detected a sizeable theme on medication. People cite a lack of alternatives to medication, side effects and complications with other medication. Some people also comment on a lack of information and signposting from their GP.

Learning from Discussion (Checklist)

GP Services – local people would like:

- Good levels of support and engagement.
- To be listened to, respected and involved.
- Specialists that are knowledgeable and empowered/equipped to help.
- Timely access to services and support while waiting.
- Optimum use of digital technology.

Learning from Discussion (Checklist)

Community Mental Health Services - local people would like:

- Holistic treatment and care, with ‘real choice’.
- Good levels of support (example increasing number of sessions).
- Timely access to services.
- Services that are responsive.

Hopsitals - local people would like:

- To be treated with dignity and respect.
- An environment conducive to recovery (with privacy and quite space).
- Timely access to services.
- Option of same or mixed-sex ward.

SPA (Single Point of Access) - local people would like:

- To be treated with dignity and respect.
- A good level of information and advice.
- Good telephone access.
- Services that are responsive.
- To be understood.

Recovery Team - local people would like:

- Adequate staffing levels
- Good telephone access.
- Good liaison and communication between services.

From Diagnosis to Ongoing Care

Assessment, Diagnosis and Treatment

It was felt that assessments should include a ‘risk assessment’, and that only Mental Health professionals should be authorised to diagnose. A good level of training was emphasised across the board – from school staff to GPs. People also stressed the importance of contact with peer workers who have recovered from similar conditions.

Follow-up treatment and support should be tailored and personal, and alternatives (such as laughter therapy, music therapy and exercise) included in the mix of options, as appropriate.

At one event, a number of people felt the ‘only way to access emergency treatment’ was through the police and that this was inappropriate.

From Diagnosis to Ongoing Care

Prevention and Early Intervention
Discussions emphasised the importance of education for new mums, children and young people, and school staff. People said that GPs should have a 'broader understanding' of mental health issues. There is also a need to educate the wider community so that people with mental health issues do not feel any different and can seek support (break down the taboo factor about mental health).

It was felt that good levels of specialist support are vital, including for continued access, and people should not be discharged prematurely.

Lack of community based projects, poor levels of information & signposting and use of 'jargon' were also cited as challenges.

Ongoing Care and Support
The ability to build relationships is considered important - a named, consistent contact (such as a care navigator) would be useful for both patients and families and volunteers could be trained to befriend and offer peer support. Carers also need greater levels of support – suggestions include drop-in centres and peer support groups.

People would also like subsidised travel, greater choice of treatment and therapies and practical support – such as assistance in applying for benefits or completing forms. It was felt that medication 'should not always be the go to approach'.

At one event, young people use the word 'frustrating' as it is felt that help 'simply isn't there' for them.

Learning from Discussion (Checklist)

Assessment, Diagnosis and Treatment – local people would like:

- Assessments that include a risk assessment.
- Diagnosis by Mental Health professionals.
- Training for medical and other professionals.
- Access to peer support.
- Holistic follow-up treatment and support, with alternative options.

Learning from Discussion (Checklist)

Prevention and Early Intervention – local people would like:

- Education for new mums, children and school staff.
- Training for GPs.
- Awareness within the wider community (break down the taboo).
- Good levels of specialist support.
- Appropriately timed discharge.
- Access to community based projects.
- Clear, and good levels of information.

Ongoing Care and Support - local people would like:

- A named contact (such as a care navigator).
- Befriending and peer support.
- Support for peer support carers.
- Subsidised travel.
- Choice of treatment and therapies.
- Practical support (such as help to apply for benefits).
- Alternatives to medication.

Communication and Engagement

Finally, we asked people how engaged they would like to be, and whether they would like to be involved in designing new services. As part of this, we asked them which aspects of communication and engagement could be improved.

It was felt that public meetings should be well communicated, to maximise turnout. Consideration should be given to having meetings at different times in the day, including evenings, so that people can attend.

Patients also need encouragement and support to get involved in engagement - Healthwatch could be useful, particularly in raising awareness, harnessing skills and building networks. Outcomes of meetings should be widely communicated and actions reported back – to keep people engaged.

Learning from Discussion (Checklist)

Communication and Engagement - local people would like:

- Good awareness of public meetings.
- Choice of times (morning, afternoon and evening).
- Good levels of engagement.
- Updates on how their feedback has/has not been used.

What did people tell Healthwatch?

Here, we take a more detailed look at the top themes emerging from discussion. Generally we asked people what they feel works well and what could work better.

1. GP Services

This section explores top themes around GP services.

1.1 What works well?

People comment on good levels of empathy from GPs, however treatment is not always effective.

GPs - what works well?

Selected comments:

"Reception staff and duty officer at Claybrook centre considered to be constructive and knowledgeable." [Hammersmith & Fulham]

"Personal touch from GPs – one participant said: "she hugged me". However, ultimately was unable to help in any meaningful way." [Hammersmith & Fulham]

"GP admitted gap in Mental Health knowledge and expressed willingness to learn more and also in alternative therapies such as music therapy." [Hammersmith & Fulham]

1.2 What could work better?

Patients comment on feeling unsupported, with GPs showing 'little interest' in their personal or social circumstances – this can affect ongoing care and early intervention. One patient had to 'persuade' the doctor that he was ill, while others say that assistance is only offered in potentially suicidal cases. Generally it is felt that mental health specialists at GPs are 'not best equipped to help' and it was also agreed that the ten minute consultation period was not sufficient.

Long waiting lists are a common theme, with people receiving little or no support in the interim.

GPs - what could work better?

Selected comments:

"Not taking early intervention seriously enough – Mental Health crises/eating disorders only addressed when they are extreme." [Westminster]

"You have to persuade the GP or doctor about that you are ill. You have to lie,

otherwise you are not taken seriously. I was really depressed, had anxiety, couldn't open my post, couldn't leave the house. I forced myself to go to the GP to get help, they asked if I was suicidal. I had not felt suicidal that week so I didn't get any help. Another time I had to lie and say I was suicidal and a danger to other people. If I didn't add any colour to my story nothing would happen." [Ealing]

"Services always ask if you are thinking about ending your life. It's the first thing they ask. If you say yes they take you seriously, If you say no you get nothing." [Ealing]

"One person had been transferred back to the mental health worker at their GP, who told them that they couldn't help with certain things because it was out of their jurisdiction. They felt like they didn't see the point of having someone there who was not equipped to deal with mental health issues." [Ealing]

"Waiting time from seeing the Dr to getting a proper diagnosis and specialised treatment can be a long time, some quoted 9 months and were not signposted to any help in the meantime." [Ealing]

1.3 What could easily be improved?

Digital technology was seen as a good way to make online appointments but there is not enough direct marketing of the service.

2. Community Mental Health Services

This section explores top themes around Community Mental Health services.

2.1 What works well?

We heard reports of attentive and thoughtful psychiatrists at the Child and Adolescent Mental Health Services (CAMHS). People were also complimentary about community services and hubs.

Community Mental Health Services - what works well?

Selected comments:

"Able to access Crisis Team very quickly and staff were knowledgeable and offered constructive help." [Hammersmith & Fulham]

"'Back on Track' self-referral allows service users to take control of their own care." [Hammersmith & Fulham]

"Recovery hub is brilliant, but they haven't done anything else. There was also regret expressed for the lack of funding for Mind services like 'Heads Up'." [Hammersmith & Fulham]

2.2 What could work better?

Some people comment on a lack of personalisation, in some cases leading to social isolation. For counseling, it is reported that the number of sessions on offer is not always effective, particularly for those with ‘complex needs’.

Waiting times are also cited as an issue, with some services not responsive following referrals.

Community Mental Health Services - what could work better?

Selected comments:

“Claybrook uses a model of therapy that doesn’t work for all - it’s based on Borderline Personality Disorder, but what if you don’t have that? I’ve had to help myself and still find myself isolated.” [Hammersmith & Fulham]

“Isolation is part of the illness, it is hard to approach someone who is depressed - inreach and outreach is the key.” [Hammersmith & Fulham]

“There is ‘little or no structure’ in group therapy sessions for the most vulnerable.” [Hammersmith & Fulham]

“The gap between in-patient and community support is too big/wide.” [Brent]

“It would be much better to have fewer more highly functioning specialist mental health centres - I would be prepared to travel” [Hammersmith & Fulham]

“Counselling is seen as a negative (even though it is good that we have it) because the contracted periods are too short for people with complex needs. [Westminster]

“Long waiting times (no interim measures in place while waiting for appointments)”. [Hillingdon]

“One participant mentioned that their GP had referred them to IAPT, who did not reply to them for two months and then failed to keep in touch.” [Ealing]

2.3 What could easily be improved?

In one case, service users have been inspired to ‘take the initiative’ and forge support networks. This has including pooling of personal budgets to book particular actitivities.

Community Mental Health Services - what could easily be improved?

Selected comments:

“Service users have worked together to create a network to seek out help from charities where there are gaps in the NHS.” [Hammersmith & Fulham]

3. Hospitals

This section explores top themes around hospital services.

3.1 What works well?

People commented on good levels of empathy and support, and timely services.

Hospitals - what works well?

Selected comments:

“Lakeside (mental health unit, Hounslow): I was in taken to Lakeside last year as there was no room at Ealing Hospital. A nurse stayed with me up until 11pm. She made time for me and sat with me to make sure I ate. I felt somebody cared.” [Ealing]

“I had a voluntary admission. Help and support at the hospital was quick.” [Ealing]

“PALS worked OK when they missed an appointment at Hillingdon Hospital.” [Hillingdon]

3.2 What could work better?

We heard experiences of poor staff attitude, a lack of quiet space or privacy on wards and an environment not conducive to recovery.

It was also suggested that cuts to community services have increased demand on hospital beds. Waiting times are also cited as an issue, particularly for Psychiatric Liaison.

Healtwatch Ealing makes an observation about mixed sex wards (St Bernards Hospital). “Service users mentioned that some wards are mixed and some are same-sex, depending on the severity of people’s illness. They mentioned that on one hand it can feel unsafe to be in a mixed ward and that they needed more support from the nursing staff than they were receiving as a result. On the other hand, some participants felt as if being in a mixed ward was better for them. They agreed overall that would like to have an option to choose what type of ward to be admitted into as part of their care plan.”

Hospitals: what could work better?

Selected comments:

“Staff are cold towards families and carers on the wards.” [Hammersmith & Fulham]

“Wards lack quiet space for recovery and respite.” [Hammersmith & Fulham]

“Thought that it wasn’t a good environment to recover in; there are no windows, it looks like a prison, is unhealthy.” [Ealing]

“Having multiple people in consultation rooms could be very uncomfortable for some, and they often do not feel like they have a choice but to allow this - it’s often student doctors. They feel as if there needs to be a relationship built with a person before they can divulge sensitive information around them. [Ealing]

“Mental Health in-patient service is like a revolving door when there is insufficient support in the community.” [Brent]

“So demands for beds outstrips needs because the support in the community doesn’t work. There are people who need to be hospitalised.” [Brent]

“Psychiatric Liaison service at Ealing Hospital: I had to wait for 4 hours. Another person identified only waiting 20 mins recently.” [Ealing]

3.3 What could easily be improved?

Being accompanied by a partner, family member or carer can make the experience more comfortable for all.

Views about mixed-sex wards differ – some people prefer them while others do not, therefore a choice would be equitable.

Hospitals: what could easily be improved?

Selected comments:

“One person said that they benefitted when their partner was transported there with them and was not separated from them.” [Ealing]

4. SPA (Single Point of Access)

This section explores top themes around SPA (Single Point of Access).

4.1 What works well?

We heard one account of a good, helpful service.

SPA (Single Point of Access) - what works well?

Selected comments:

"SPA played a role in getting me the help I needed. The first call was not good. The second call was very helpful." [Ealing]

4.2 What could work better?

Many people commented that the service is 'not empathetic' and offers advice of little value - such as 'make a cup of tea, listen to music or go for a walk'. Telephone access and waiting times for callbacks are also noted as issues.

SPA (Single Point of Access) - what could work better?

Selected comments:

"Not very empathetic when people phoned up feeling suicidal, they were giving useless advice such as "watch TV, listen to your favourite music or go for a walk", therefore people questioned whether or not they are even trained. Some people have had experiences of being automatically signposted rather than SPAs helping them deal with the situation. Many people said they would rather use the Samaritans because they are more empathetic and supportive - "you get the feeling that they actually want to talk to you"." [Ealing]

"I had a 10 minute call. I felt rushed. She left me crying on the phone." [Ealing]

"Can't get through on the phone. Have to wait too long." [Ealing]

"They left me in a worse state when I got off the phone. They told me the clinician would call back in 20 minutes. 12 hours later they finally called back." [Ealing]

4.3 What could easily be improved?

To improve understanding and empathy, it was suggested that staff should include people who have had similar mental health illnesses.

SPA (Single Point of Access) - what could easily be improved?

Selected comments:

"It was suggested that the staff employed by phone services should be people who have had similar mental health illnesses to them because people who have not gone through it themselves do not understand their situation. This suggestion was a two-fold solution 1) to help recruit more understanding and helpful staff 2) Most mental health SUs do not have employment and this could be a way to help them regain confidence and self-respect, and therefore improve their mental health." [Ealing]

5. Recovery Team

This section explores top themes around Recovery Team services.

5.1 What works well?

We hear accounts of compassionate staff, however people note the service is 'over stretched'.

Recovery Team - what works well?

Selected comments:

"Staff are good and compassionate but people do not see them often, and the staff seem overstretched, which means that they lack a proper human connection." [Ealing]

5.2 What could work better?

Many people experience poor telephone access, with one person trying to make contact for one week.

It is also reported that communication and liaison between services and GPs is poor.

Recovery Team - what could work better?

Selected comments:

"Many phone call services do not pick up their phone lines - especially detrimental as people usually call when they are in a crisis. One SU called the Limes as we spoke and only got through to the answering machine." [Ealing]

"One person has been trying to contact for one week - impossible to get through!" [Ealing]

“Communication between Avenue House and the GP is poor.” [Ealing]

“When you go and see the duty team at Avenue House the information does not get logged. I have no confidence in the service. I’m not being listened too.” [Ealing]

“Staff are always rushing at Avenue House. It makes you feel like an inconvenience. There are not enough CPNs there. CPNs have been cut and the workload has gone up. They have no time. They have just paperwork and deadlines. Even getting allocated a social worker is difficult.” [Ealing]

5.3 What could easily be improved?

It was felt that home visits for the housebound would be a good idea.

Recovery Team - what could easily be improved?

Selected comments:

“There should be a home visit service for people unable to leave home.” [Ealing]

6. Co-ordination between services

Trends were also established on service coordination. We heard accounts of administrative problems, poor communication and liaison between services plus a ‘postcode lottery’ across boroughs.

The complexity of referral pathways can also delay treatment.

Co-ordination between services

Selected comments:

“Since 2013, patients have been referred for Cognitive Behavioural Therapy then to secondary care and then on to primary care - there seems to be an issue with information not being sorted/archived correctly.” [Hammersmith & Fulham]

“Postcode lottery for treatment of mental health.” [Hammersmith & Fulham]

“Lack of coordination with/access to out-of-borough Mental Health services; lack of community support.” [Westminster]

“Services not working in an integrated way (having to tell my story more than once).” [Hillingdon]

"Feeling that services were passing the buck and blaming each other." [Hillingdon]

"There is also a lack of communication between GPs and other services; GPs are not getting records from Avenue House - again this can cause a problem between medications." [Ealing]

"The layers that exist between you and getting help need to be removed. You go from the GP – consultant – psychiatric nurse – psychiatrist back to consultant etc. It takes months in between each appointment and every time it's a new person." [Ealing]

7. Travel and Transport

In one experience, a journey to visit a partner involved 3 buses – each way. Other people cited financial cost and waiting times as issues.

By one person, the Freedom Pass was regarded as 'a lifeline'.

Travel and Transport

Selected comments:

"My partner doesn't drive and it took him 3 buses to come and see me at West Middlesex hospital every day. The travel took a lot out of him (more so as he has back problems). The distance of treatment to where your family/support network is makes all the difference to your recovery and their ability to support you." [Ealing]

"The financial cost of travel for partner/family/support network limits the support they can provide." [Ealing]

"Ealing hospital transferred me to Lakeside. The longest wait was for the transport. They took my partner with me in the transport. This was a massive help and very reassuring. The services were quick, but the transport slow. This was a voluntary admission." [Ealing]

"The freedom pass is a lifeline." [Ealing]

8. Co-morbidities

When talking about co-morbidities we detected a sizeable theme on medication. People cite a lack of alternatives to medication, side effects and complications with other medication. Some people also comment on a lack of information and signposting from their GP.

Co-morbidities

Selected comments:

“People said they would rather get therapy than take pills, and felt that medication was overprescribed, however in some cases people have waited for over 2 yrs for a therapist.” [Ealing]

“There is too much medication. Everytime you go they give you something new. There are too many side effects and too many problems caused by the medications.” [Ealing]

“I am not getting my diabetes medicine as I am on too many other medications, 12 all together. My daughter is a doctor. She helps and advises me.” [Ealing]

“The GP and Psychiatrist do not understand each other’s medicine. It’s dangerous.” [Ealing]

“One person has learning difficulties as well, and therefore they find it hard to find information about services, and about their mental health. Therefore they need more support from Drs than they are getting, just someone to give them proper face-to-face information and signposting.” [Ealing]

From Diagnosis to Ongoing Care

We talked about various aspects around assessment, diagnosis, treatment, early intervention and ongoing care and support.

9. Assessment, Diagnosis and Treatment

It was felt that assessments should include a ‘risk assessment’, and that only Mental Health professionals should be authorised to diagnose. A good level of training was emphasised across the board - from school staff to GPs. People also stressed the importance of contact with peer workers who have recovered from similar conditions.

Follow-up treatment and support should be tailored and personal, and alternatives (such as laughter therapy, music therapy and exercise) included in the mix of options, as appropriate.

At one event, a number of people felt the ‘only way to access emergency treatment’ was through the police and that this was inappropriate.

Assessment, Diagnosis and Treatment

Common themes:

Assessment:
An assessment should involve a comprehensive risk assessment before crisis point. Any non-specialist staff involved should be trained to spot the signs and this should be the protocol across the boroughs. School staff should be trained to spot the signs of mental health so that it could be identified before becoming a crisis. Training should also be provided to GPs and/or their staff to help identify issues and to have a better understanding of how to manage the person/patient.

Specialist Diagnosis
Only a Mental Health professional should be authorised to provide a diagnosis with a full evaluation of environmental and familial factors included with an emphasis on the cause, not the effect. These diagnoses should also be earlier rather than at crisis point - there is anecdotal evidence that incorrect assumptions by non-specialist staff can lead to misdiagnosis and unsuitable treatment.

Peer Support
Participants stressed the importance of contact with peer workers who have recovered from similar conditions.

Follow-Up
People agreed that follow-ups should be tailored to the case. For example, it may be necessary to follow up once a day for some patients and once a month for others. Isolation is often part of the illness in mental health cases, but attempting to contacting patients via various means of communications is important. One participant suggested follow-up calls should have a caller ID so patients know who the call is coming from even if they are unable to answer.

Alternative Treatment
Popular examples include laughter therapy, music therapy and exercise should be considered viable options for treatment.

Assessment, Diagnosis and Treatment

Summary of other popular themes:

- **GP Support:** The GP turns people away unless the situation is life threatening. It feels like this pushes people to hurt themselves.
- **Diagnosis:** Advice should be given at the point of diagnosis as well as guidance to how better to manage while waiting for appointments. This would help the patient to cope better.

- **Treatment:** Emergency metal health needs should be accessible without having to contact the Police. There needs to be a way of accessing treatment after the short-term Cognitive Behavioural Therapy (CBT) and Talking Therapy as when these have stopped it can have devastating effect for some people. More specialists are needed to resolve the waiting time issue.
- **Protocol:** Should be more awareness that some unwell patients are unable to manage schedule of appointments and travel to services and that this needs to be a joined-up, team effort between patient and service provider.
- **Gateway to Treatment:** Treatments other than CBT should be available, but a risk assessment and proper diagnosis are needed first.

10. Prevention and Early Intervention

Discussions emphasised the importance of education for new mums, children and young people, and school staff. People said that GPs should have a ‘broader understanding’ of mental health issues. There is also a need to educate the wider community so that people with mental health issues do not feel any different and can seek support (break down the taboo factor about mental health).

It was felt that good levels of specialist support are vital, including for continued access, and people should not be discharged prematurely.

Lack of community based projects, poor levels of information & signposting and use of ‘jargon’ were also cited as challenges.

Prevention and Early Intervention

Common themes:

Further Training
Discussions emphasised the importance of education for new mums, children and young people, GPs and school staff. Children should be educated to understand feelings and emotions and how to manage them. There is also a need to educate the wider community so that people with mental health issues do not feel any different and can seek support (break down the taboo factor about mental health). GPs should have a broader understanding of mental health issues e.g. triggers and support needs for different conditions.

Specialist Support
Having more specialists to reduce waiting time is crucial both in terms of treatment, early intervention and prevention. Within this aspect of the service having a continued access to the healthcare professional is crucial. Not being discharged too early from treatment is important.

Community
There is a ‘dearth’ of projects within communities. More accessible activities are needed to combat isolation and prevent crises recurring.

Service Signposting
There needs to be better mapping of available services in local areas and a directory of services in surgeries and practices, and in the community.

Jargon
Language of othering e.g. DNA (Did not attend) and ‘flow’ as a synonym for patients is not helpful and should be stopped – patients who do not attend appointments may not have been able to due to factors like severe isolation and fear so more teamwork is required in ensuring patients get the correct and timely treatment.

Prevention and Early Intervention

Summary of other popular themes:

- **Role of GPs:** There was a strong view that patients with health care should be informed of any GP/s in their practice with specific knowledge of mental health.
- **Tackling Conditions Early**: An early recognition apparatus needs to be instated for particularly complex/serious cases to trigger a package of services and care as early as possible.
- **Navigating Crises**: Crisis/recovery cafes in the community that are periodically staffed with mental health and peer support workers.
- **Monitoring:** For those people who don’t meet the threshold would help people who are close to crisis point. Parents and carers should be trusted more when they report their concerns about an individual.

11. Ongoing Care and Support

The ability to build relationships is considered important - a named, consistent contact (such as a care navigator) would be useful for both patients and families and volunteers could be trained to befriend and offer peer support. Carers also need greater levels of support – suggestions include drop-in centres and peer support groups.

People would also like subsidised travel, greater choice of treatment and therapies and practical support – such as assistance in applying for benefits or completing forms. It was felt that medication ‘should not always be the go to approach’.

At one event, young people use the word ‘frustrating’ as it is felt that help ‘simply isn’t there’ for them.

Ongoing Care and Support

Common themes:

Trusted Connections
One point of contact (such as a ‘trusted’ care navigator) would help with on-going care and support and this should not be the GP. There should be a process of checking up on the clients so that it is not always the client chasing up issues related to appointments and medicine needs. This would help reassuring patients who are having to wait a long time for support. Patients need more regular monitoring that is currently available.

Volunteers and Befriending
Training for volunteers on how to befriend patients taking in to account their specific needs and triggers. Volunteers should commit to regular, timetabled interactions to provide consistency and continuity and build trust with the patient.

Family Guidance
Families need guidance and support on how to negotiate and manage certain situations – there is a massive divide between what family and patient understand to be real and how to communicate.

Support for Carers
We need more support for carers who are caring for long term mental health service users. There should be support groups for carers specifically focusing on mental health. There should be drop-in centres for people particularly for males who are 50+ after the meds have been prescribed. Support should also be available via websites which would also allow people to keep in touch. Families should be involved in on-going care of patients.

Flexible Travel
Subsidised travel should be available for most ill/vulnerable.

Choice
A more diverse selection of therapies should be available, such as music therapy, exercise and laughter therapy and more investment in social prescription.

Practical Help
Further help is needed with practical tasks like filling out PIP and benefits forms. Mind provided this service in the past but it has been cut – it should be an NHS service!

Medication
Need for specialist mental health pharmacist who understands the complexities of multiple prescribing and can offer a person-centred approach as medication should not always be the go-to response.

Ongoing Care and Support

Summary of other popular themes:

- **Pro Choice:** Established specialist centres - service users and care navigators should be given option to choose centre based upon Ofsted-like ratings.
- **Improved Outreach:** Peer support workers should be available around the clock to offer support advice to patients and their families when it is needed most.
- **Practical Considerations:** The standard twelve appointments for long term mental health conditions is not enough and should be person-centred.
- **Quality of Service:** There is a concern about the quality of services in different parts of the country (postcode lottery). One person was concerned about her impending relocation to another borough whether the care and support would be continuing, who to contact and the quality of communication between the services. Shortage of staff particularly when patients are seeing different professionals has an impact on the quality of care and support.
- **Admissions:** There is a need for more long-term beds for those with mental health particularly for teenagers. There needs to be some transport support to get people home from hospital particularly when they have been referred to out of Borough hospitals. There is a need for some form of support for teenagers who have been diagnosed with mild mental health conditions.

12. How could communication and engagement be improved?

Finally, we asked people how engaged they would like to be, and whether they would like to be involved in designing new services. As part of this, we asked them which aspects of communication and engagement could be improved.

It was felt that public meetings should be well communicated, to maximise turnout. Consideration should be given to having meetings at different times in the day, including evenings, so that people can attend.

Patients also need encouragement and support to get involved in engagement – Healthwatch could be useful, particularly in raising awareness, harnessing skills and building networks.

Outcomes of meetings should be widely communicated and actions reported back – to keep people engaged.

How could communication and engagement be improved?

Common themes:

Attendance and Representation
Meetings should be 'better communicated' so that patients and carers can attend. One 'critical meeting' was not communicated adequately to the people who need it most, therefore it was poorly attended - it was suggested that Healthwatch could be a vehicle for creating awareness of meetings. Consideration should be given to having meetings at different times in the day, including evenings, so that people can attend.

Closing the 'Feedback Loop'
Outcomes of meetings should be widely communicated and actions to be reported back. Some people wanted a follow-up event where they could get feedback on how the information and ideas they came up with during the focus group was used. They want to know whether or not their feedback has reached the right people and why/why not it was taken on board.

Decision Making
Those with mental illness and supporters of better care for mental health need to be more political in their approach to influencing policy and services – these are the people that should be part of any decision that is taken.

How could communication and engagement be improved?

Summary of other popular themes:

- **Meetings:** There should be more of these types of meetings with key decision makers in attendance (commissioners, services, police and social services and other Local Authority representatives). One group suggested three monthly meetings.
- **Database:** Should be available that shows what meetings are taking place, what these are about and who is attending.
- **Patient Power:** Need to be at the centre of the treatment, more focus groups are required and advocated with lived experience - service users should be involved at every level.
- **Using Skills:** Healthwatch should utilise skills of the Discussion Group and members, capturing their expertise and using them as expert contributors in future groups and discussions.
- **Community Forum:** Healthwatch should consider creating forums open to all with access to expert advice and services and an option to add friends in need.
- **Follow-Up:** People also wanted to be included in the write-up process before the report is disseminated to make sure that it is a proper reflection of their ideas and experiences.
- **Official Representation:** Some people would like to sit on official boards and committees, to be 'genuinely involved' in decisions.

13. Case Study on Good Practice - The Solace Centre

The Solace Centre is an out of hours community service in Ealing, and regarded as a centre of good practice.

The Solace Centre

Selected statements:

- Staff treat everyone like human beings, they feel as if they are a family unit. People can discuss problems and get help from staff. It is an environment in which everyone is respected.
- It's open 365 days a year, and long hours (4pm - 7.45pm and weekends). Its open on Christmas day and the staff drive around and pick people up to bring them here for Christmas when there are no buses running to get there by yourself.
- The centre provides many services including cooking, washing. There is a book club, a women's group, a men's group, a baking group, a wellbeing group, benefits help, advice around budgeting.
- The Solace Centre has Saturday meals and discussion which people find important especially if they do not have other family. The centre is open on Christmas for people to come to.
- The service gives you "the power and means to make connections" - very important as many people have lost touch with family and friends.
- Also because they see same people, do not have to repeat their story again and again, and risk triggering.
- Several service users highlighted the woman's forum, describing it as "empowering" and "refreshing".

Glossary of Terms

CAMHS	Child and Adolescent Mental Health Services
CPN	Community Psychiatric Nurse
CWL	Central West London
IAPT	Increasing Access to Psychological Therapies
NHS	National Health Service
LTP	Long Term Plan
PALS	Patient Advice and Liaison Service
SLaM	South London and Maudsley NHS Foundation Trust
SPA	Single Point of Access

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> “Young people with mental health issues feel life has no value.
>
> We [the system] need to act to inspire them”.

Healthwatch official

healthwatch

NHS Long Term Plan Engagement

A focus on Learning Disabilities

Shaping the future of our NHS in North West London

healthwatch

> “Medical professionals are informed, and we trust that they know what they are talking about.”

Local resident and service user

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This includes making it easier to access support closer to home and via technology, doing more to help people stay well, and providing better support for people with long-term health conditions.

Engaging Local People

Whilst the national plan has set some clear goals, it's up to local areas to decide how they're achieved – that means engaging with local people and listening to their experiences and expectations of current and future services.

Healthwatch organisations in North West London, alongside the national Healthwatch network has collected local views on the Long Term Plan through surveys, focus groups and events between April and June 2019, to give tens of thousands of people the opportunity to help local hospitals, GP surgeries and community services hear about the changes people would like to see.

In this report, we look at experiences and expectations associated with Learning Disabilities.

What matters most to people in North West London?

Engaging with 75 people – service users, families and carers we found that:

Learning Disability Services

GP Services
When talking about local GP services, people comment on feeling excluded or ignored, and not being able to understand written or spoken information. It was suggested that increased training and awareness could do much to address this.

Some people also felt that levels of support could be greater, for example longer appointments and shorter waiting times for people with a learning disability. It was suggested that the system could 'flag' disabilities so staff know when to make reasonable adjustments.

Hospital Clinics and Services
We heard accounts of good levels of involvement, communication and support from hospital doctors, nurses and other staff. Levels of expertise and knowledge are also particularly appreciated.

However, lengthy waits can be uncomfortable and problematic for patients, families and carers. It was suggested that use of Health Passports could help staff to prioritise. Some patients would also like more information in easy read format.

People were appreciative of specialist nurses and doctors, but question staffing levels (one particular nurse has a catchment of three major hospitals).

Learning from Discussion (Checklist)

GPs, Hospitals and Clinics - local people would like:

- Recognition of their disability or condition.
- To be included, involved and respected.
- Good levels of awareness (training for staff).
- Clear written and oral language and effective communication.
- A level of support that reflects their condition or need.
- Well resourced specialist nurses and doctors.
- Awareness and active use of Health Passports.

From Diagnosis to Ongoing Care

We talked about various aspects around assessment, diagnosis, treatment and ongoing care and support.

Assessment, Diagnosis and Treatment
People felt that assessment, diagnosis and treatment at the right time is very important. Most people agreed that it was more important to see a medical person who was qualified who was free immediately if it was urgent. However, if less urgent it helps if ‘someone knows you and your history’.

Ongoing Care and Support
We heard accounts of good levels of support and communication. When asking what could work better, people are quick to comment on long waiting lists and lack of support overall. Some people suggested more emotional support for patients and carers, plus practical assistance (such as help to fill in a form).

We also asked people to consider what could be ‘easily’ improved. Suggestions included enhanced training and awareness, and clearer communication to patients, and professionals.

Learning from Discussion (Checklist)

Assessment, Diagnosis and Treatment - local people would like:

- Timely diagnosis and treatment.
- Continuity (choice of professional) if required.
- Timely access to specialists and support.
- Emotional and practical support for patients and carers.
- Good levels of awareness - training for staff and education for the general public.
- Clear communication, including professional-to-professional.

What did people tell Healthwatch?

Here, we take a more detailed look at the top themes emerging from discussion. Generally we asked people what they feel works well, what could work better, and what in their view could be improved ‘easily’.

1. GP Services

This section explores top themes around GP services.

1.1 What works well?

People were complimentary about automated signing-in systems, choice of appointment times and in one case, accessible information.

GPs: What works well?

Selected comments:

"Signing in technology at appointments is accessible." [Harrow]

"I can go to the GP in the morning, afternoon or evening – that's a good thing."

"Doctor provides easy read (a carer)." [Brent]

"I have a good relationship with my GP and am involved in my treatment plan, though I accept that is 'quite rare'." [Hounslow]

1.2 What could work better?

People comment on feeling excluded or ignored, and not being able to understand written or spoken information. It was suggested that increased training and awareness could do much to address this. Some people also felt that levels of support could be greater, for example longer appointments and shorter waiting times for people with a learning disability.

GPs: What could work better?

Selected comments:

"Where medical professionals talk to the parent/carer rather than the person with a learning disability." [Harrow]

"Received a text and didn't understand the message, patient thought they would have to pay if they miss the appointment." [Brent]

"Information and forms not always provided in an accessible way - complex language (jargon) used." [Harrow]

"One person said that when he asked his doctor for more information on his medication, the doctor refused to sit down and explain as he was too busy." [Hounslow]

"Receptionists should be more sensitive on the phone and have a better understanding of learning disability." [Harrow]

"Reasonable adjustments not always made (double appointments not offered)." [Harrow]

"Patients with learning disabilities need more support and less medication."

[Brent]

"Appointments don't run on time - get anxious while waiting - don't get given an update on how long the delay will be." [Brent]

"Can't book appointments to be seen on the same day." [Brent]

1.3 What could easily be improved?

People want clearer written and oral communication and some cited greater levels of training and awareness. It was felt that the system could 'flag' disabilities so staff know when to make reasonable adjustments (such as shorter waiting times or double appointments).

GPs: What could easily be improved?

Selected comments:

"Information and forms being provided in easy read. Removing complex language and acknowledging the Accessibly Information Standard." [Harrow]

"GP's to break down the information and ensure it has been understood." [Brent]

"Medical professionals and staff receiving more training about learning disability." [Harrow]

"Inform patients if there is a delay and ensure people with learning difficulties have understood." [Brent]

"Some way of people knowing that you have a learning disability, so they know to make/offer reasonable adjustments such as double appointments at the doctors." [Harrow]

"Learning disability nurses having more time / resource so they are not spread too thin." [Harrow]

2. Hospitals and Clinics

This section explores top themes around hospitals and clinics.

2.1 What works well?

We heard accounts of good levels of involvement, communication and support from hospital doctors, nurses and other staff. Levels of expertise and knowledge are also particularly appreciated.

People were appreciative of specialist nurses and doctors, but question staffing levels (one particular nurse has a catchment of three major hospitals).

Hospitals and Clinics: What works well?

Selected comments:

“Good explanation while being treated.” [Brent]

“Assistance from the nurses and staff is good.” [Brent]

“There is a learning difficulties nurse that helps and supports patients - although one nurse for 3 hospitals - NPH, CMH and Ealing.” [Brent]

“Staff listened to what the patients had to say and were patient.” [Brent]

“Doctors - knowledgeable, helpful and we trust them.” [Harrow]

2.2 What could work better?

Lengthy waits can be uncomfortable and problematic for patients, families and carers. Some patients would also like more information in easy read.

Hospitals and Clinics: What could work better?

Selected comments:

“A family member had to go A&E and waited for 5 hours. It was stressful, and no one gave any update to when we’d be seen.” [Brent]

“There should be no waiting time for patients if they have Autism. Carers find it very stressful to manage the patient when they become restless and start to get aggressive or anxious and worried.” [Brent]

“Two cases where people had to wait 24 hours to be seen in A&E, and another had to wait 8 hours.” [Hounslow]

“Not enough information available in easy read.” [Harrow]

“Health Passports aren’t always recognised or used by some medical professionals.” [Harrow]

“Concerned about patient confidentiality - their hospital passport is on display at the end of their beds and “nosey patients” might see them.” [Hounslow]

2.3 What could easily be improved?

People felt that greater levels of training and awareness would enhance support, including while waiting. Active use of Health Passports could help staff to prioritise.

Hospitals and Clinics: What could easily be improved?

Selected comments:

“Take into consideration if a patient with autism is being restless and may need to be seen before other patients.” [Brent]

“All staff need to have awareness on Autism and best way to manage and help patients.” [Brent]

“All medical professionals to be aware of Health passports and know to use them.” [Harrow]

“Difficult to remember where the hospital is or how to get there. May need a map printed out for them with directions.” [Brent]

“West Middlesex Hospital should adopt a ‘numbers system’ for queuing.” [Hounslow]

From Diagnosis to Ongoing Care

We talked about various aspects around assessment, diagnosis, treatment and ongoing care and support.

3. Assessment, Diagnosis and Treatment

People felt that assessment, diagnosis and treatment at the right time is very important.

Most people agreed that it was more important to see a medical person who was qualified who was free immediately if it was urgent. However, if less urgent it ‘helps if someone knows you and your history’.

4. Ongoing Care and Support

We heard accounts of good levels of support and communication. When asking what could work better, people are quick to comment on long waiting lists and lack of support overall. Some people suggested more emotional support for patients and carers, plus practical assistance (such as help to fill in a form).

We also asked people to consider what could be ‘easily’ improved. Suggestions included enhanced training and awareness, and clearer communication to patients, and professionals.

4.1 What works well?

We heard accounts of good levels of support and communication.

Ongoing Care and Support: What works well?

Selected comments:

“Support from nurses and carers.” [Brent]

“When appointment details are written down and explained.” [Brent]

“Support to stay stable and mind positive.” [Brent]

“Receive support for medication.” [Brent]

4.2 What could work better?

When asking what could work better, people are quick to comment on long waiting lists and lack of support overall. Some people suggested more emotional support for patients and carers, plus practical assistance (such as help to fill in a form).

Ongoing Care and Support: What could work better?

Selected comments:

“Not enough support especially from mental health specialist.” [Brent]

“Long waits to get support from a specialist.” [Brent]

“Whilst they appreciate the support of their learning disabilities group, the staff do not always take the time to understand service user’s individual needs. For example, one of the service users who is blind was not allowed on a trip and another with lymph edema was not given adequate physical support on an outing.” [Hounslow]

“Not able to get appointments to see specialists, such as psychiatrists.” [Brent]

“Some can’t fill in forms and there is not always support available to help.” [Brent]

“More emotional support for carers and those living with learning difficulties.” [Brent]

“Do not understand information they receive from the NHS.” [Brent]

“GPs and nurses do not understand learning difficulties needs.” [Brent]

“The group agreed that they would like to receive home visits from district nurses after discharge.” [Hounslow]

4.3 What could easily be improved?

We also asked people to consider what could be ‘easily’ improved. Suggestions included enhanced training and awareness, and clearer communication to patients, and professionals.

Ongoing Care and Support: What could easily be improved?

Selected comments:

“Extra training for nurses on how to deal with learning disability issues.” [Harrow]

“Educating the users of on-going services about learning difficulties.” [Brent]

“Less jargon from professionals and communication between carers and health professionals in simple English.” [Brent]

“Not all disabilities are visible, but should all get equal care.” [Brent]

“They would like their names called instead of being displayed in the banner.” [Brent]

“Better if the appointment were running on time.” [Brent]

“Being able to choose the gender of your doctor and option of treatment locally.” [Hounslow]

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> Local young person

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In this report, we look at experiences and expectations associated with Children and Young People.

What matters most to people in North West London?

Engaging with 10 young people, we found that:

Children & Young People's Services

Schools
Students have opportunities to volunteer in the community (for example supporting elderly people in care homes) and this is seen as good way to 'learn how to communicate with individuals who have health problems'.

Some students feel that care in school is not focused enough and there is not enough empathy from staff – the perception is that young people's health complaints are not taken seriously. It is also suggested that school nurses are 'not trained properly' and 'offer ice packs for everything'.

Communication is also noted as a problem – teachers will often send an email to the nurse about a student's health concern that is not picked up until the end of the day.

Mental health issues are addressed at assemblies, however students cite a shortage of named teacher contacts, and lack of follow up.

It was felt that schools could be more inclusive by appointing health prefects and monitors who are trained in Mental Health First Aid, so young people have someone to talk to of their own age.

Primary Care Services
Young people cite good support from NHS 111 and GPs, and a 'good atmosphere' at the pharmacy. However, it is noted that 'staff are overworked' and this impacts on quality.

Some people comment on a lack of information from their GP and poor liaison between GPs and Pharmacists.

Emergency and Acute Services
An example was given of 'a clear and supportive' service from 999, however some young people feel they 'won't be taken seriously' and this can be a disincentive.

Learning from Discussion (Checklist)

Local children and young people would like:

- A ‘focused’ approach to care within schools.
- To be respected and involved.
- Well trained school nurses.
- Timely communication between staff.
- Access to named teacher contacts.
- Good levels of support and peer support.

From Prevention to Support

We talked about various aspects around prevention and support.

Key themes emerging from a Westminster workshop include how to successfully promote healthy eating, how to utilise technology to engage young people, how to highlight the adverse health outcomes of smoking and how to create an inclusive and nurturing environment for open conversations about mental health.

Communication and Engagement

Finally, we asked people how engaged they would like to be, and whether they would like to be involved in designing new services. As part of this, we asked them which aspects of communication and engagement could be improved.

It was felt that…

- There was a preference for group forums over other types of engagement.
- Volunteering should be flexible, young people have different interests and ideas so some room for manoeuvre would be helpful.
- The desire to be involved in the co-design and production of solutions for problems with NHS healthcare.

What did people tell Healthwatch?

Here, we take a more detailed look at the top themes emerging from discussion. Generally we asked people what they feel works well and what could work better.

1. Schools

Students have opportunities to volunteer in the community (for example supporting elderly people in care homes) and this is seen as good way to 'learn how to communicate with individuals who have health problems'.

Some students feel that care in school is not focused enough and there is not enough empathy from staff – the perception is that young people's health complaints are not taken seriously. It is also suggested that school nurses are 'not trained properly' and 'offer ice packs for everything'.

Communication is also noted as a problem – teachers will often send an email to the nurse about a student's health concern that is not picked up until the end of the day.

Mental health issues are addressed at assemblies, however students cite a shortage of named teacher contacts, and lack of follow up.

Schools

Selected comments:

"I would never go to a teacher as you just get sent to the nurse and given an ice pack, whatever the issue!" [Westminster]

"Our health isn't taken seriously at school – it puts some people off asking for help." [Westminster]

"Student wellbeing should be a priority and should override any suspicion that a young person may be trying to skip class." [Westminster]

"Health services not embedded/normalised in daily school life." [Westminster]

2. Primary Care Services

Young people cite good support from NHS 111 and GPs, and a 'good atmosphere' at the pharmacy. However, it is noted that 'staff are overworked' and this impacts on quality.

Some people comment on a lack of information from their GP and poor liaison between GPs and Pharmacists.

Primary Care

Selected comments, GPs:

“Provides good support and reminds you to stay healthy and make regular appointments.” [Westminster]

“Staff are overworked so can’t provide optimal care.” [Westminster]

“Information in the surgeries, and what is given from GPs, on specific conditions is sporadic.” [Westminster]

“You can be charged for medication with no guarantee that it will be effective.” [Westminster]

There is not enough consistency or communication between the doctors and the patient and within and between services. The impact of this on the patient is strong because they can feel lost in everything that is happening and they need stability to help their recovery. [Hillingdon]

YP are ready to do anything to get a diagnosis including travelling for a couple of hours but they feel it it’s better if services are closer to them. [Hillingdon]

Selected comments, Pharmacies:

“In general, the atmosphere is calm which helps to relieve stress form patients.” [Westminster]

“Not enough staff to serve at the counter so wait times can be very long.” [Westminster]

“Sometimes pharmacies run out of stock. [Westminster]

“Communication between GPs and surgeries is not good – you can be given the wrong medication or they are unsure of what dosage. [Westminster]

Selected comments, other services:

“NHS 111 is a really efficient service” – they give you good instructions and keep you calm.” [Westminster]

“NHS 111 - Some questions you are asked seem irrelevant and there is some time-wasting. If you have a serious issue these unnecessary delays could be life threatening.” [Westminster]

“NHS Go - Very little awareness that it exists – worrying because it was specifically designed for 16-25 year olds.” [Westminster]

3. Emergency and Acute Services

An example was given of ‘a clear and supportive’ service from 999, however some young people feel they ‘won’t be taken seriously’ and this can be a disincentive.

Emergency and Acute Services

Selected comments:

“999 - Emergency call staff are supportive and give you clear steps on what to do.” [Westminster]

“999 - It is rarely used by young people – partly due to the fear that they won’t be taken seriously.” [Westminster]

“Hospitals - There is not enough balance – there should be more hospitals in the less affluent areas.” [Westminster]

“Hospitals - There can problems with treatment: “I was given the wrong cast at St. Charles and had to go to St. Mary’s.” [Westminster]

“Hospitals “A&E waiting times are too long rooms and waiting rooms are too cramped which heightens the risk of stress and the spread of disease.” [Westminster]

4. Experiences - From Prevention to Support

We talked about various aspects around assessment, diagnosis, treatment and ongoing care and support.

Key themes emerging from a Westminster workshop include how to successfully promote healthy eating, how to utilise technology to engage young people, how to highlight the adverse health outcomes of smoking and how to create an inclusive and nurturing environment for open conversations about mental health.

Prevention to Support

Responses to Key Themes:

- **Physical and psychological impact of smoking:** Regular engagement e.g. school assemblies on the dangers of smoking with real people who had lived through the damage it can do to body and mind – an accord was established that creating fear amongst young people of the impact of smoking was the best way to prevent it.

- **Early recognition:** Training for teachers and parents to identify signs of stress in young people that could lead to harmful behaviours like smoking.
- **Taking lessons from elsewhere:** There are adverts on TV about spotting the early signs of stroke, this should be applied for mental health issues amongst young people.
- **One-stop shop:** The NHS Go app should offer a young person needs to stay healthy, for example, you should be able to scan barcodes on food packaging to see the product's fat and sugar levels and the same process should be available with medication to establish if it suitable for you. However, there is an issue with data storage here.
- **Educational games:** Unlikely to rival the popularity of the big, commercial video games, but games with health messages should be available in GP waiting rooms and time should be dedicated to them at school in subjects like PHSE. Game apps would need to be free to attract young people out of school.
- **Tackling mental health stigma:** Teachers should take more responsibility in reassuring young people that it's good to talk through health concerns. This should include regular health 'check-ins' and a daily presentation at the end of the day discussing issues like exam stress and healthy eating.
- **Support for young people from young people:** Schools should have health prefects and monitors who are trained in Mental Health First Aid to offer support to young people and take their concerns seriously.
- **A place to go:** There is a real lack of free youth clubs. More work should be done to provide free access to these facilities. A great example of a successful and free youth club is 'Four Feathers' in Westminster.
- **Exercise in school:** Participation in group activities should be encouraged more as competition and feeling like part of a team are good for mental health.
- **Food warnings:** A traffic light system should be used for school meals. Any meals high in fat and sugar should have a clear red light next to them (and all around them) and healthy and nutritious options should have green light signposting.
- **Communication hubs:** A safe place to talk face-to-face with a professional should be available in the community and at school, websites and social media isn't enough.
- **Basic training:** Teachers should be given basic medical training so they are more able to establish waning signs early and can work together with school nurses.
- **Fizzy drinks:** Carbonated drinks that are high in sugar should not be allowed in hospital waiting rooms or schools, or at least they should have warning messages on them similar to cigarettes.
- **GPs Direct**: Young people should be able to have direct contact with their GPs to establish a rapport with them and build trust.

5. How could communication and engagement be improved?

Finally, we asked people how engaged they would like to be, and whether they would like to be involved in designing new services. As part of this, we asked them which aspects of communication and engagement could be improved.

How could communication and engagement be improved?

Key Themes - it was felt that:

- There was a preference for group forums over other types of engagement.
- Volunteering should be flexible, young people have different interests and ideas so some room for manoeuvre would be helpful.
- The desire to be involved in the co-design and production of solutions for problems with NHS healthcare.

Selected comments:

In a positive way, there is a lot of promotion of different options for self-care. [Hillingdon]

Generally, the process is too slow and it's not helpful so YP lose faith in the fact that doctor will find a diagnosis for them. [Hillingdon]

Acknowledgements

We would like to thank all those participants who gave up their time to contribute to the focus groups and completed the national survey.

This project was undertaken by the following Healthwatch organisations:

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Distribution and Comment

This report is available to the general public, and is shared with our statutory and community partners. Accessible formats are available.

If you have any comments on this report or wish to share your views and experiences, please contact us.

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> “NHS 111 is a really efficient service – they give you good instructions and keep you calm.”
>
> Local young person

Survey Results

As part of the engagement we hosted two surveys, one about general health and another focusing on long term conditions.

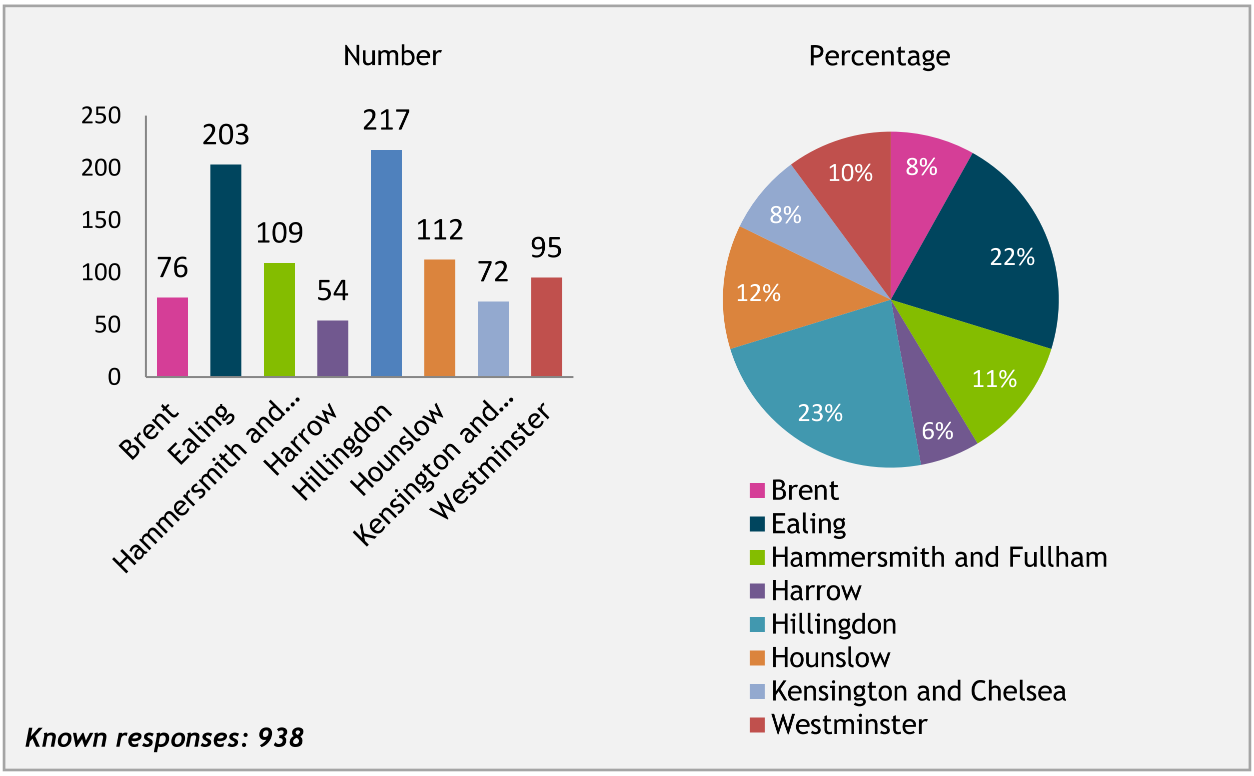
General Survey

The general survey covered three topic areas:

- Managing and choosing support.
- Keeping independent and staying healthy as you get older.
- Interacting with the local NHS.

It was completed by 938 people who live in North West London:

London Borough

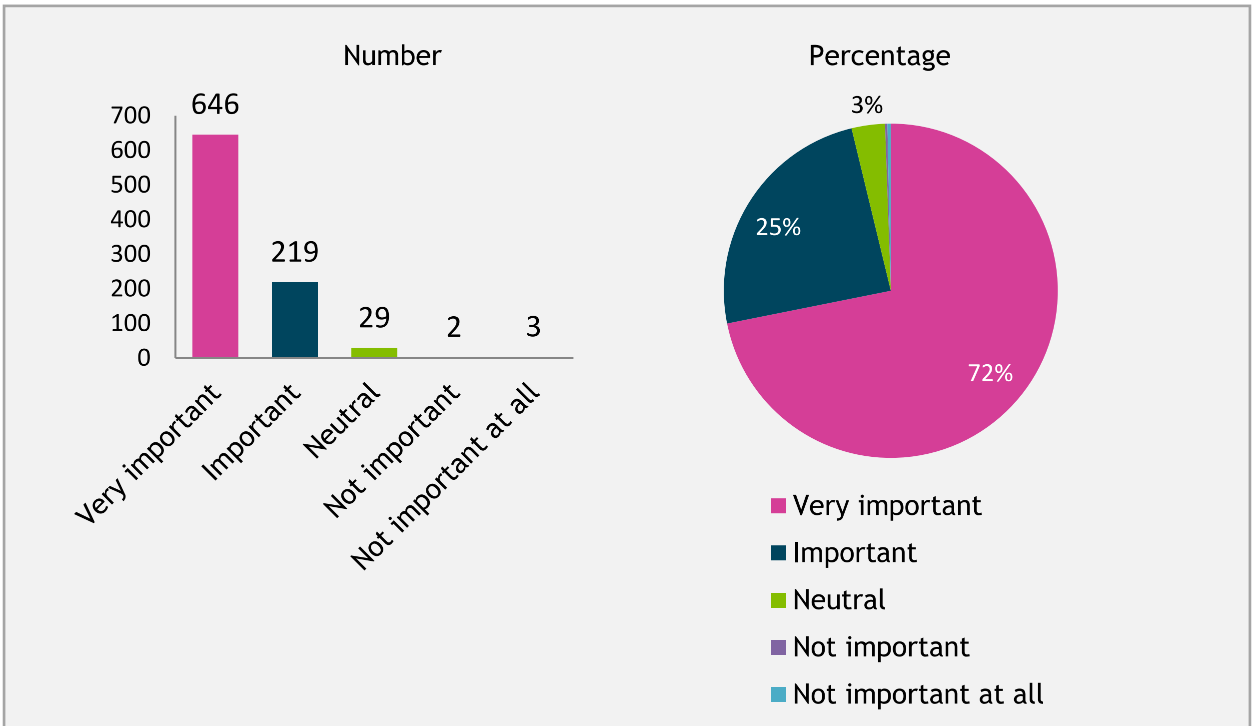


Known responses: 938

In the next section we show the survey results.

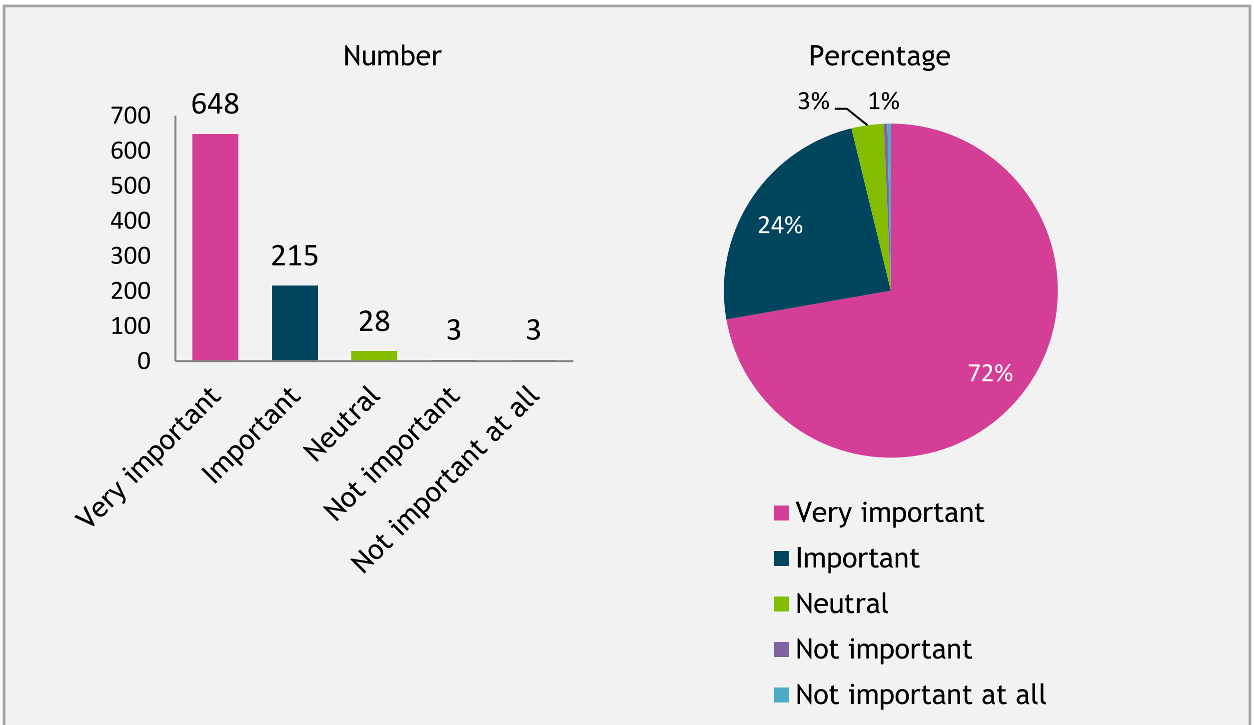
How important are the following in helping to live a healthy life?

Easy access to the information I need to help me make decisions about my health and care



Known responses: 899

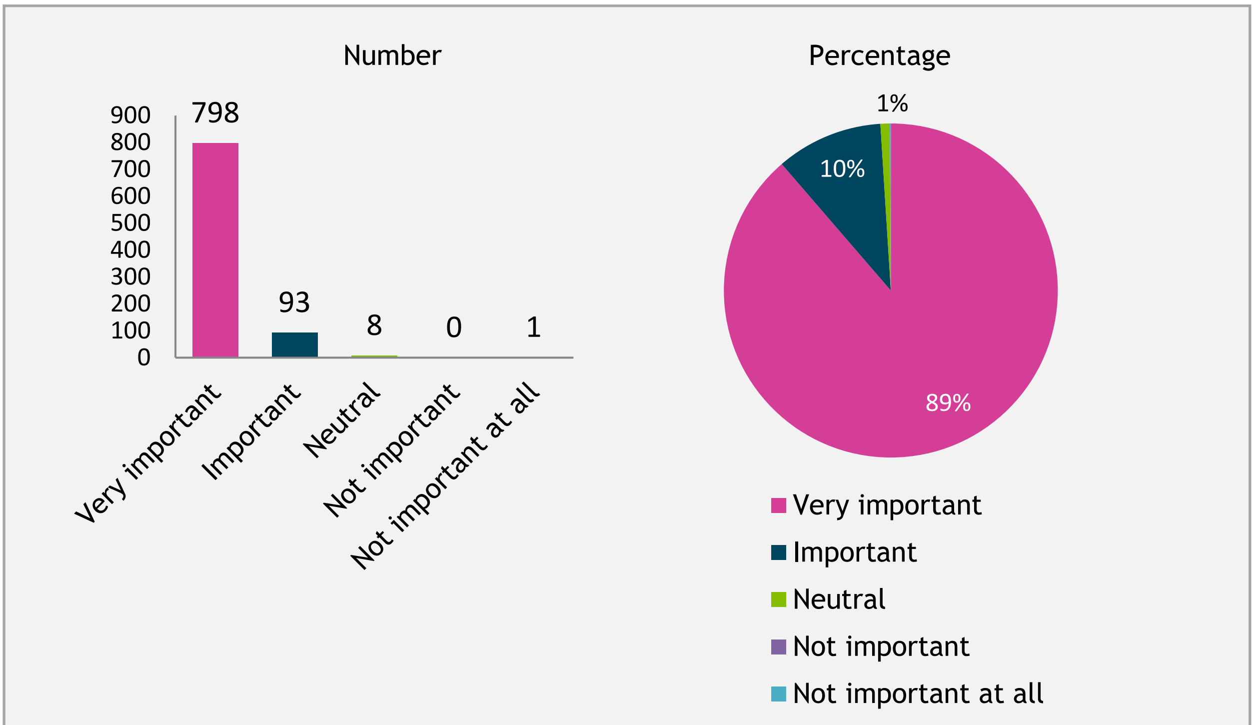
Having the knowledge to help me do what I can to prevent ill health



Known responses: 897

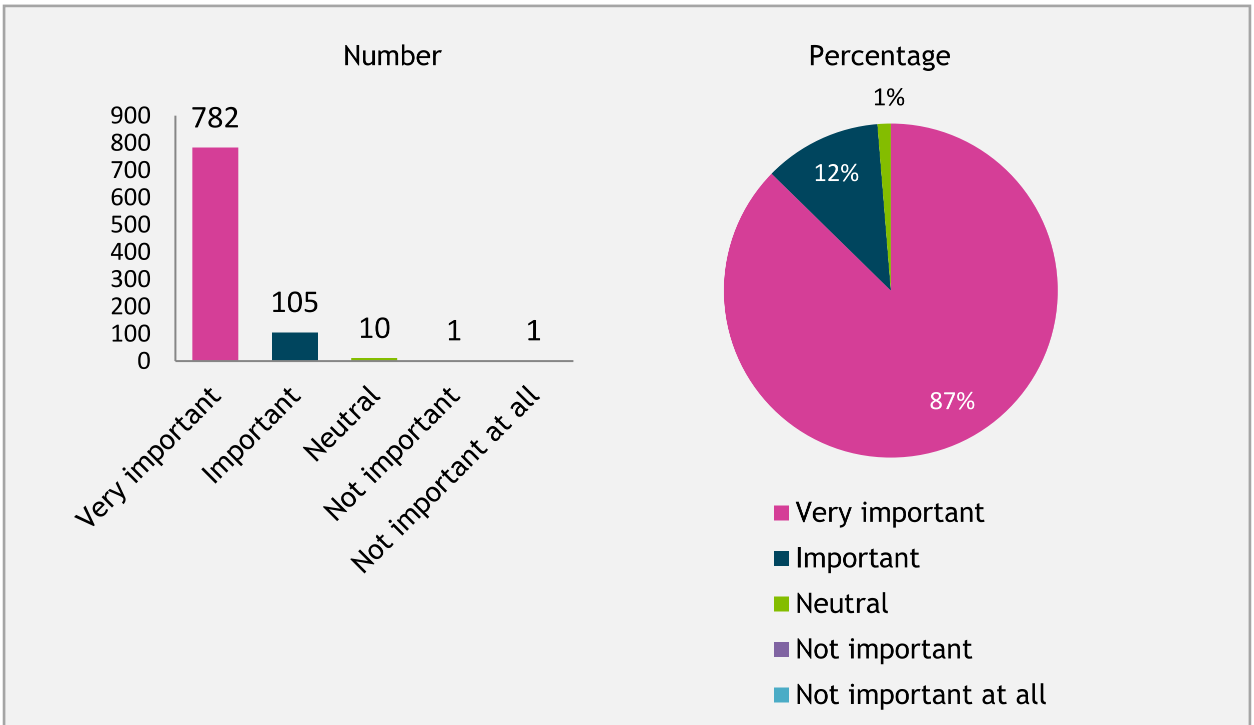
How important are the following in helping to live a healthy life?

Access to the help and treatment I need when I want it



Known responses: 900

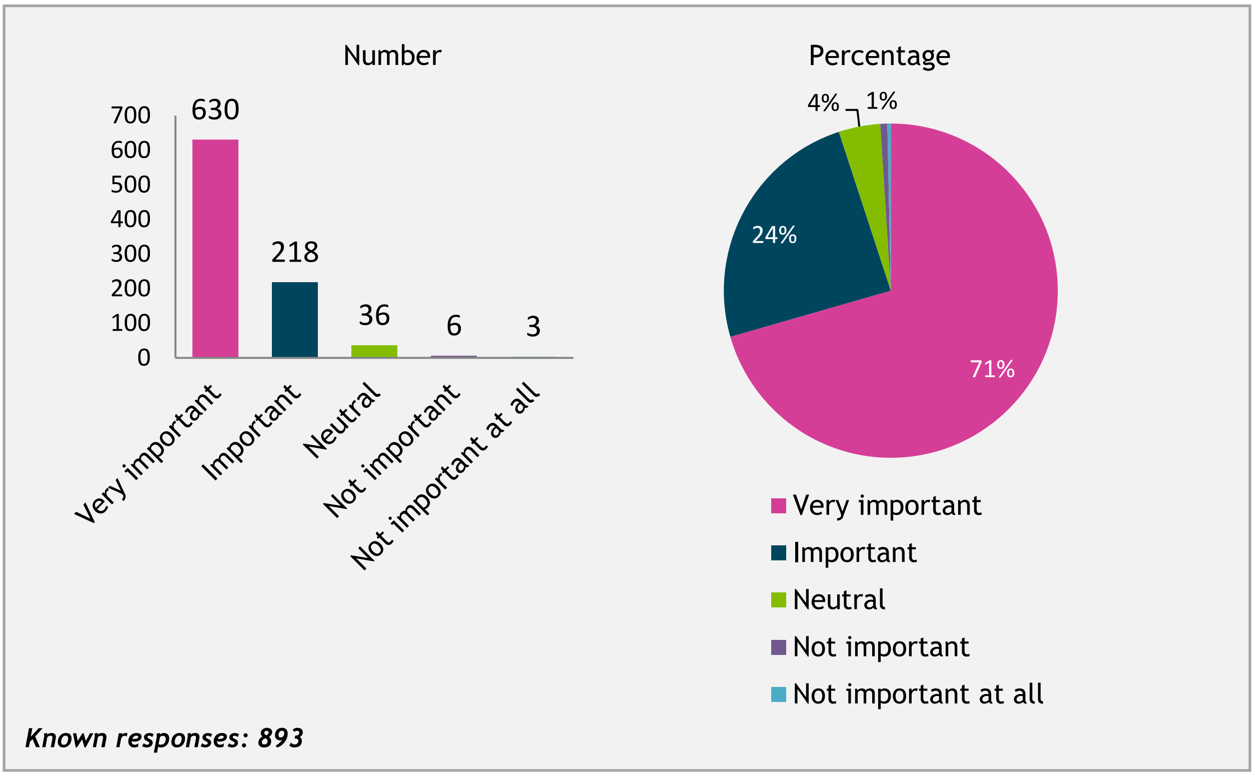
Professionals that listen to me when I speak to them about my concerns



Known responses: 899

How important are the following in helping to live a healthy life?

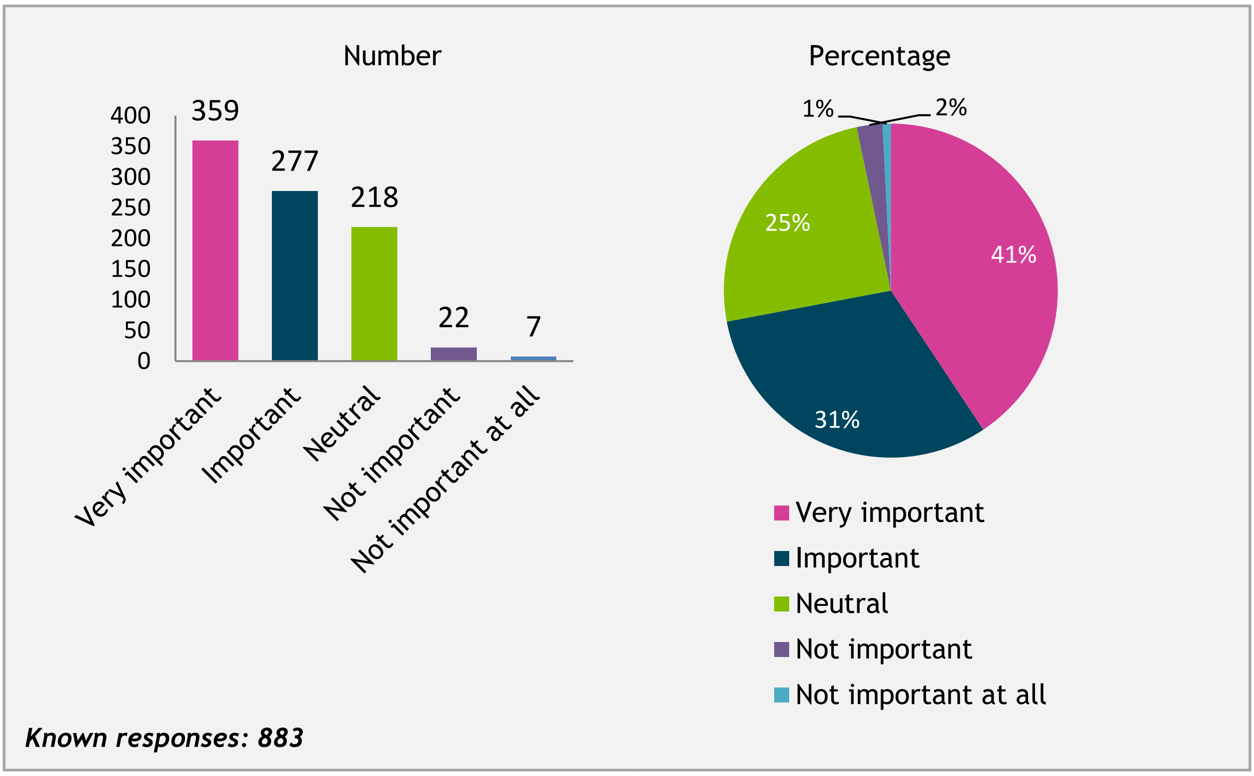
For every interaction with health and care services to count; my time is valued



Known responses: 893

How important are the following in managing and choosing support?

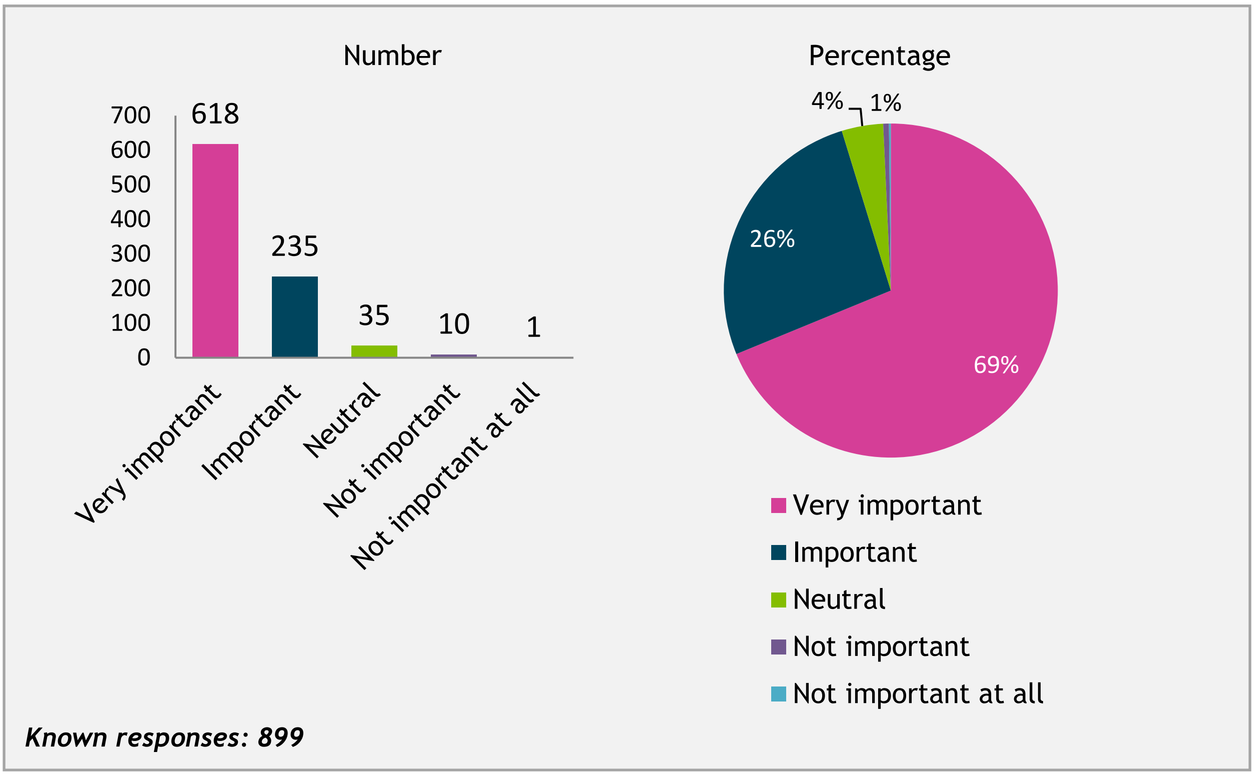
If I have a long term condition I decide how the NHS spends money on me



Known responses: 883

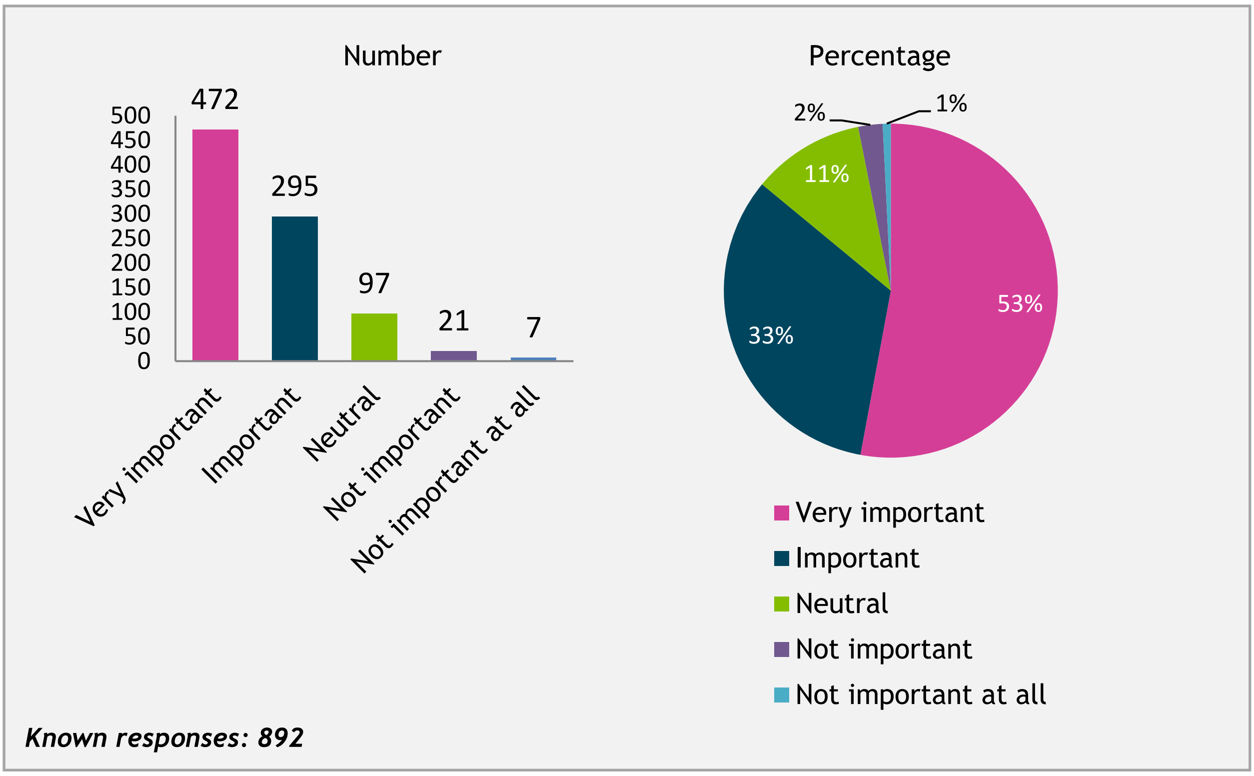
How important are the following in managing and choosing support?

Choosing the right treatment is a joint decision between me and the relevant health and care professional



Known responses: 899

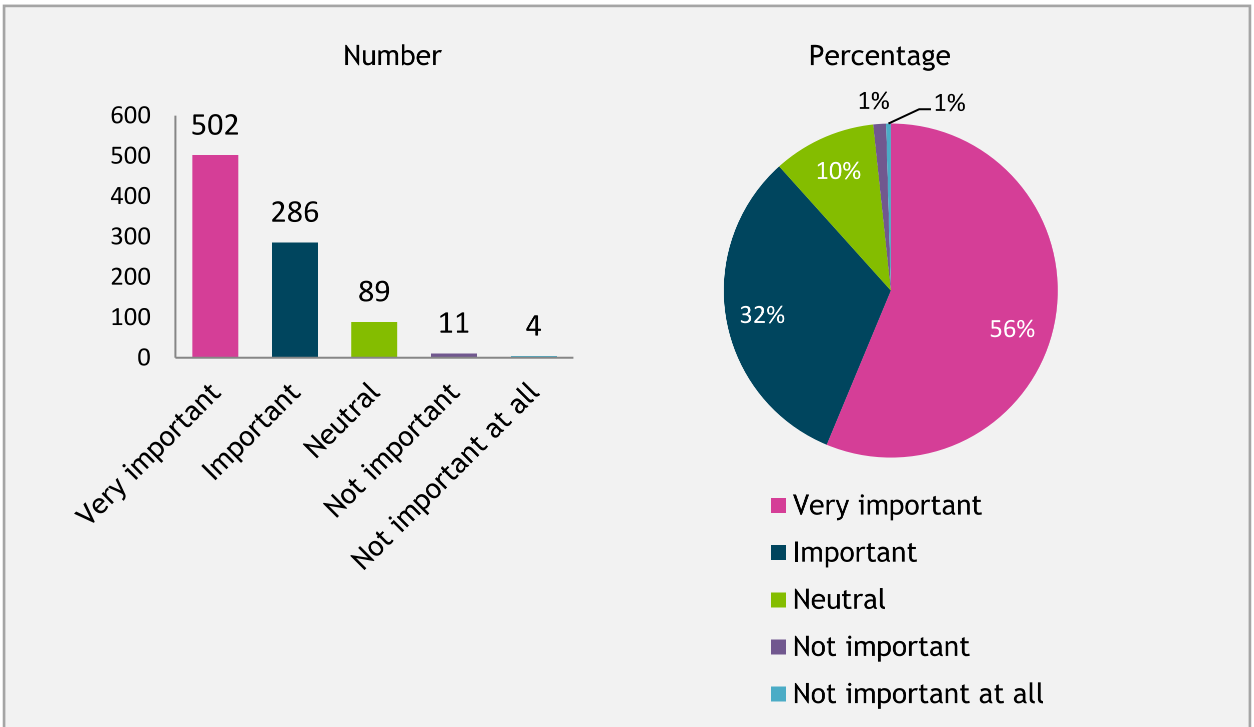
I make the decision about where I will go to receive health and care support



Known responses: 892

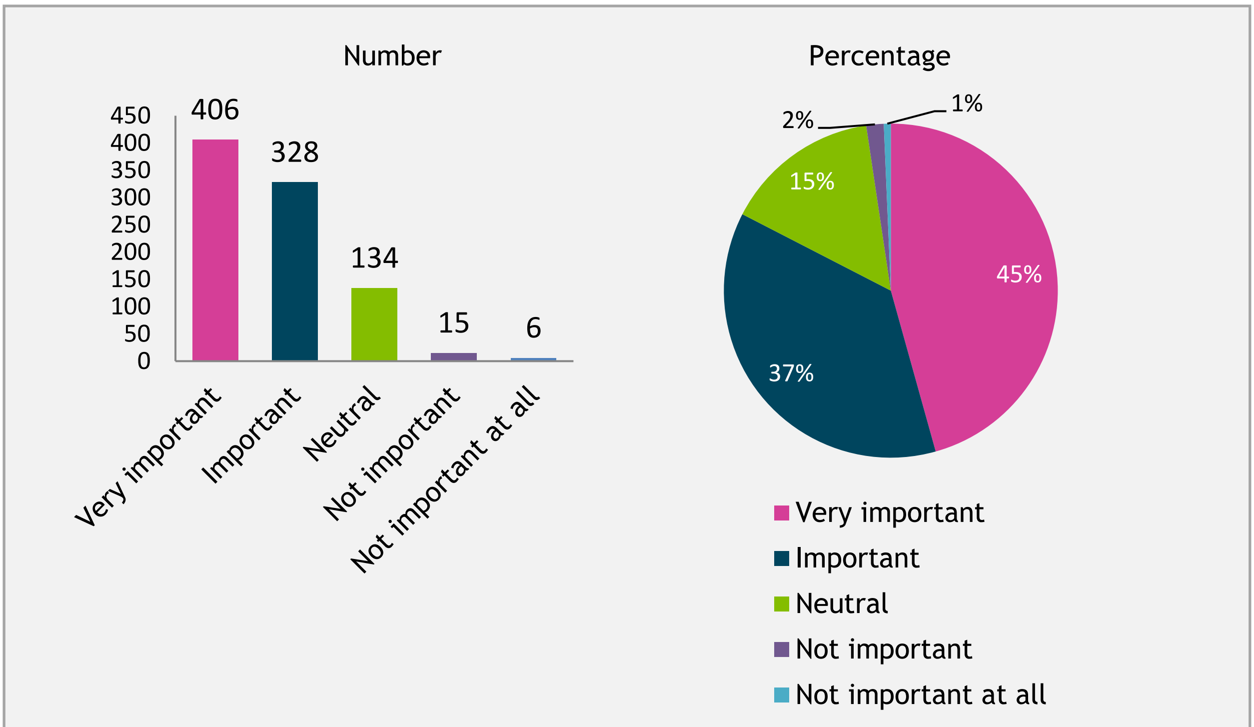
How important are the following in managing and choosing support?

I should be offered care and support in other areas if my local area can’t see me in a timely way



Known responses: 892

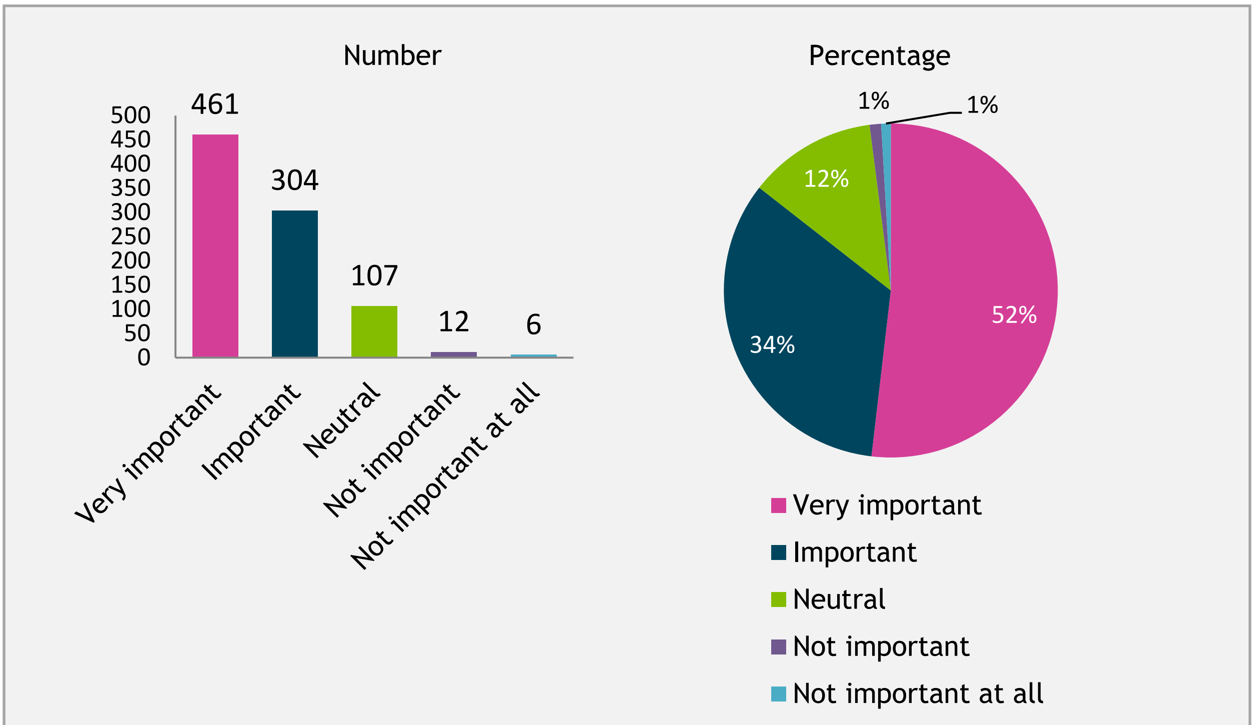
I make the decision about when I will receive health and care support



Known responses: 889

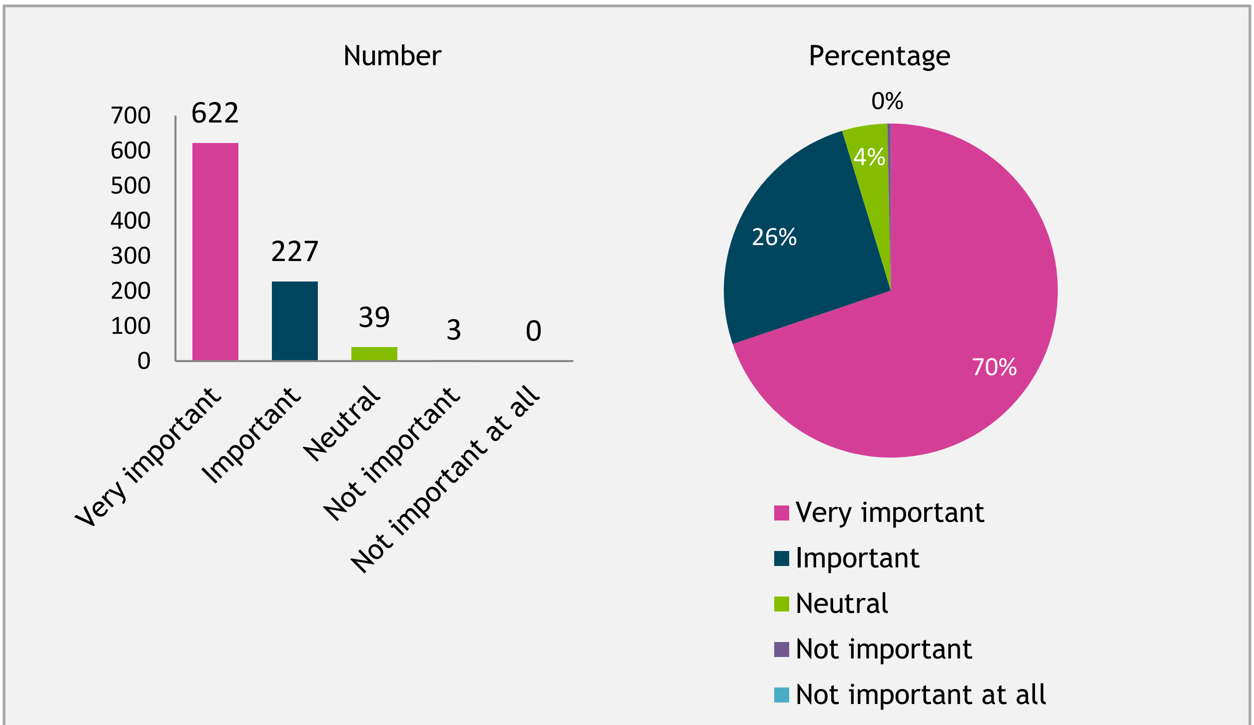
How important are the following in managing and choosing support?

My opinion on what is best for me, counts



Known responses: 890

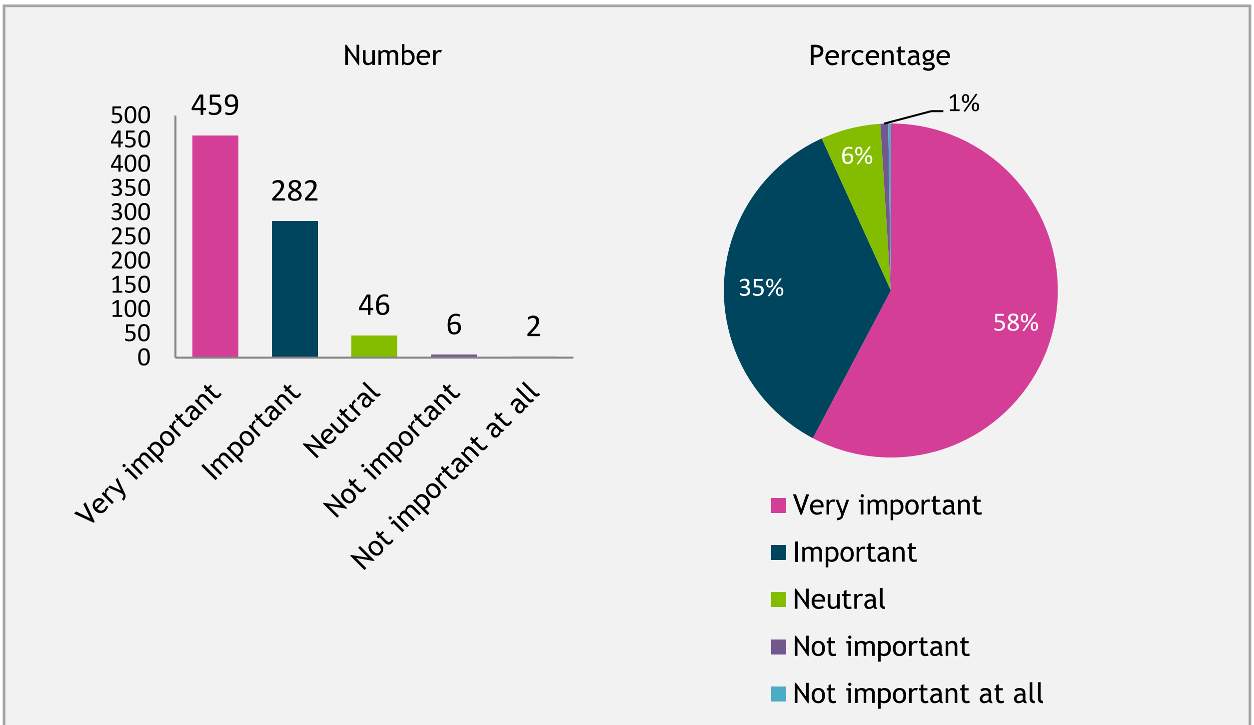
Communications are timely



Known responses: 891

How important are the following in managing and choosing support?

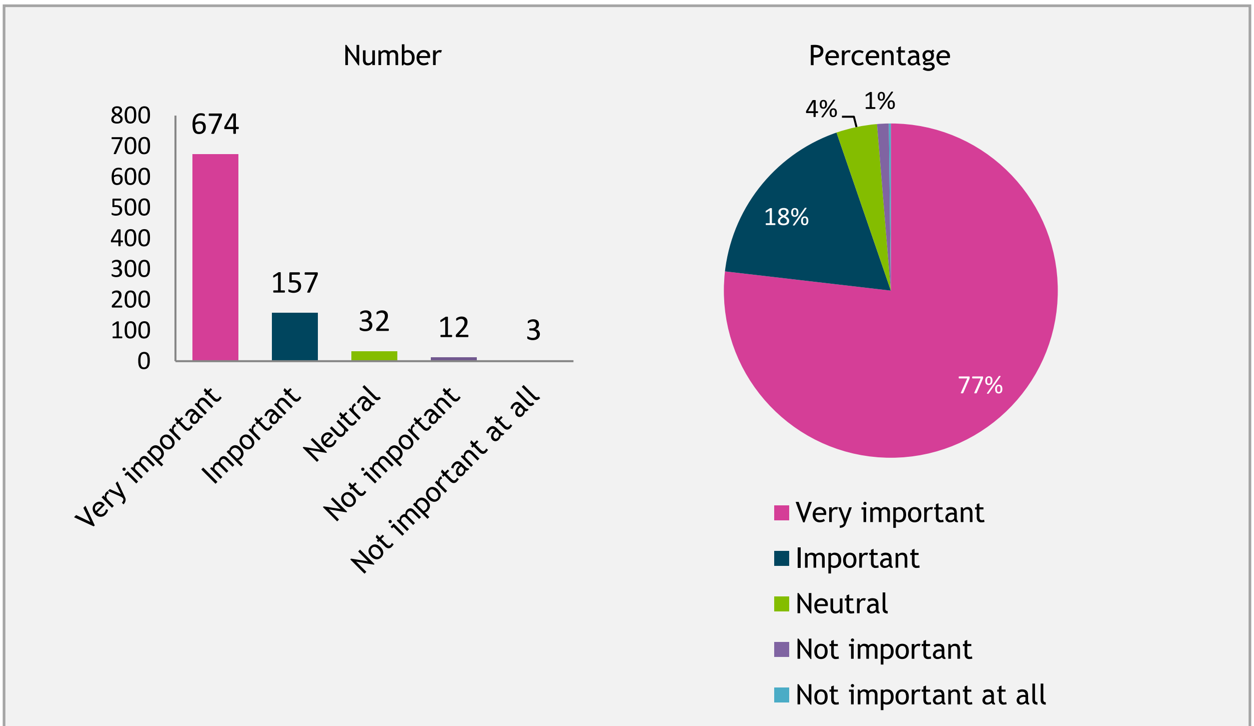
I have time to consider my options and make the choices that are right for me



Known responses: 795

How important are the following, as you get older?

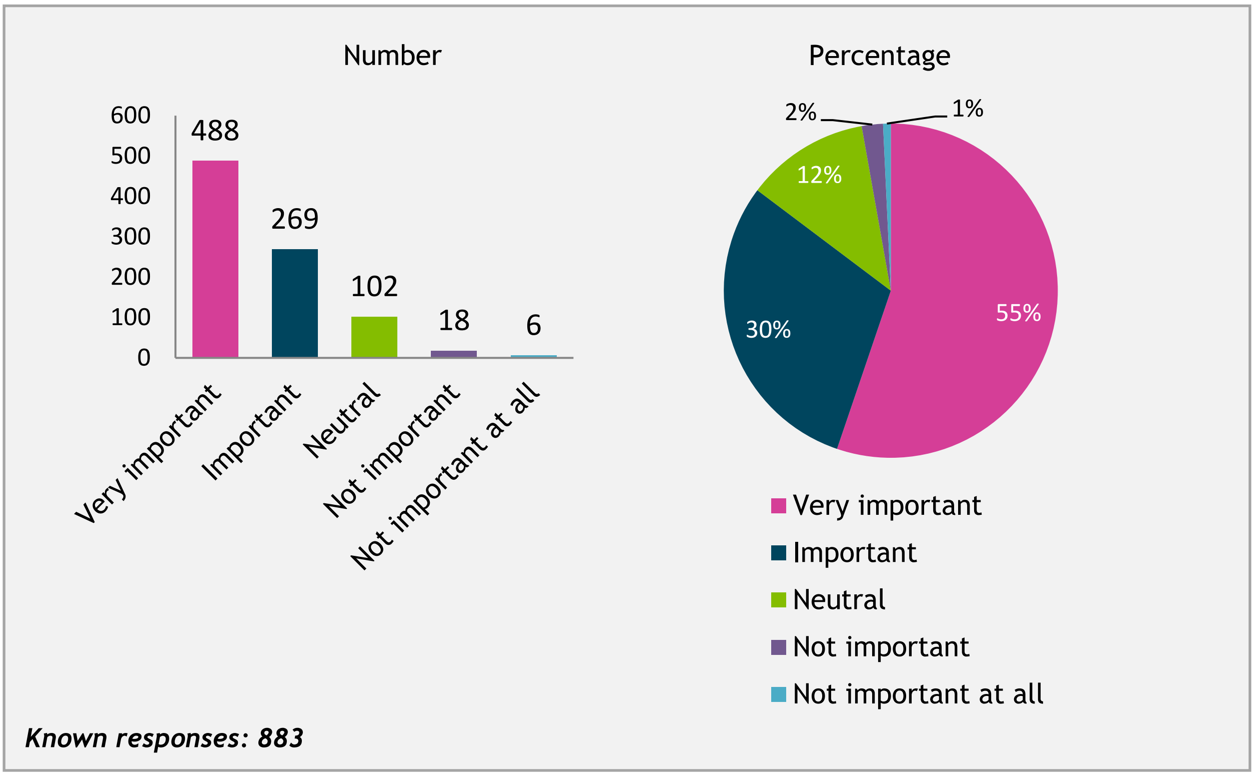
I want to be able to stay in my own home for as long as it is safe to do so



Known responses: 878

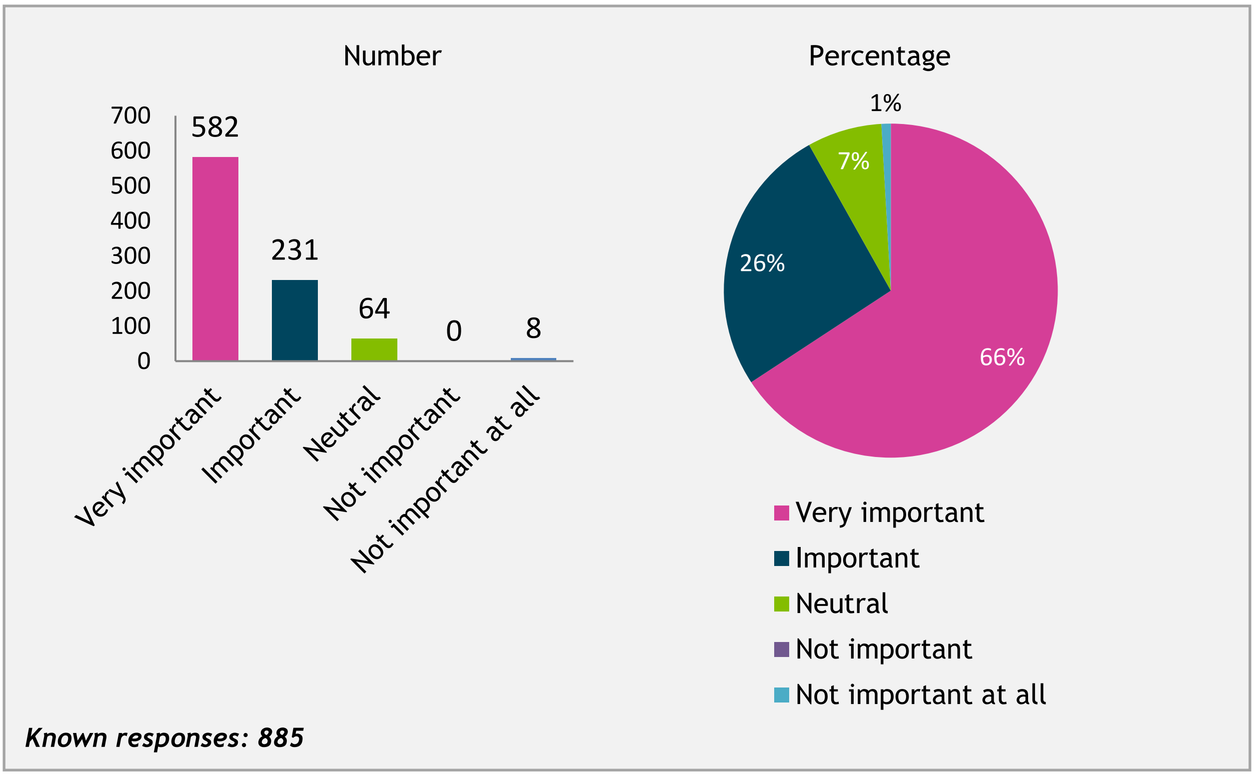
How important are the following, as you get older?

I want my community to be able to support me to live my life the way I want



Known responses: 883

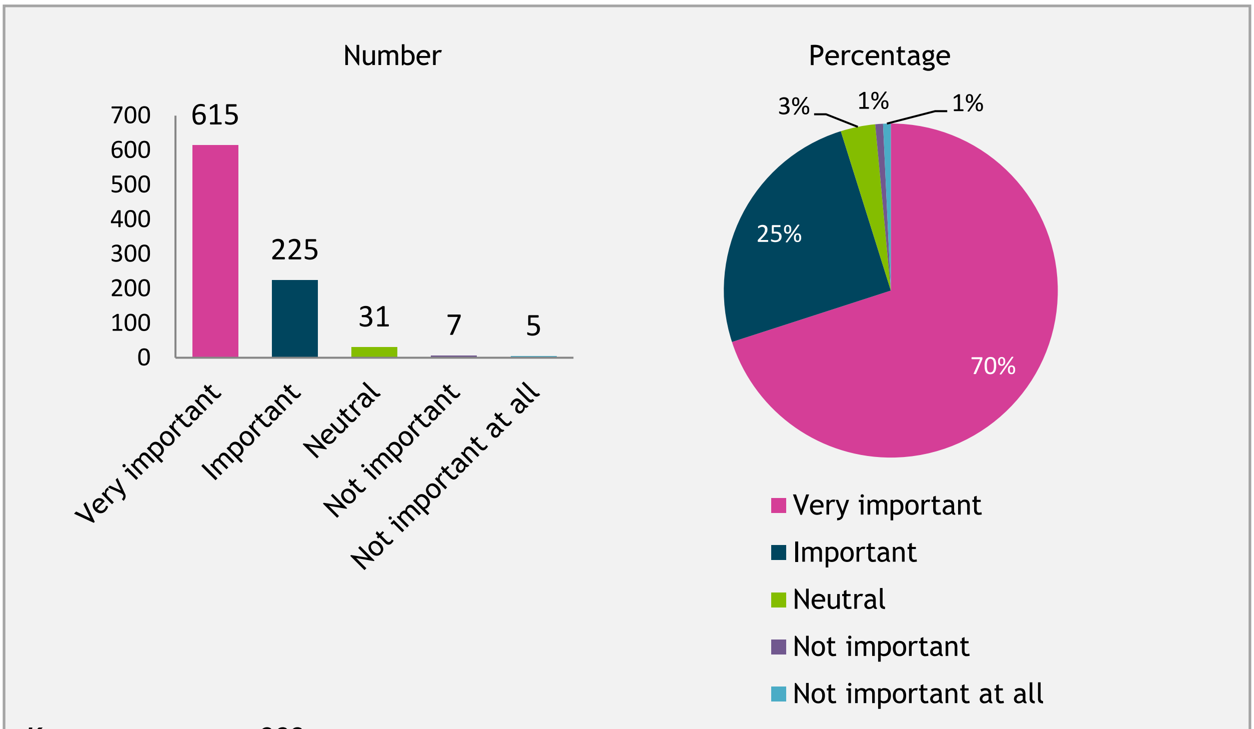
I want my family and friends to have the knowledge, to help and support me when needed



Known responses: 885

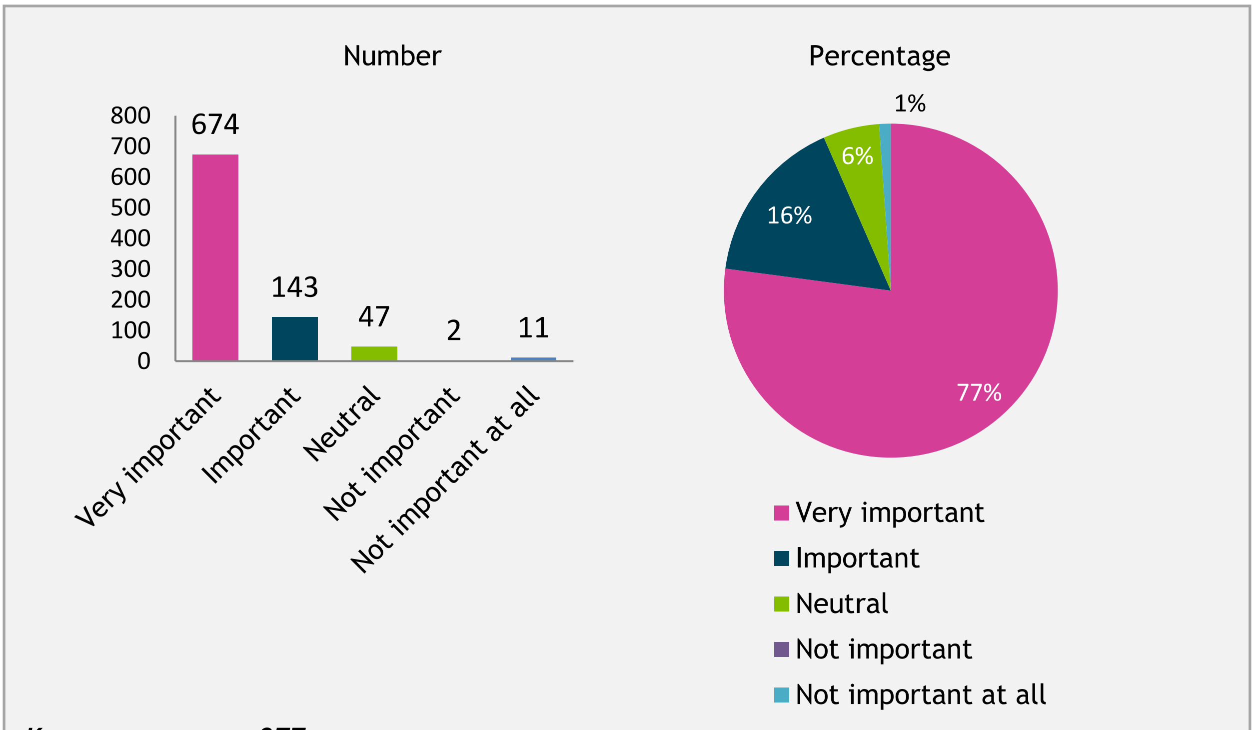
How important are the following, as you get older?

I want there to be convenient ways for me to travel to health and care services when I need to



Known responses: 883

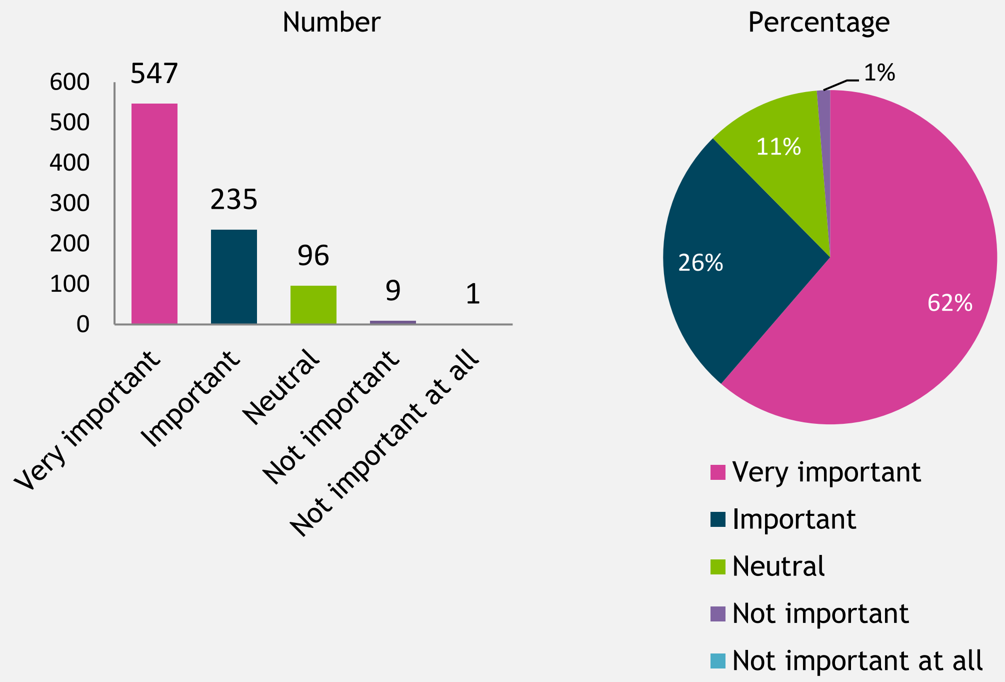
I want my family and me to feel supported at the end of life



Known responses: 877

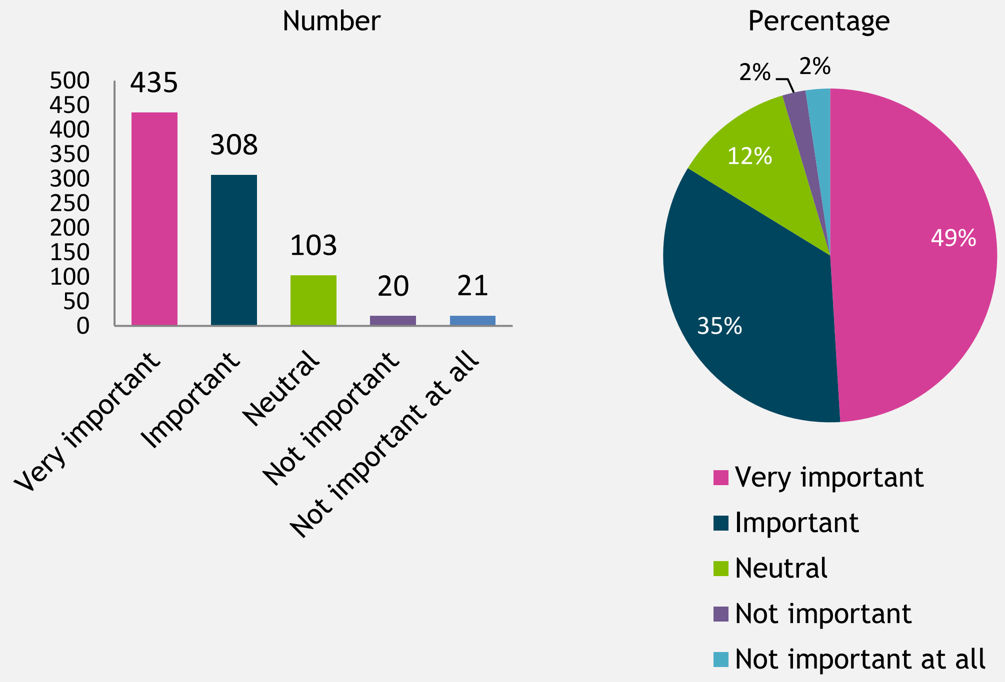
How important are the following, when interacting with the NHS?

I have absolute confidence that my personal data is managed well and kept secure



Known responses: 888

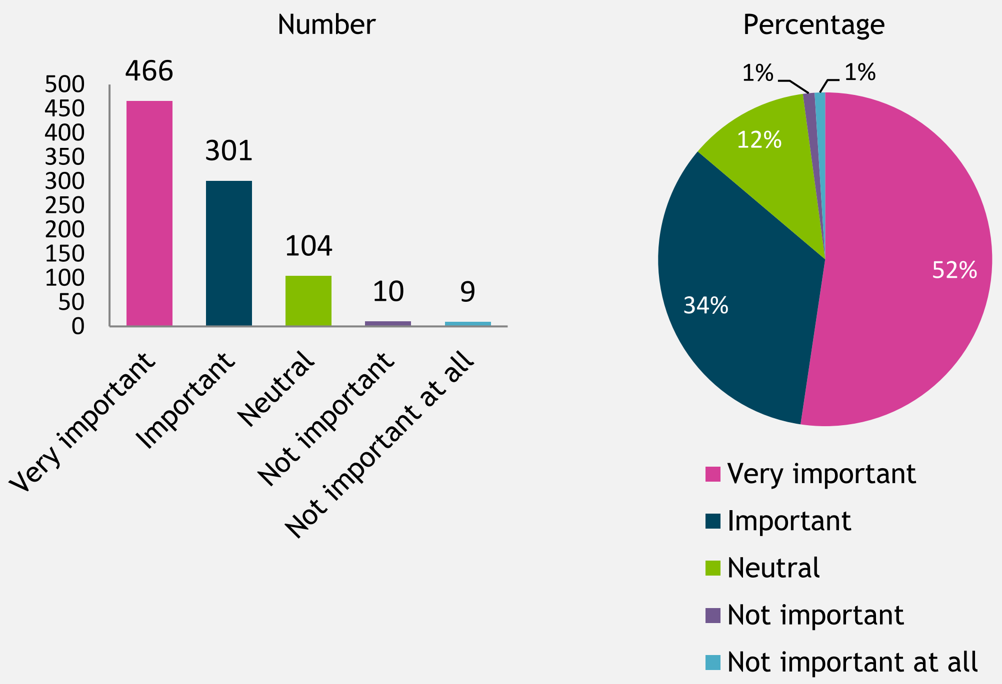
I can access services using my phone or computer



Known responses: 887

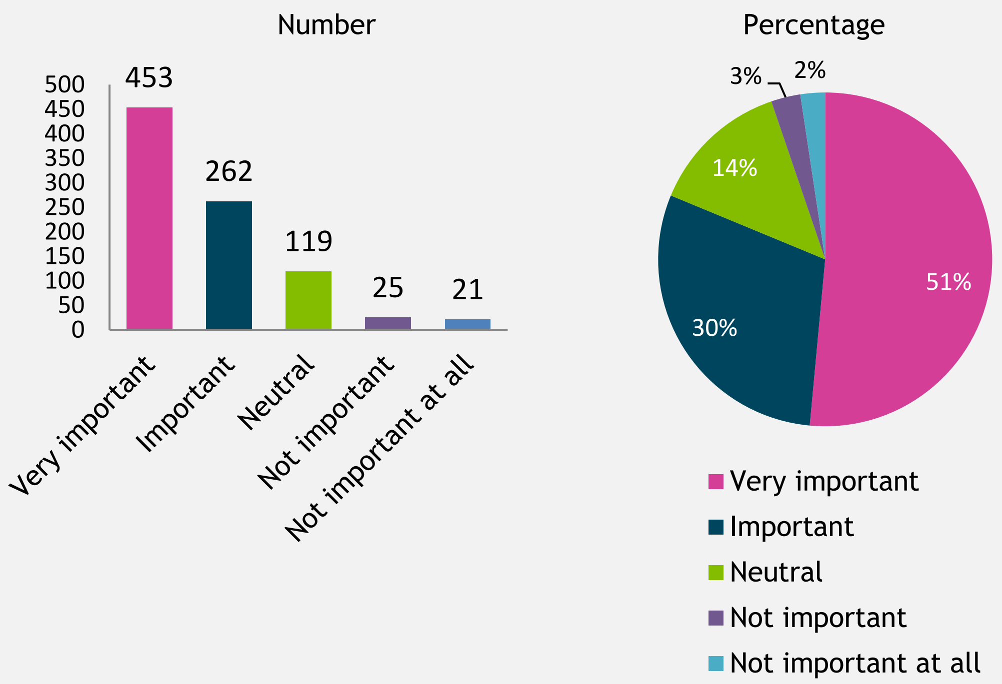
How important are the following, when interacting with the NHS?

I can talk to my doctor or other health care professional wherever I am



Known responses: 890

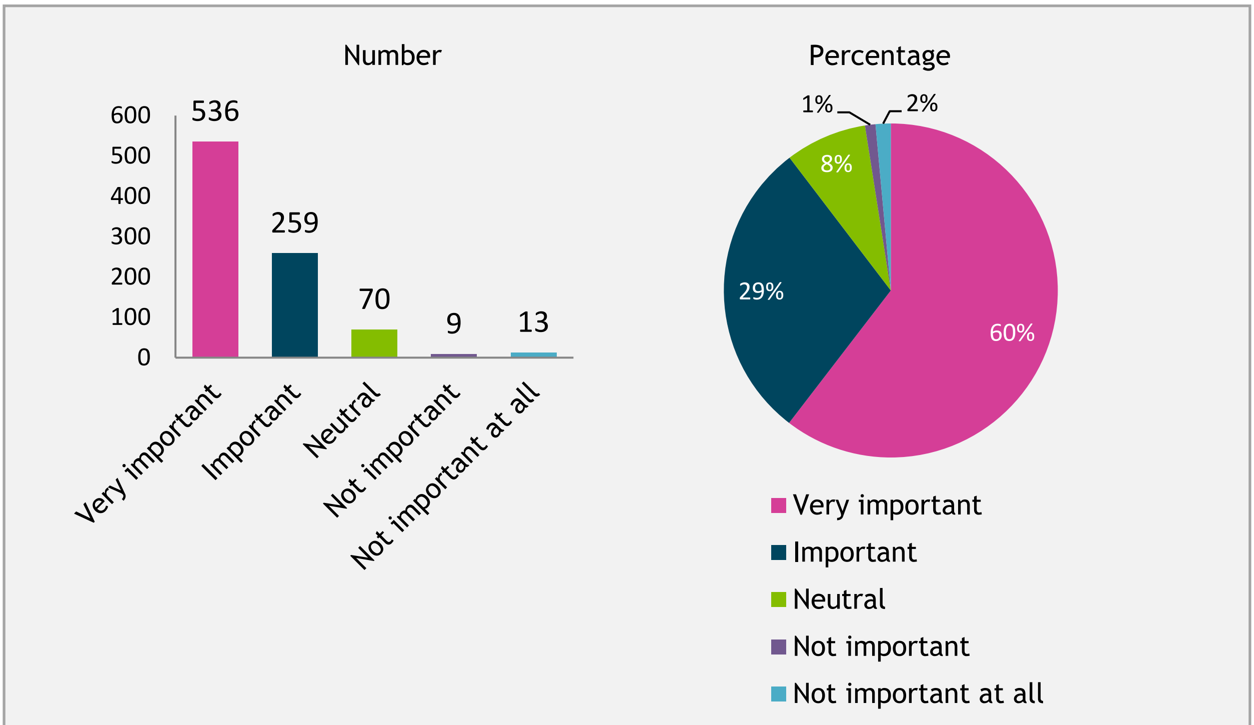
I can make appointments online and my options are not limited



Known responses: 880

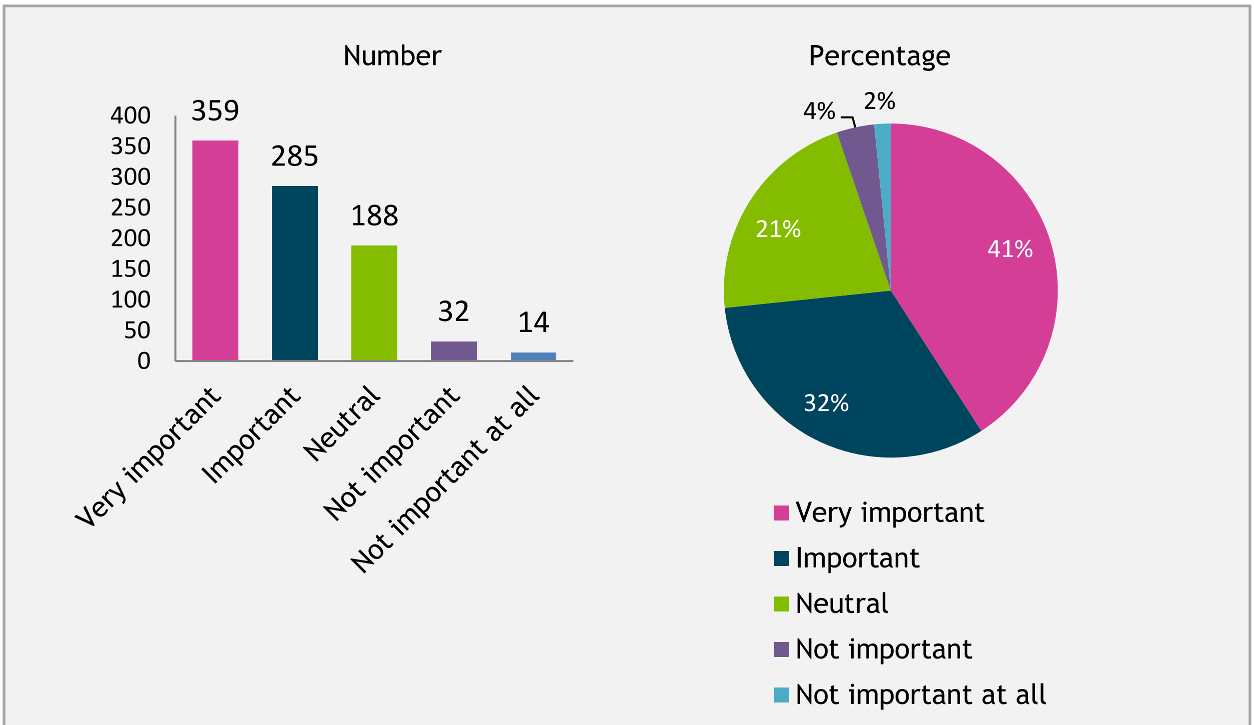
How important are the following, when interacting with the NHS?

Any results are communicated to me quickly making best use of technology



Known responses: 887

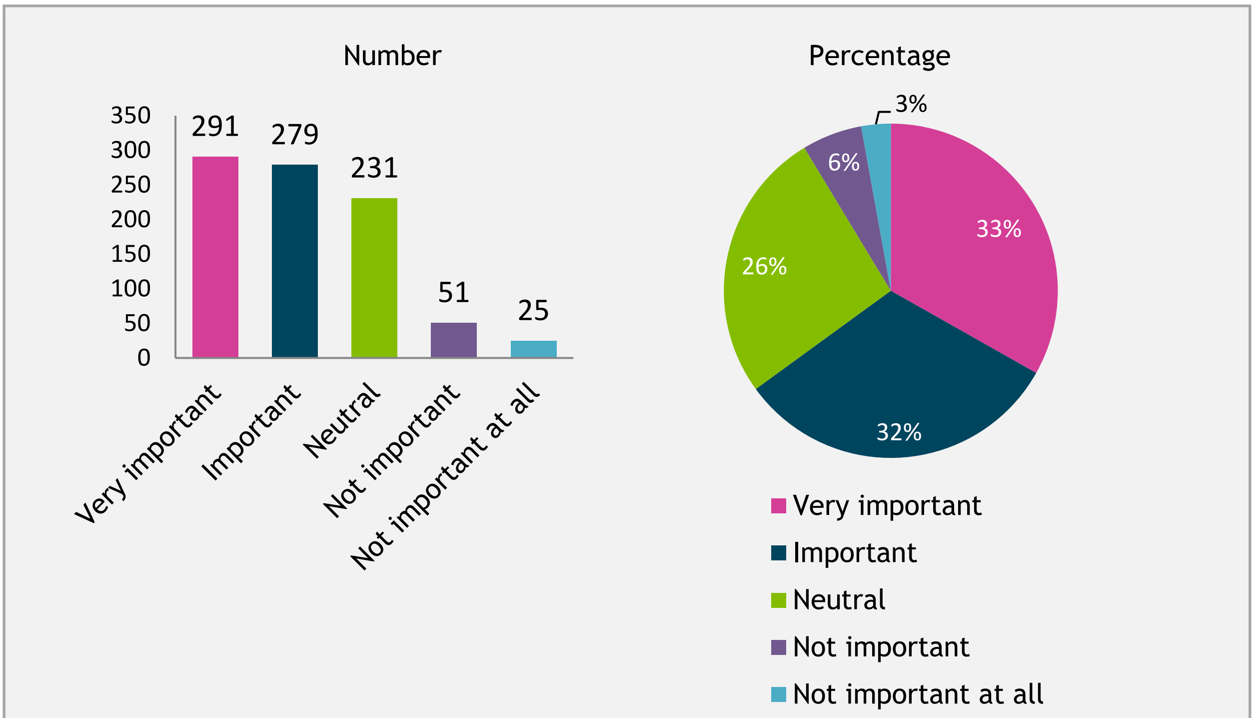
I manage my own personal records so that I can receive continuity in care



Known responses: 878

How important are the following, when interacting with the NHS?

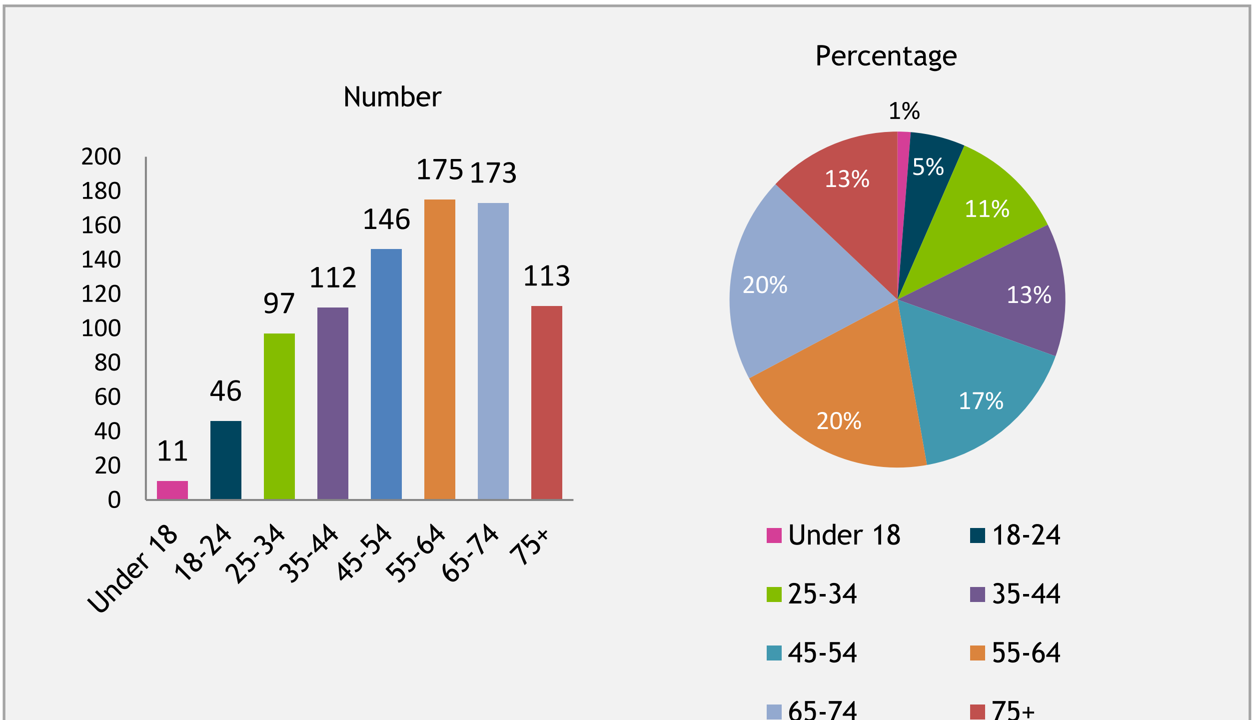
I am able to talk to other people who are experiencing similar challenges to me to help me feel better



Known responses: 877

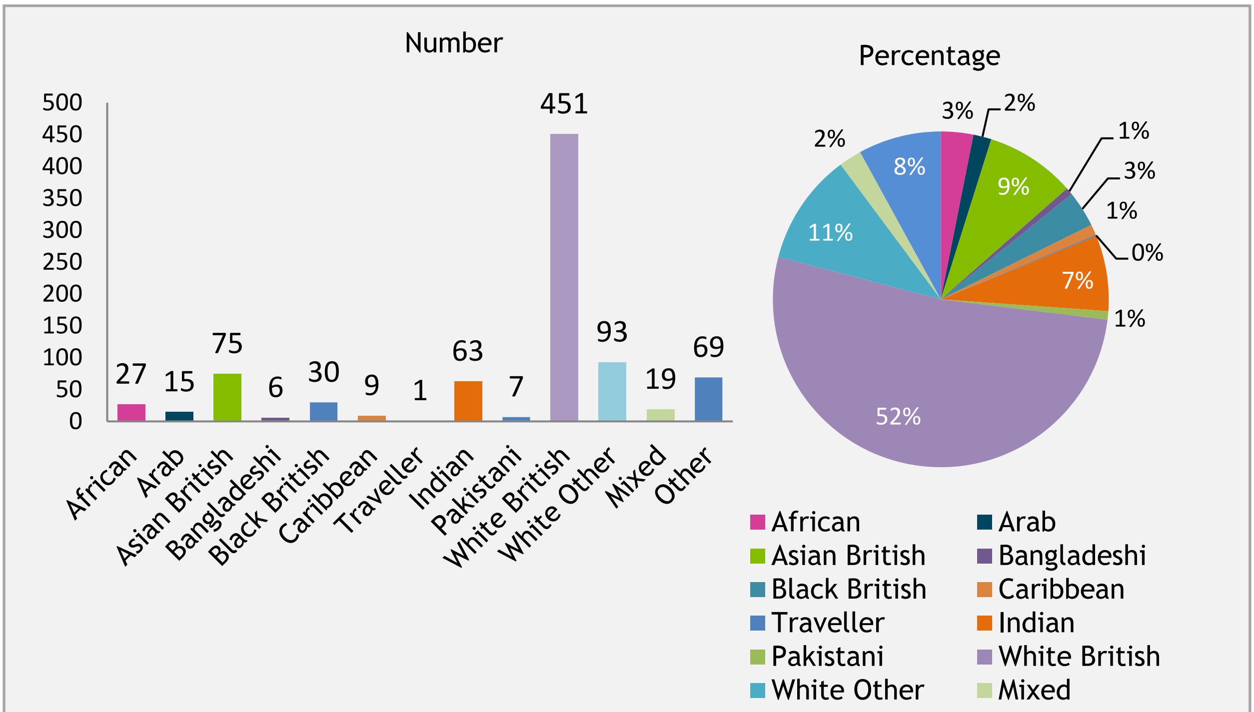
Demographics

Age



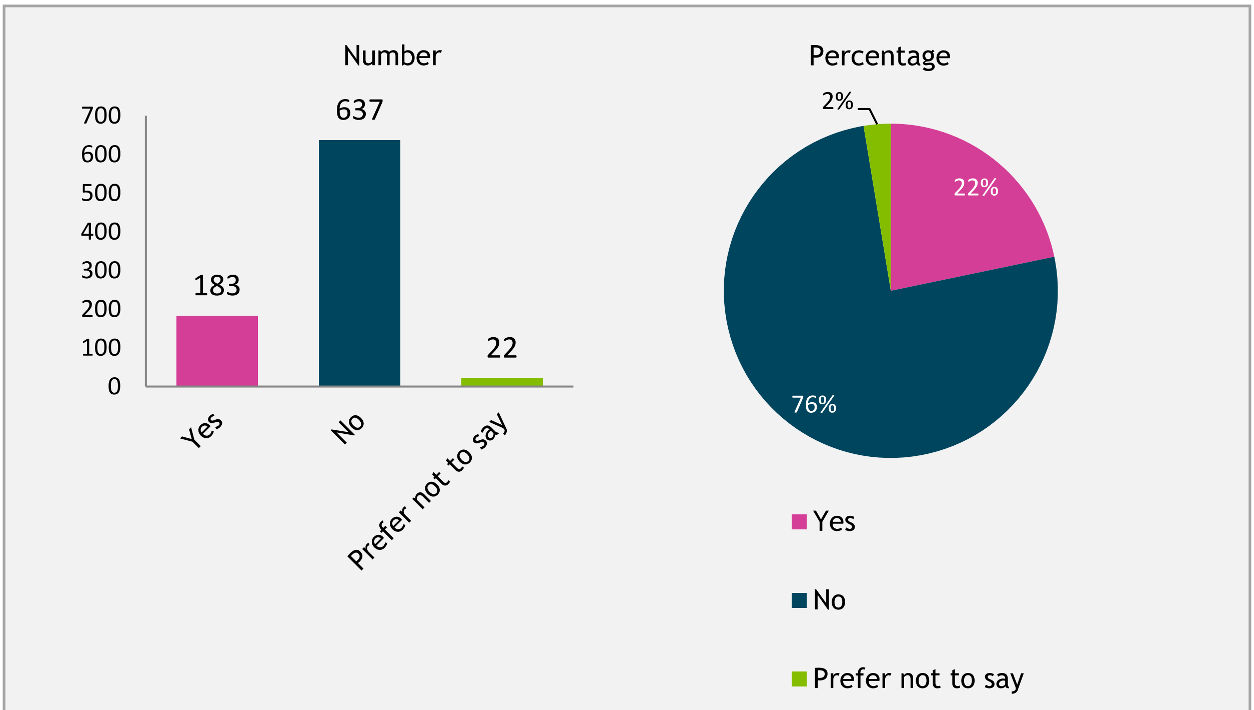
Known responses: 873

Ethnicity



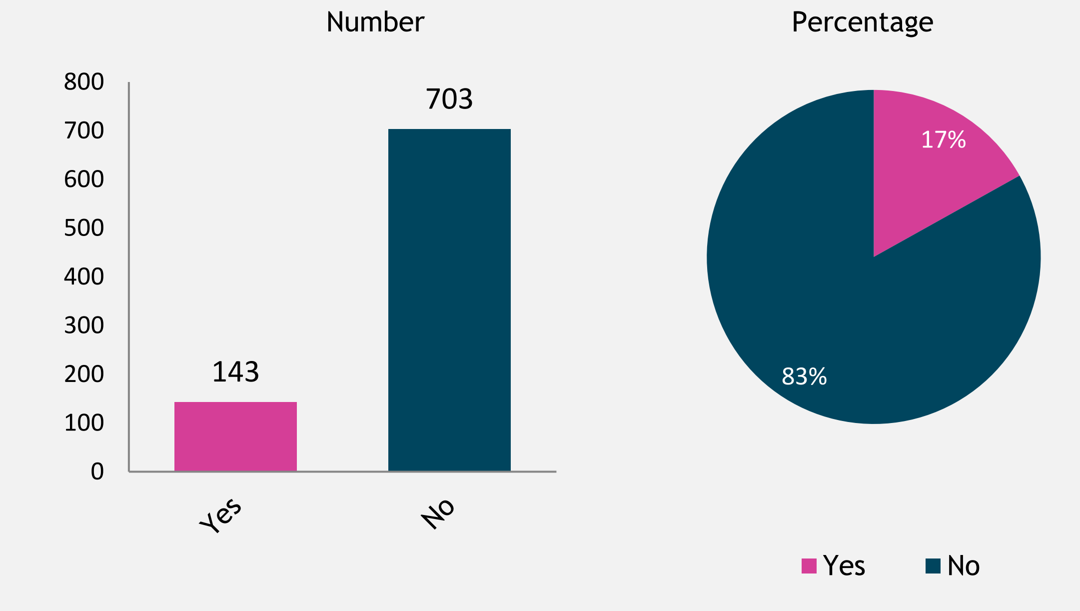
Known responses: 865

Do you consider yourself to have a disability?



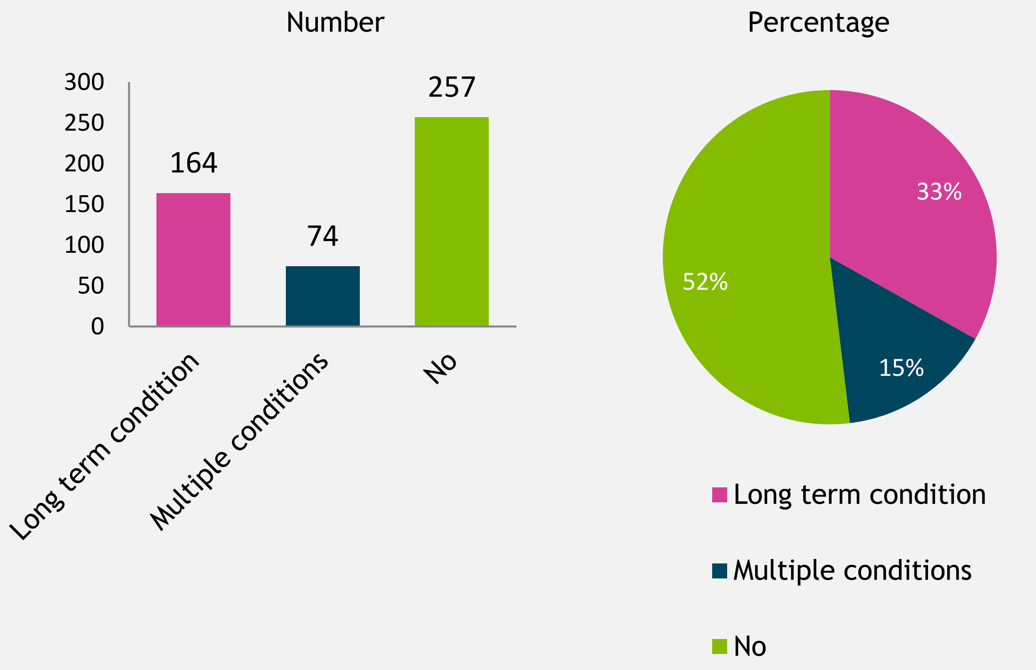
Known responses: 842

Are you a carer?



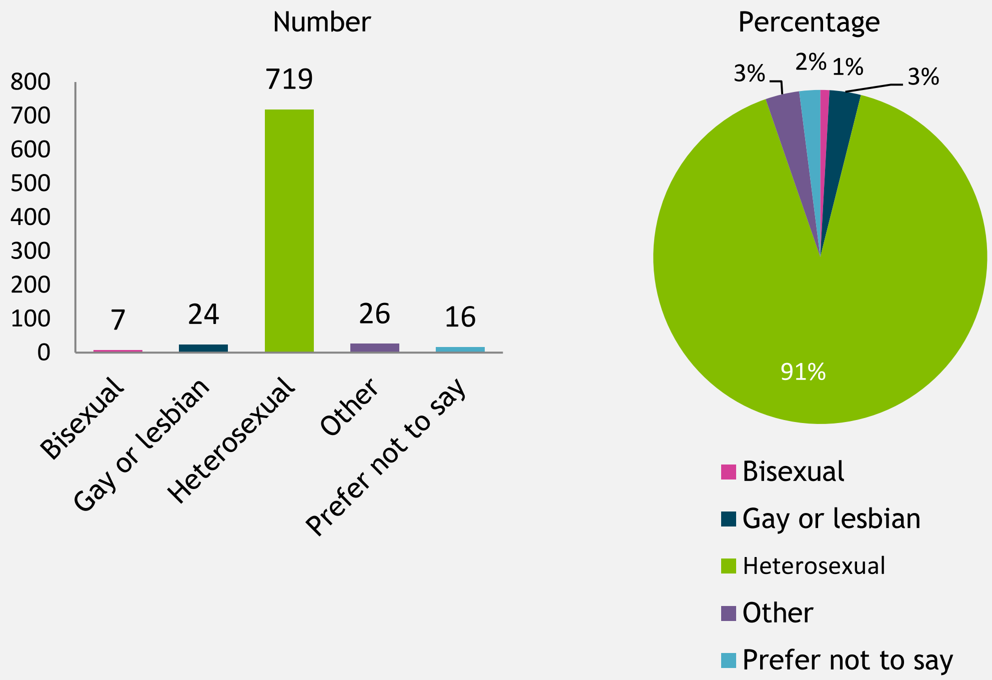
Known responses: 846

Do you have a long term health condition?



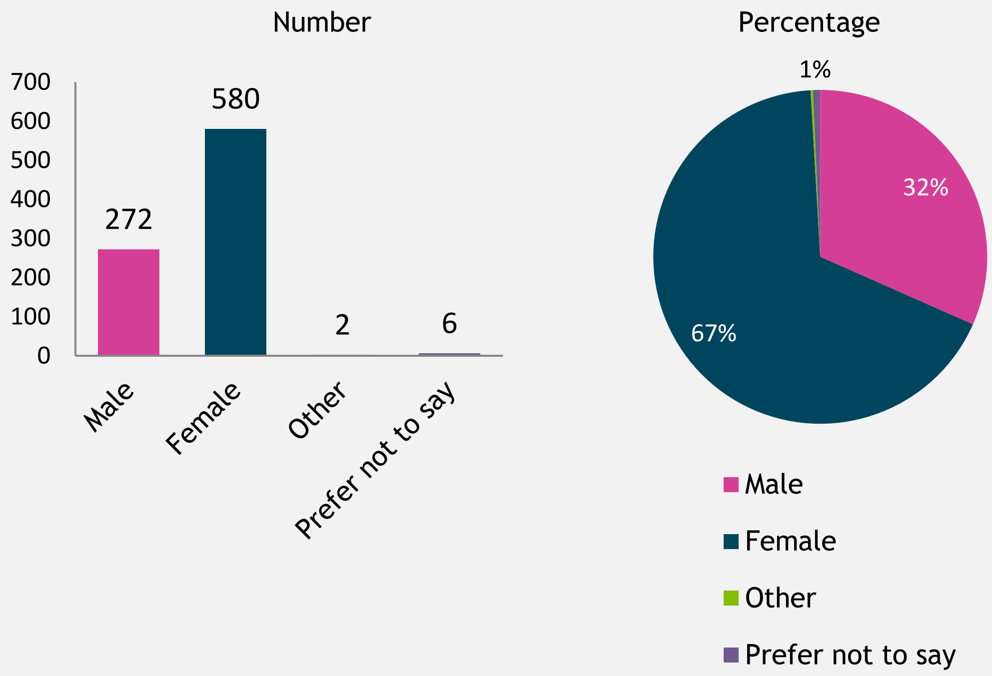
Known responses: 495

Sexuality



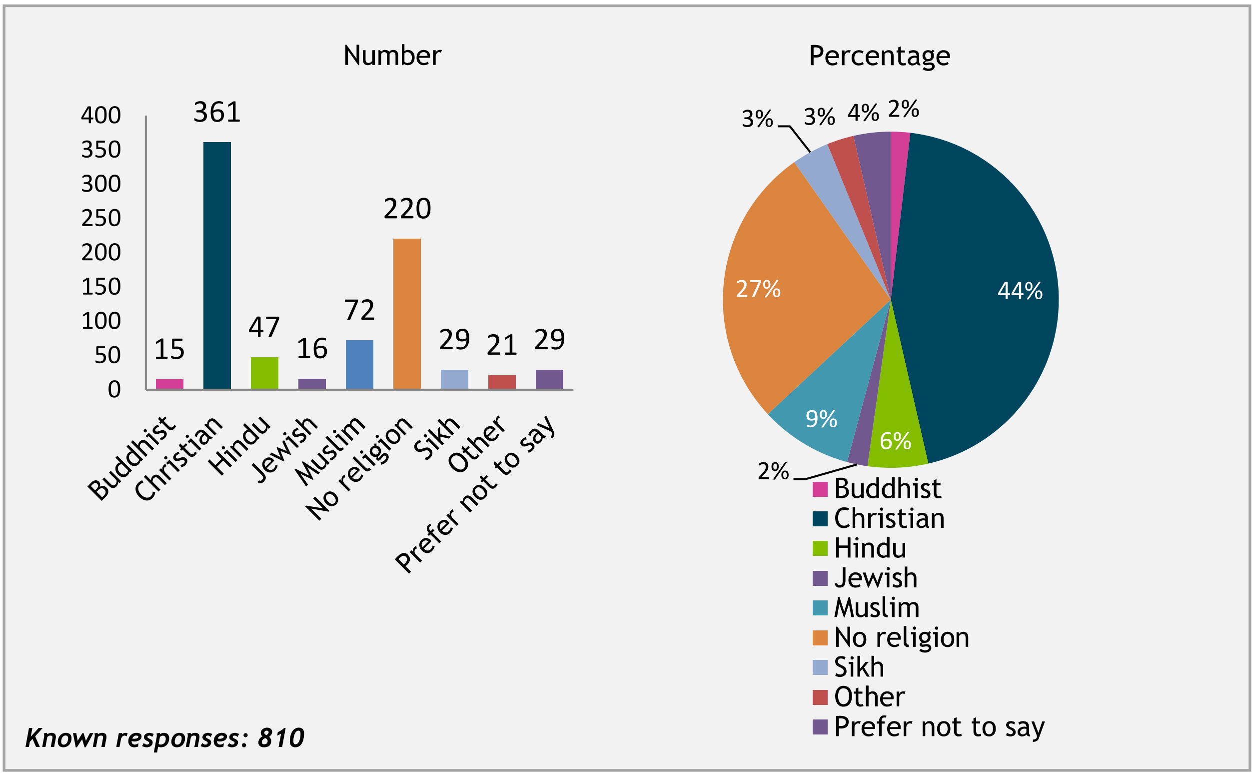
Known responses: 792

Gender



Known responses: 860

Religion



Known responses: 810

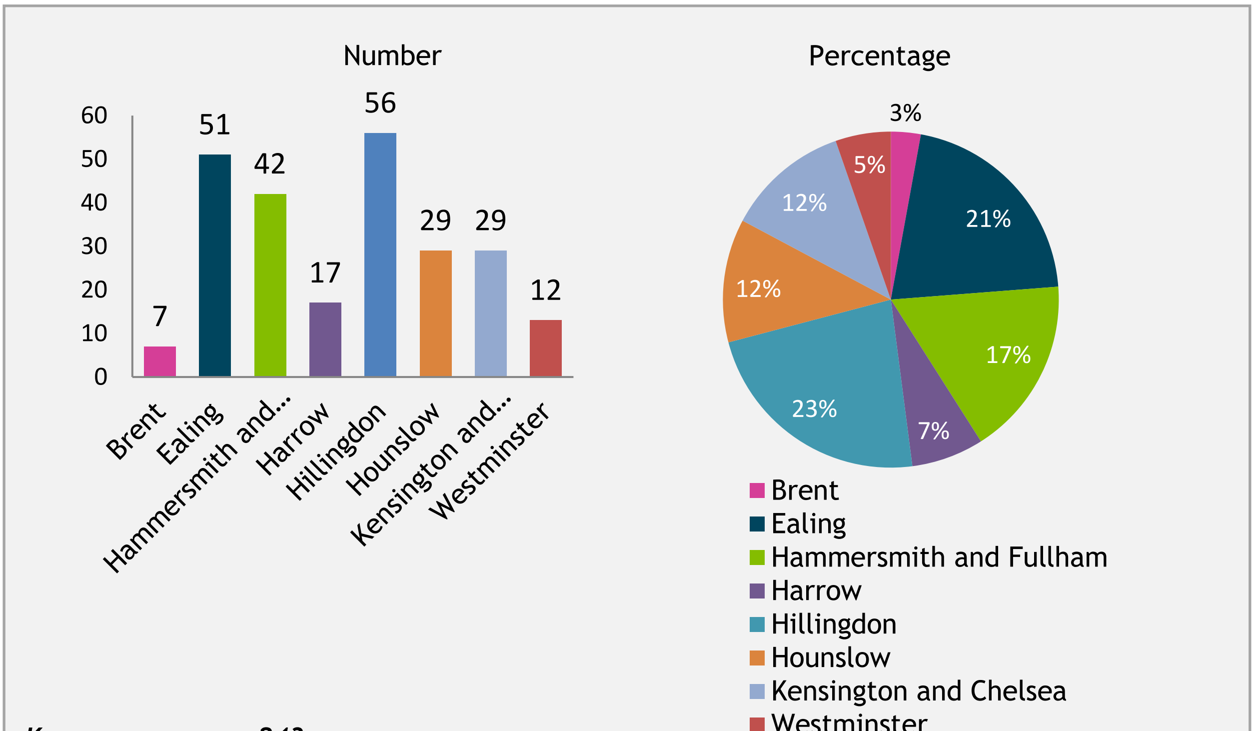
Long Term Conditions Survey

The long term conditions survey looks primarily at these areas:

- Waiting times - from diagnosis and referral to long term support.
- Levels of support.
- Travel and transport.
- Preferences (waiting for your preferred doctor, or seeing somebody else sooner).
- Levels of support required to stay healthy.

It was completed by 243 people who live in North West London:

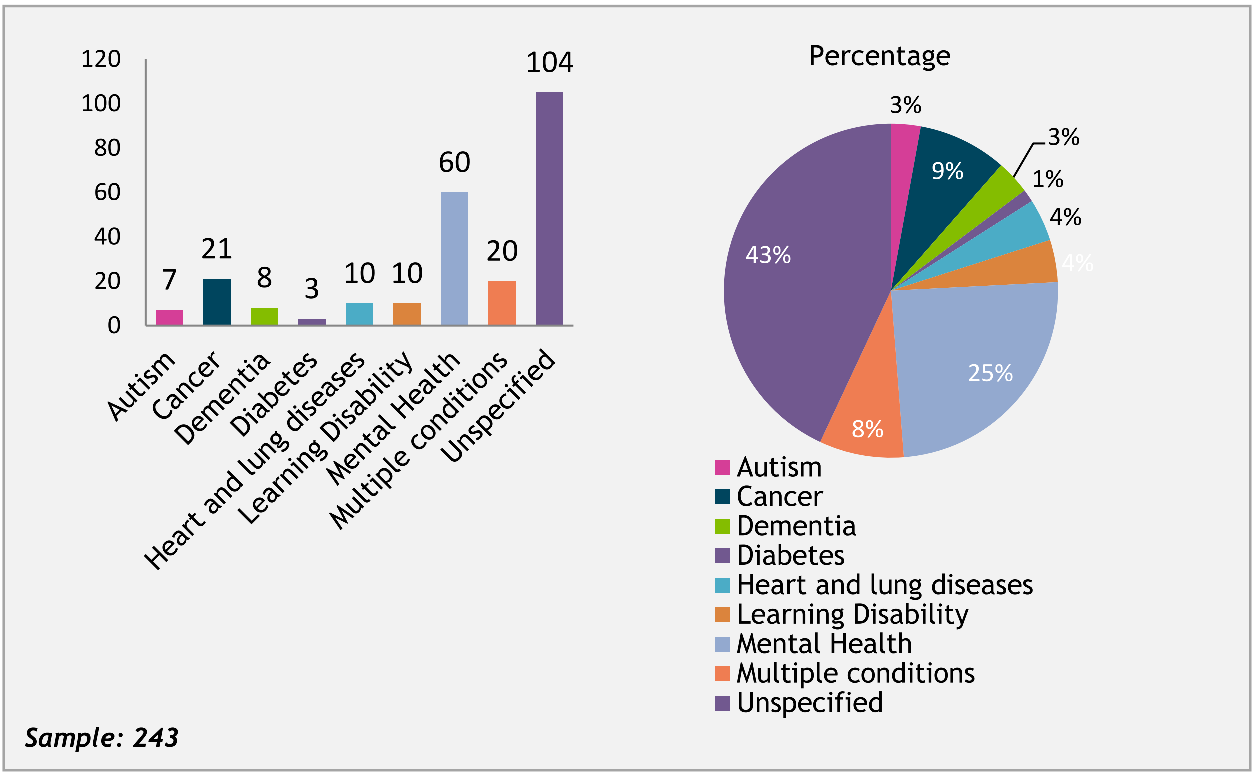
London Borough



Known responses: 243

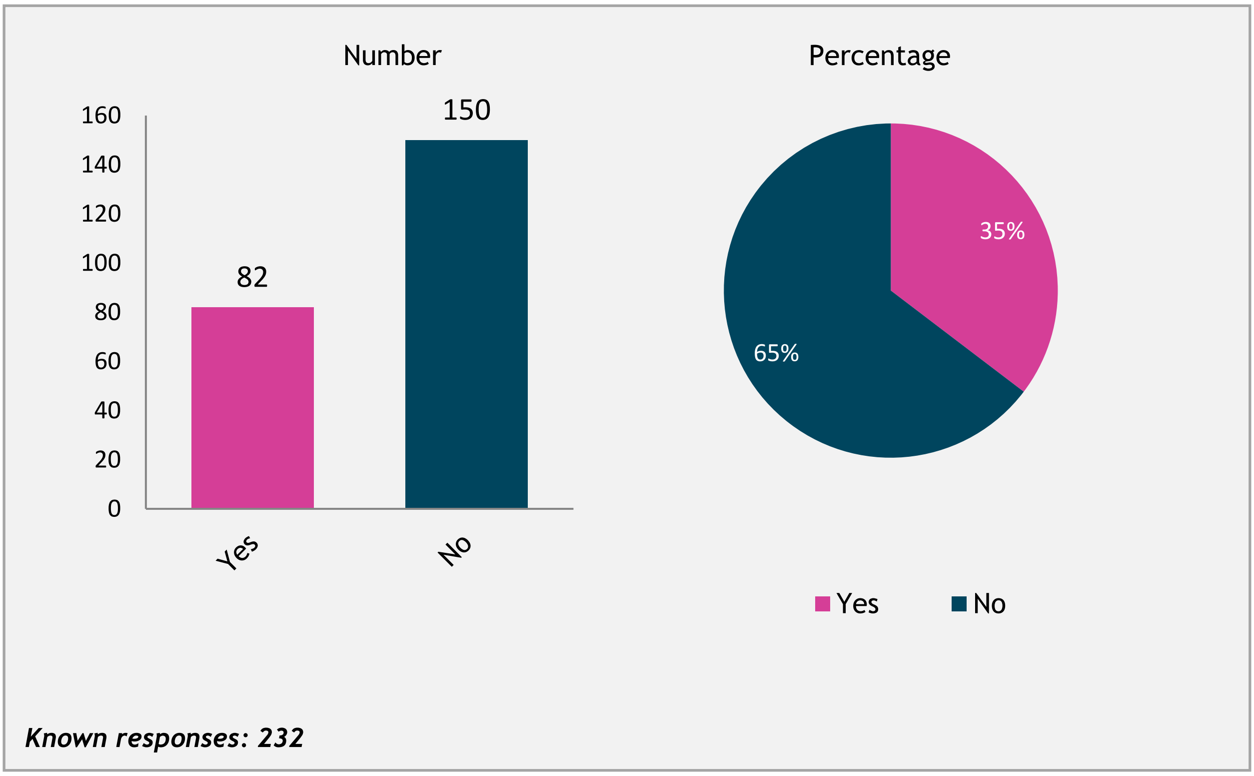
In the next section we show the survey results.

Which condition would you like to tell us about?



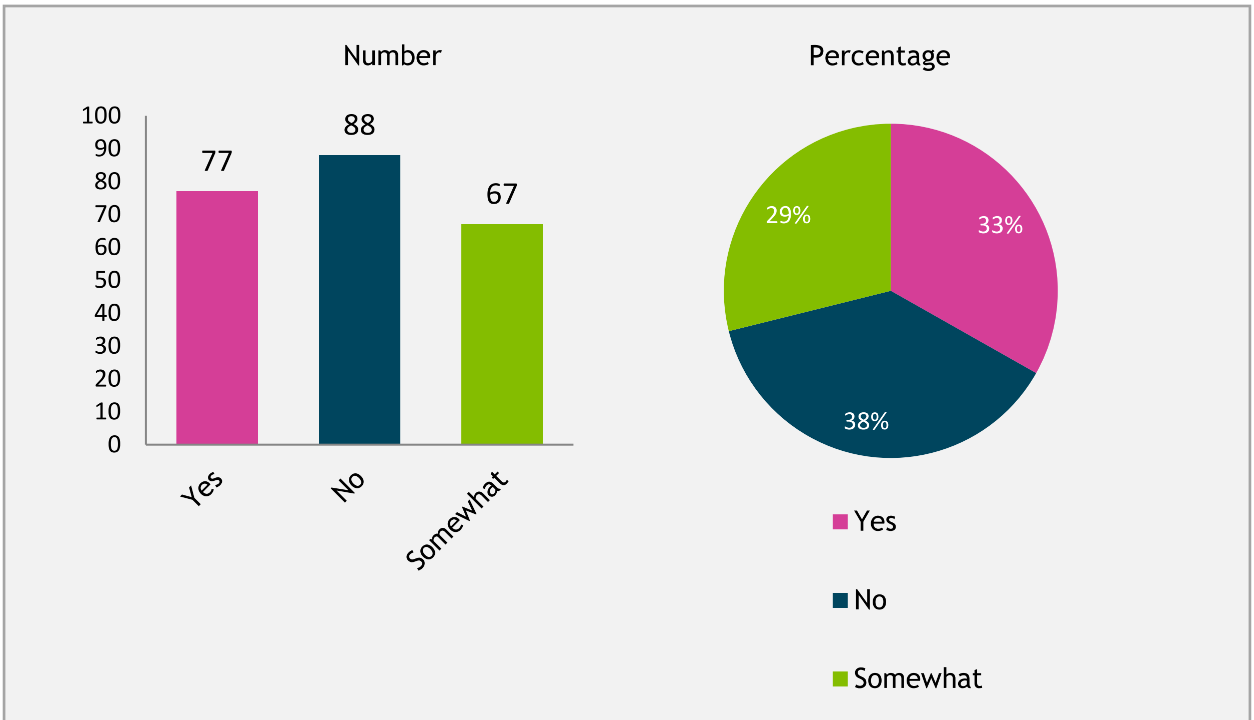
Sample: 243

Has the condition you are telling us about started within the last 3 years?



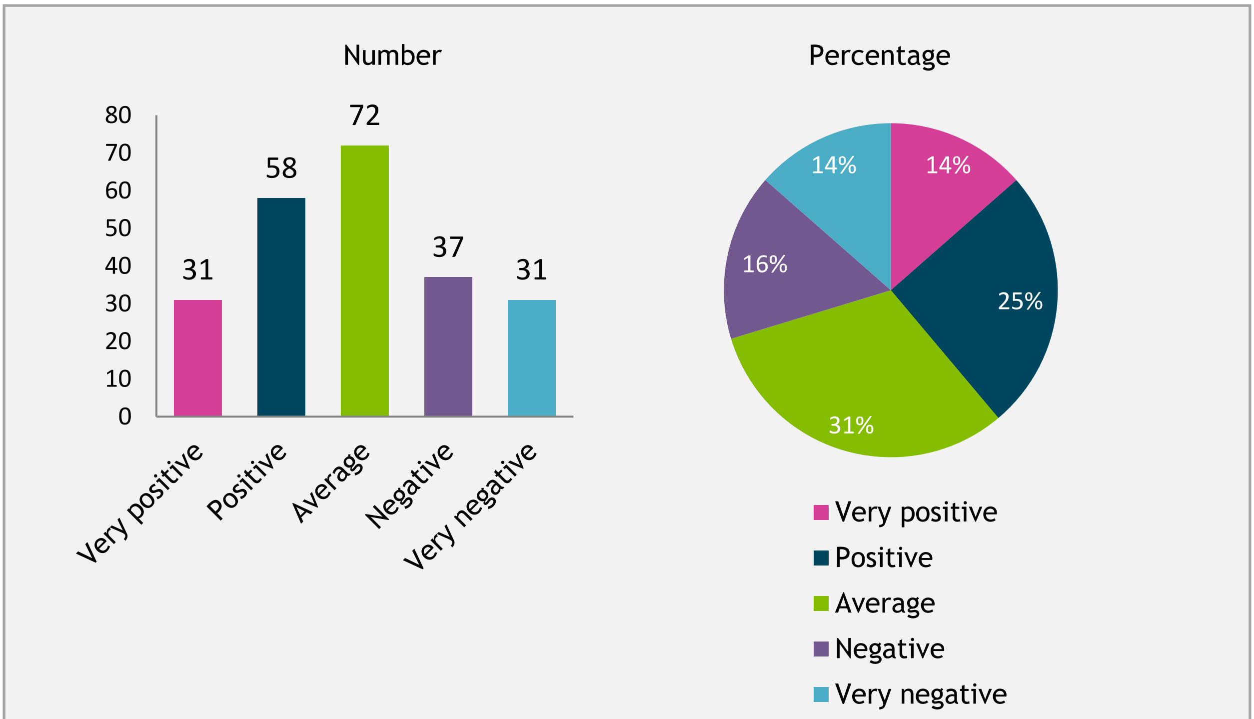
Known responses: 232

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



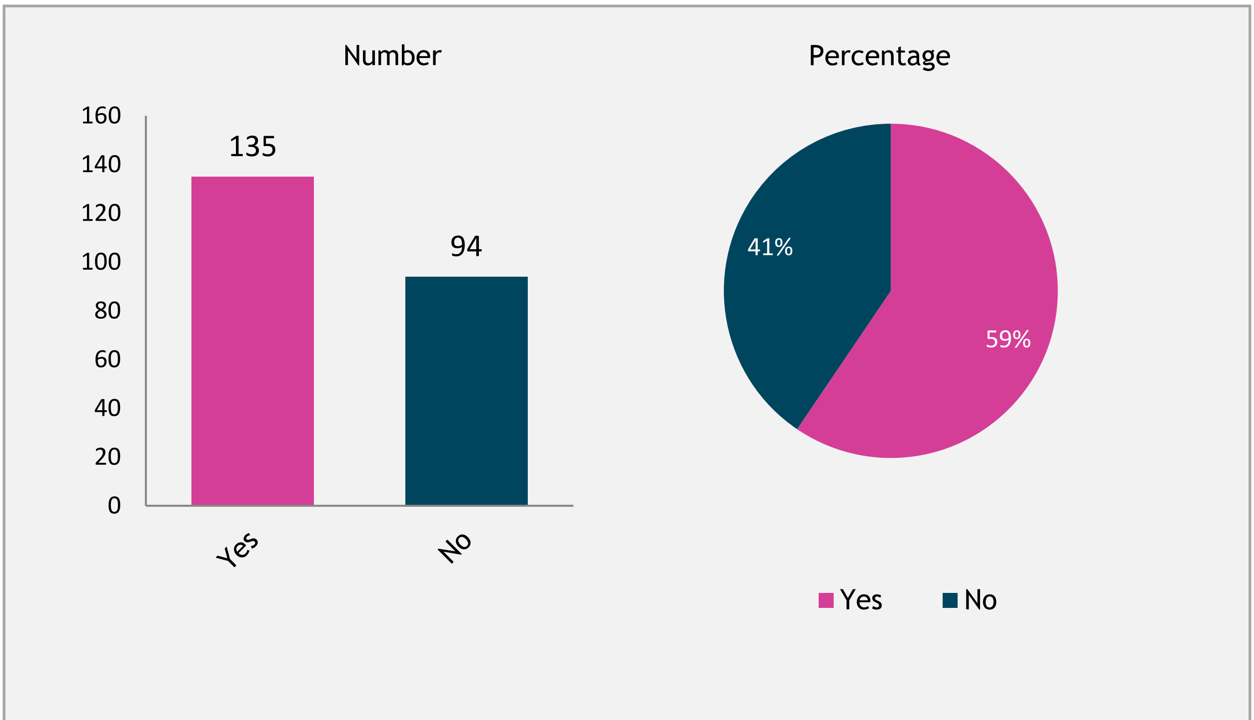
Known responses: 232

How would you describe your overall experience of getting help?



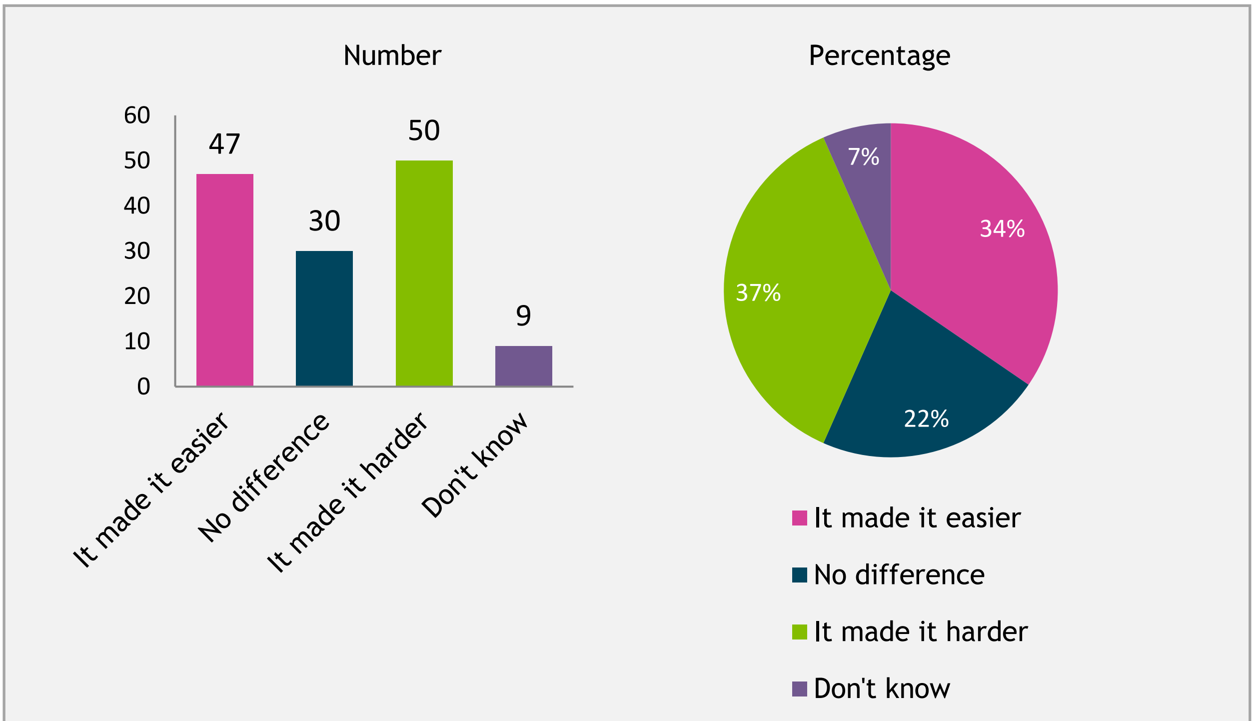
Known responses: 229

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



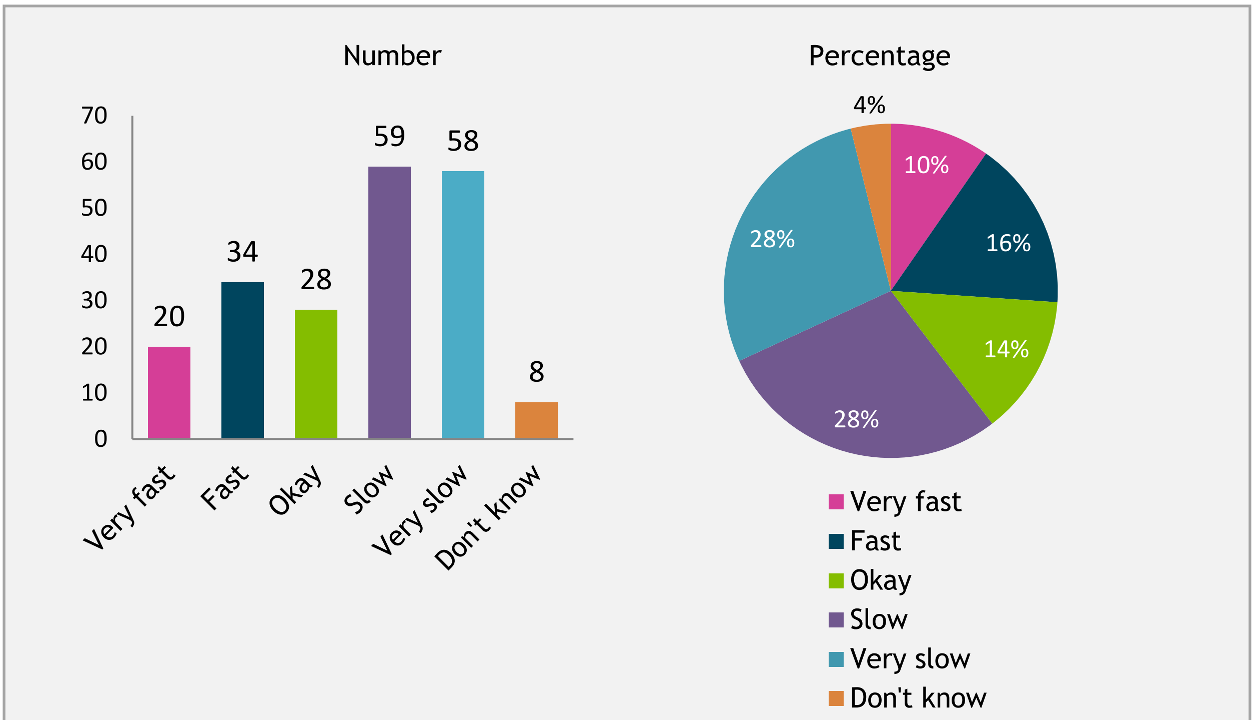
Known responses: 229

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



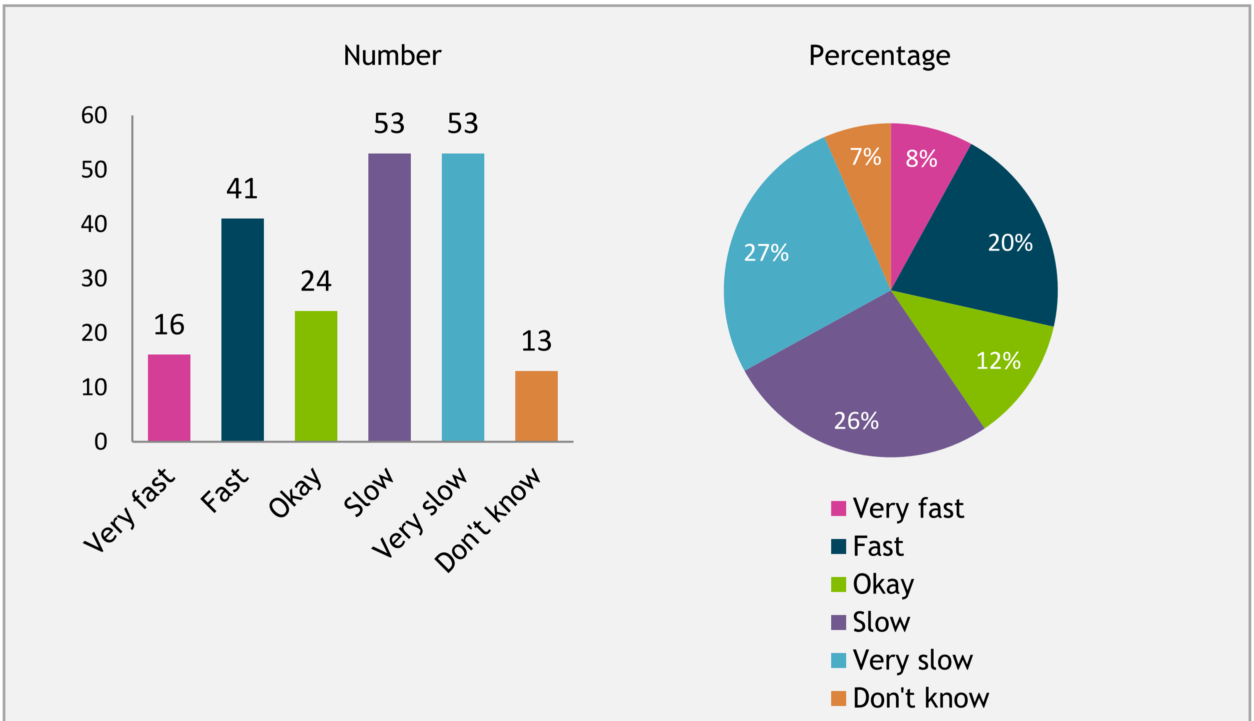
Known responses: 136

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



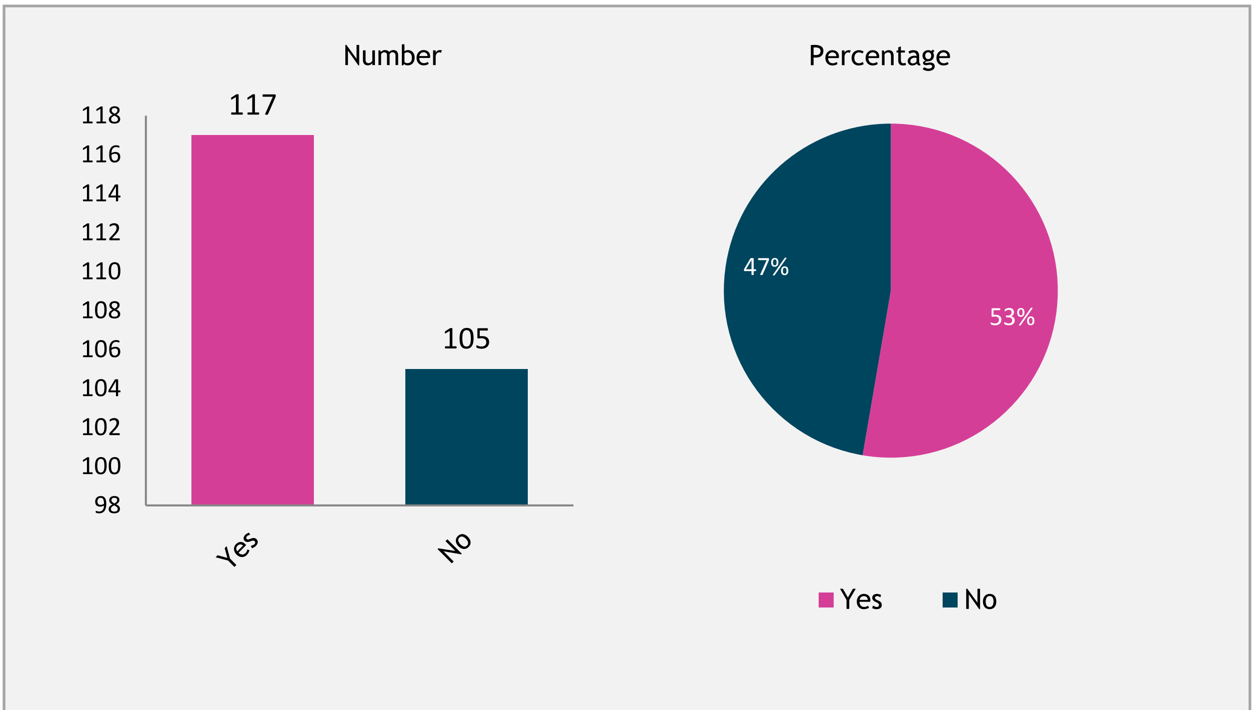
Known responses: 207

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



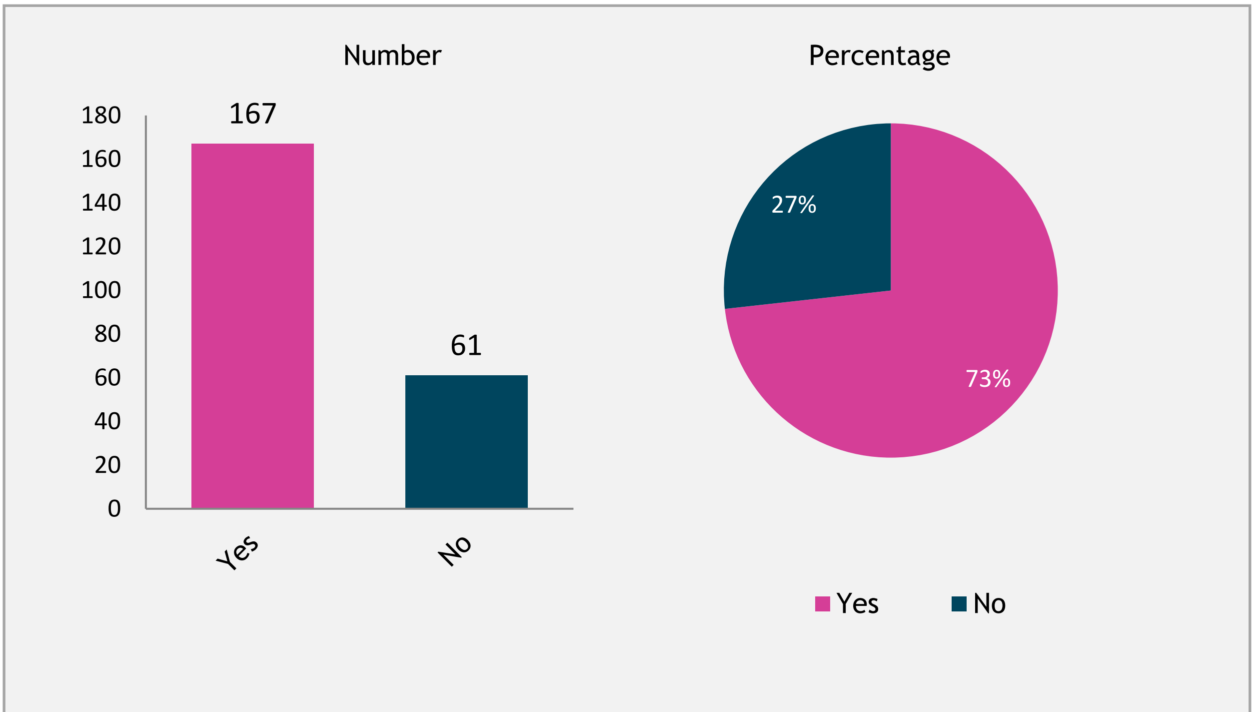
Known responses: 200

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



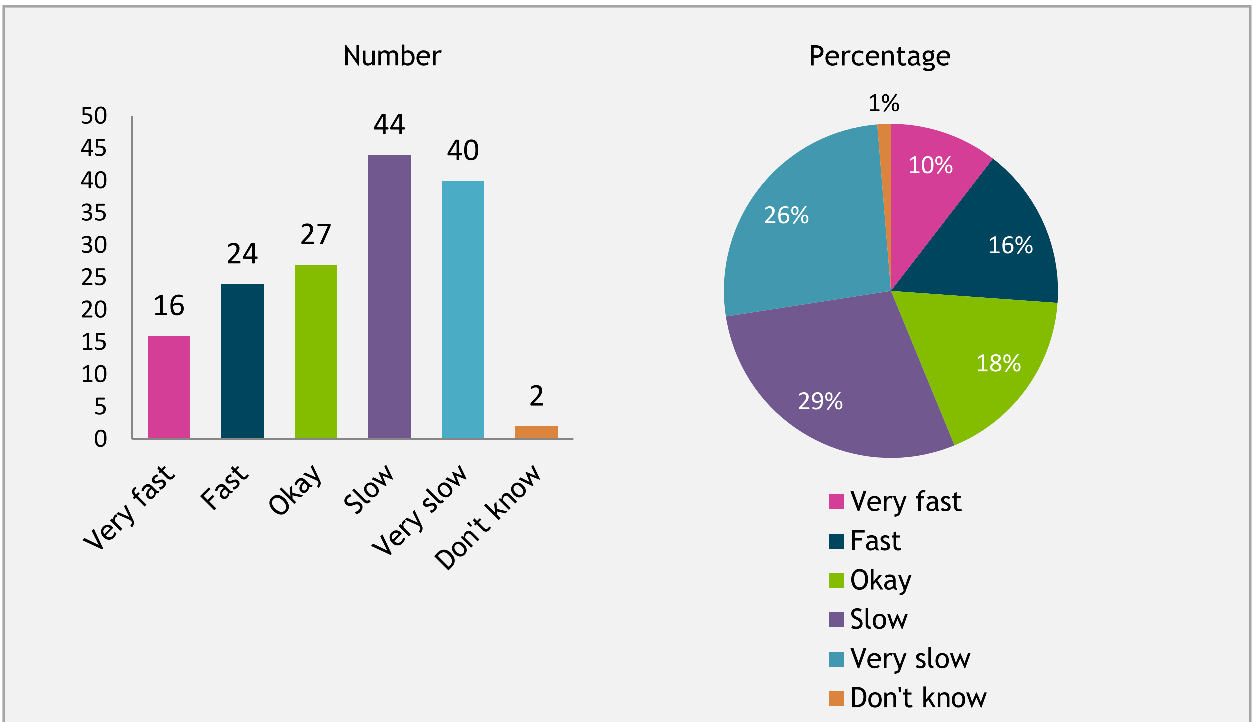
Known responses: 222

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



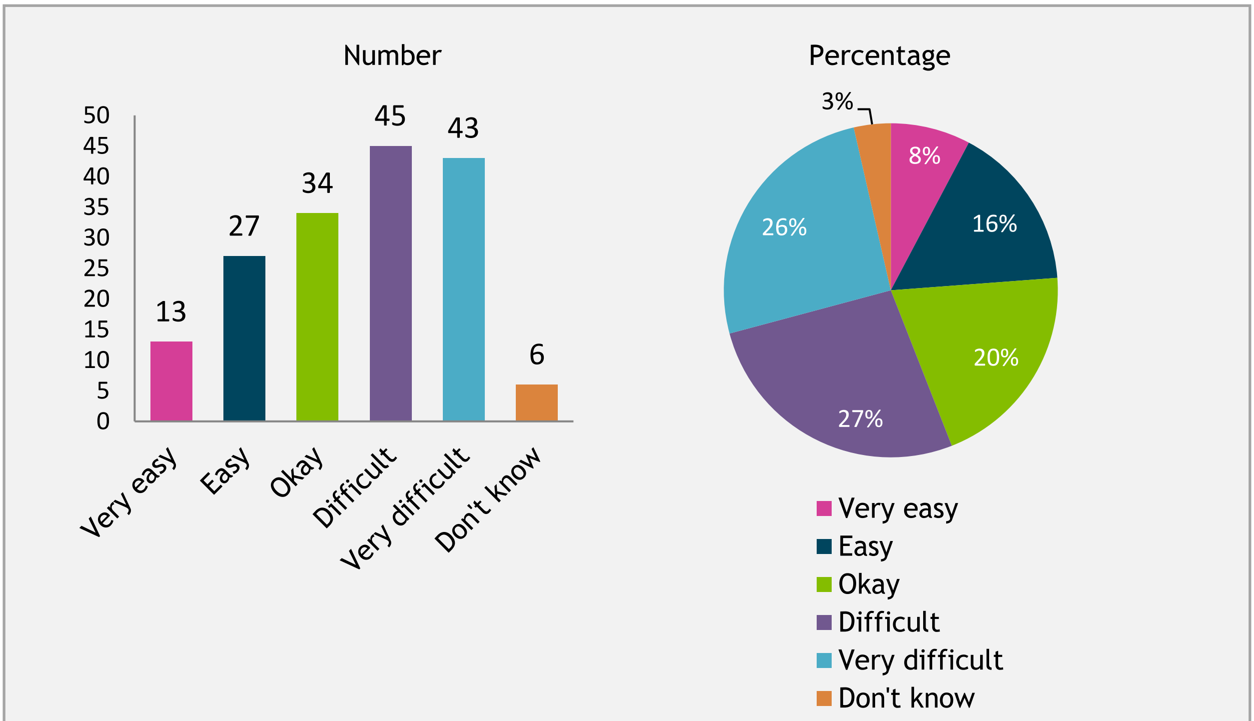
Known responses: 228

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



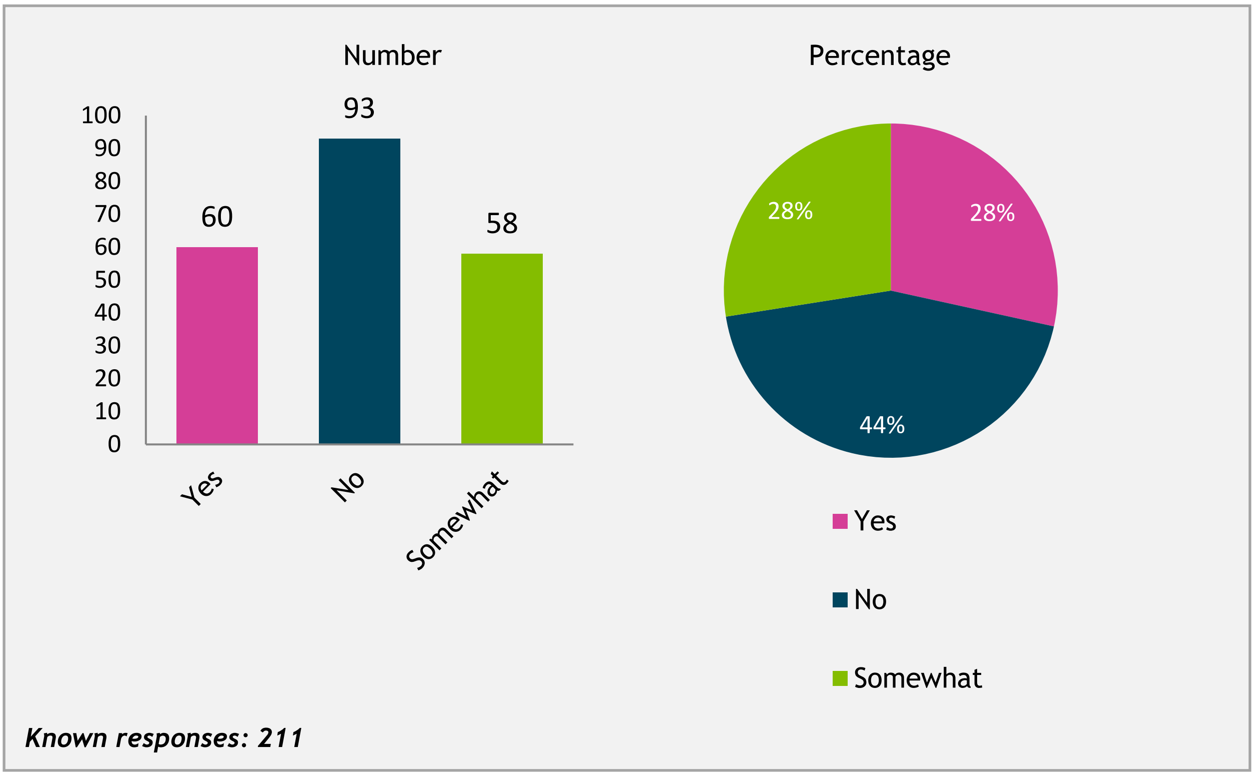
Known responses: 153

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



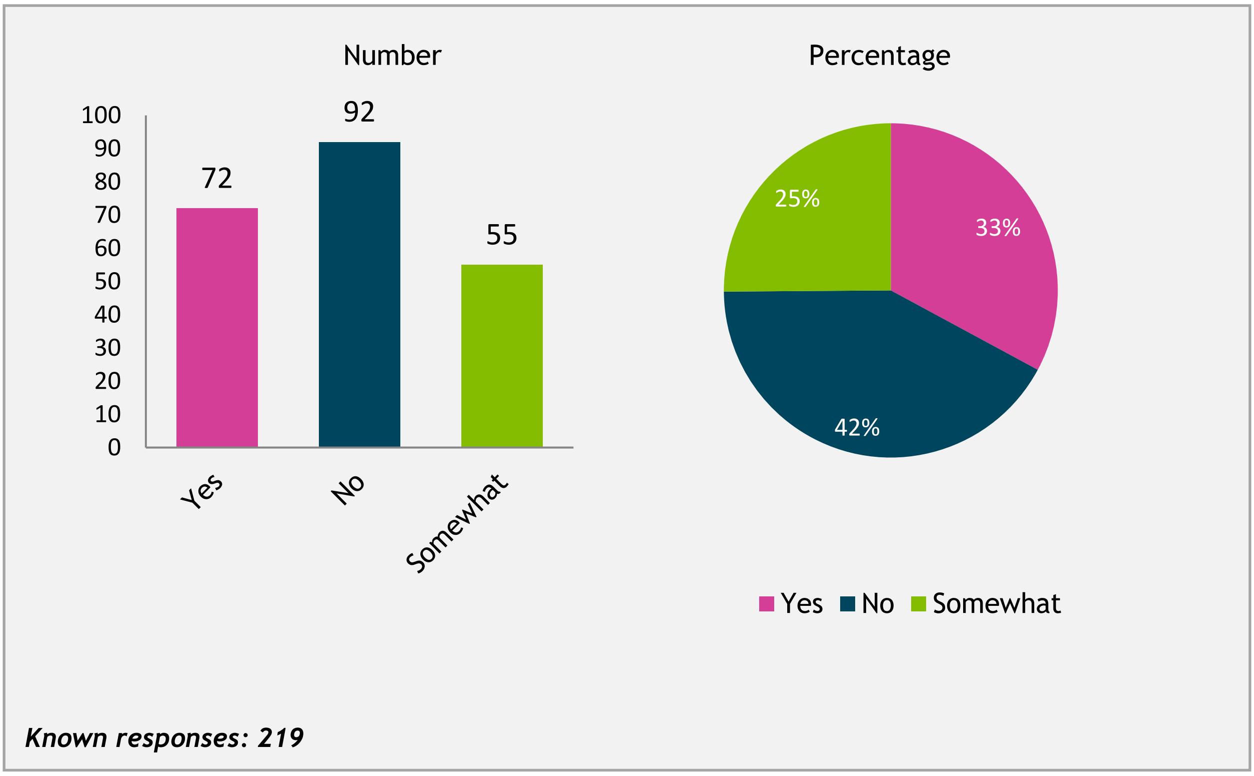
Known responses: 168

Did the support options you were offered meet your expectations?



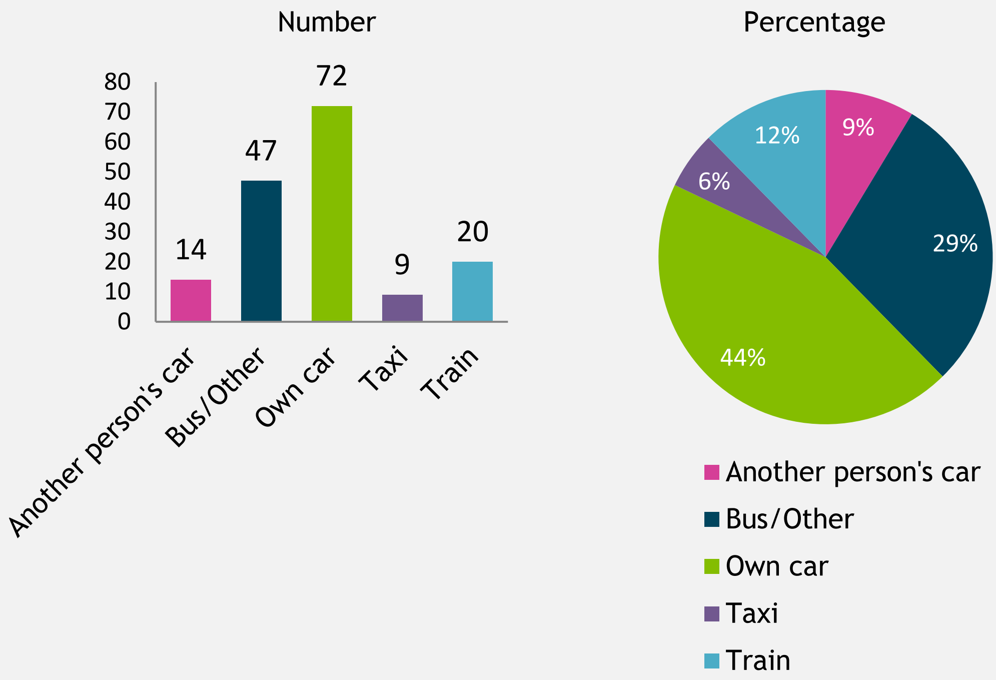
Known responses: 211

During your whole experience of getting support did you receive timely and consistent communication?



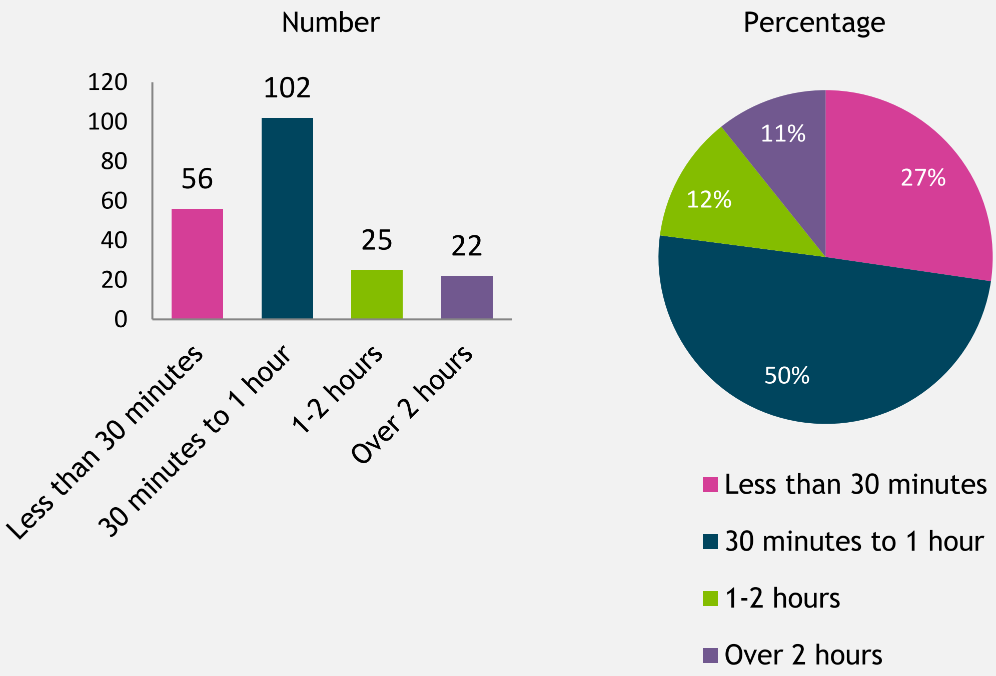
Known responses: 219

What is your main means of transport?



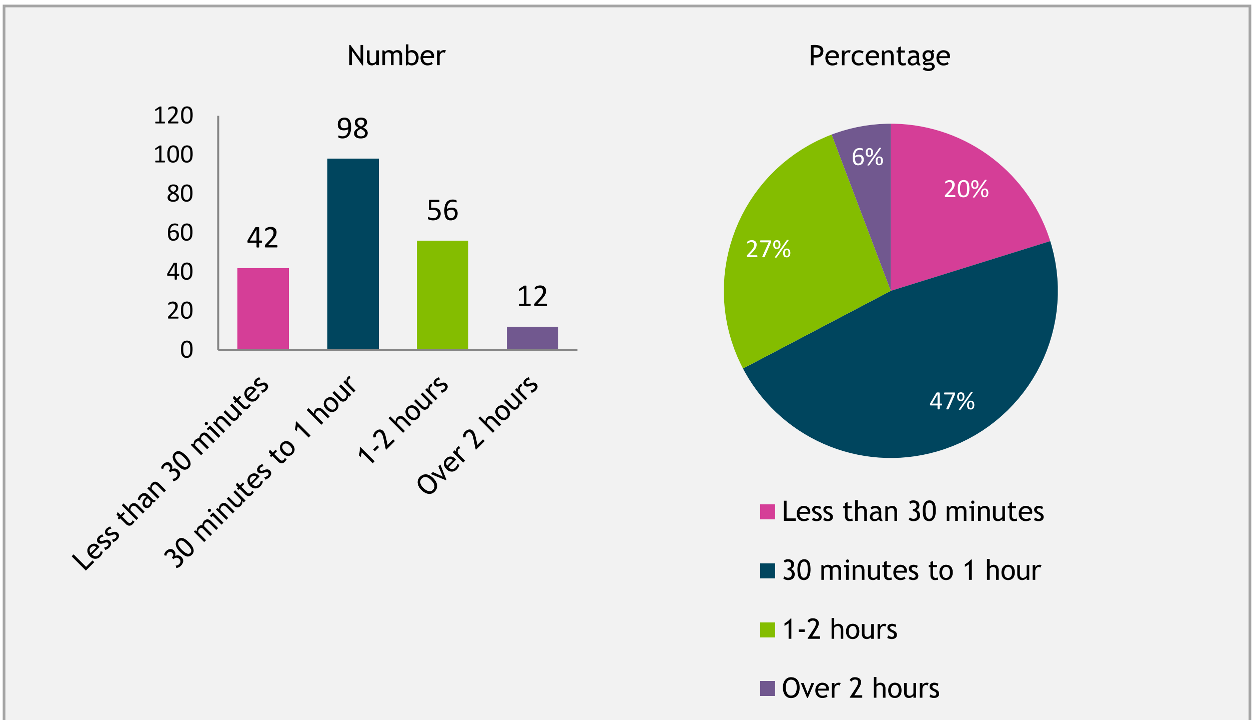
Known responses: 162

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



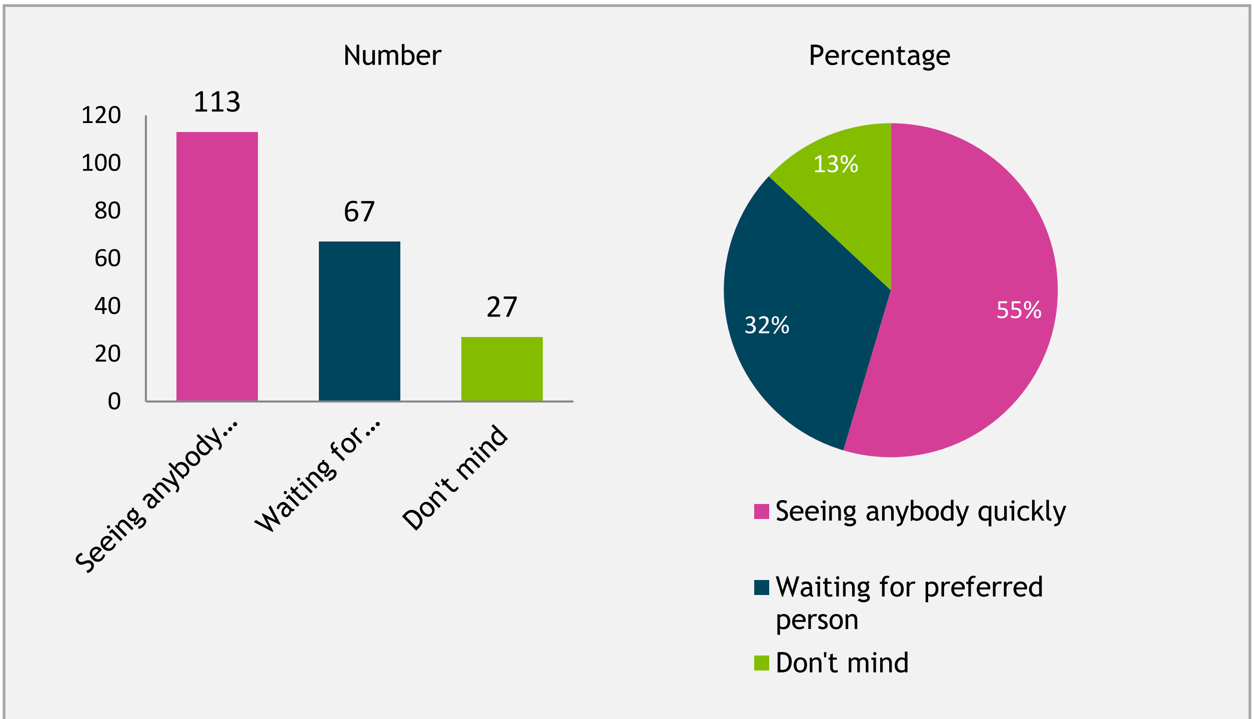
Known responses: 205

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



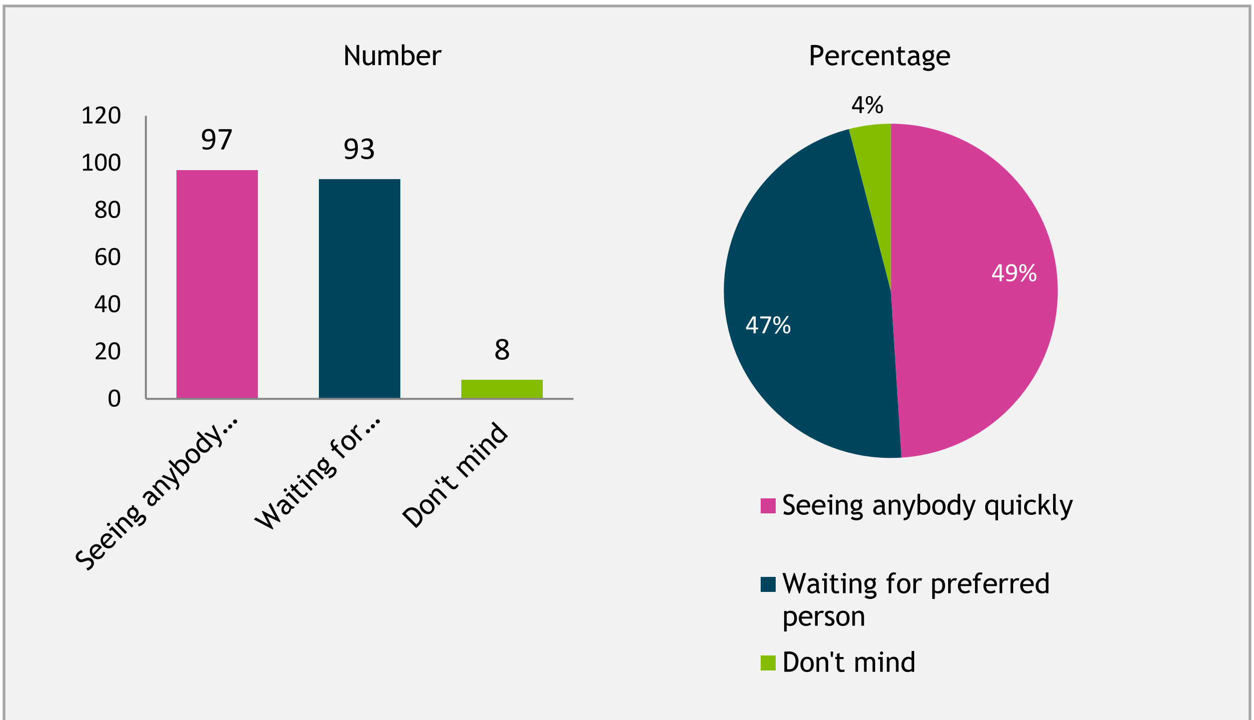
Known responses: 208

What is most important to you - when first seeking help?



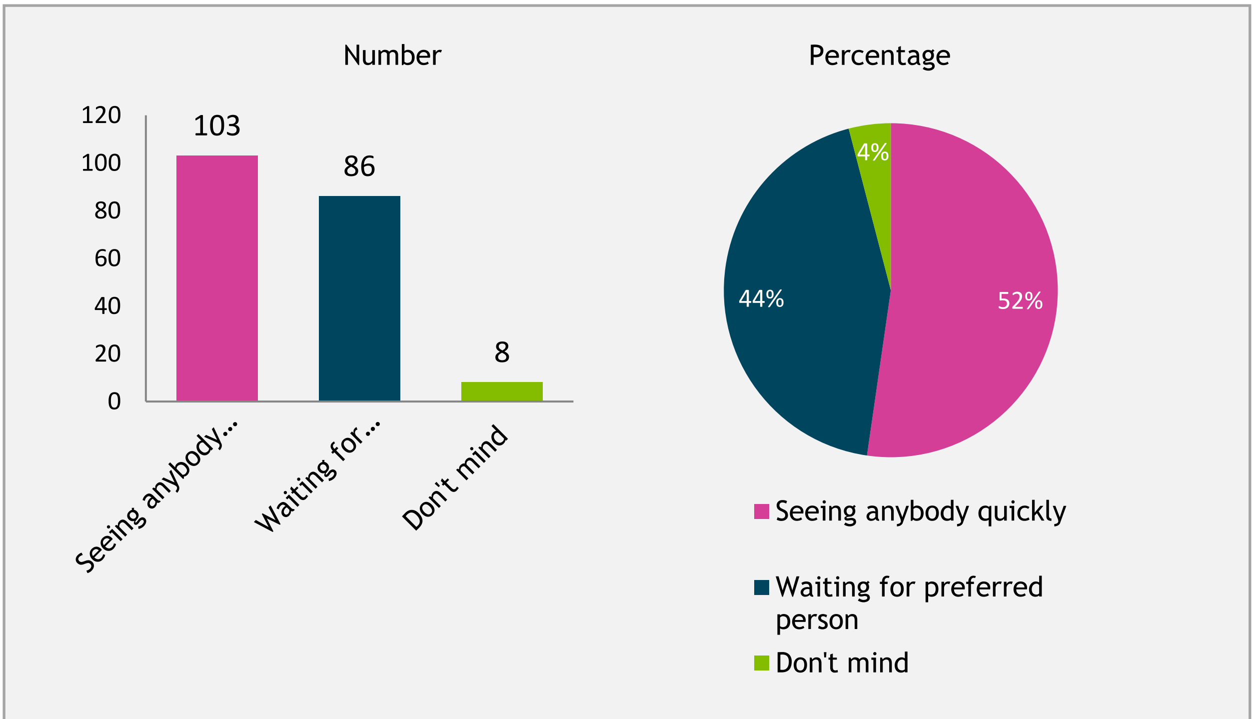
Known responses: 207

What is most important to you - when you received a diagnosis and explanation of treatment and support options?



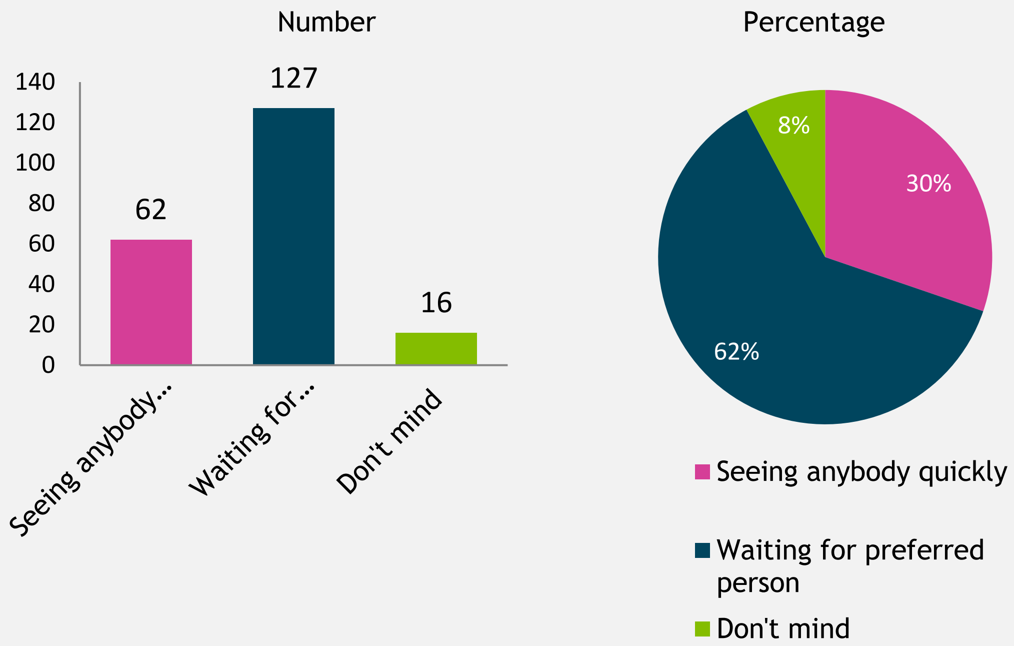
Known responses: 198

What is most important to you - during your initial treatment or support?



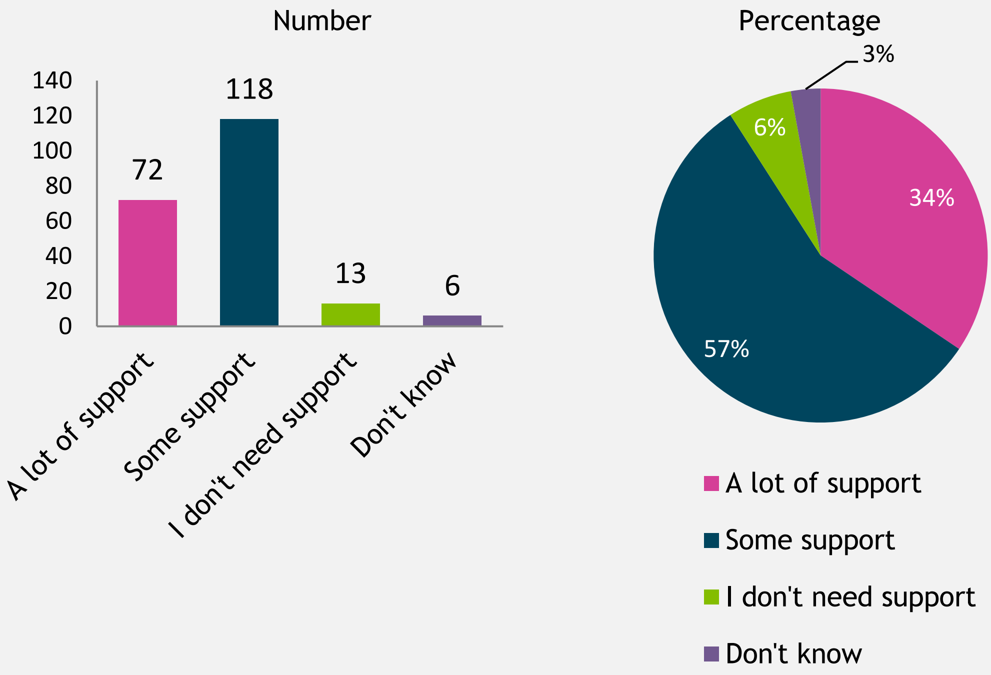
Known responses: 197

What is most important to you - during your long term support?



Known responses: 205

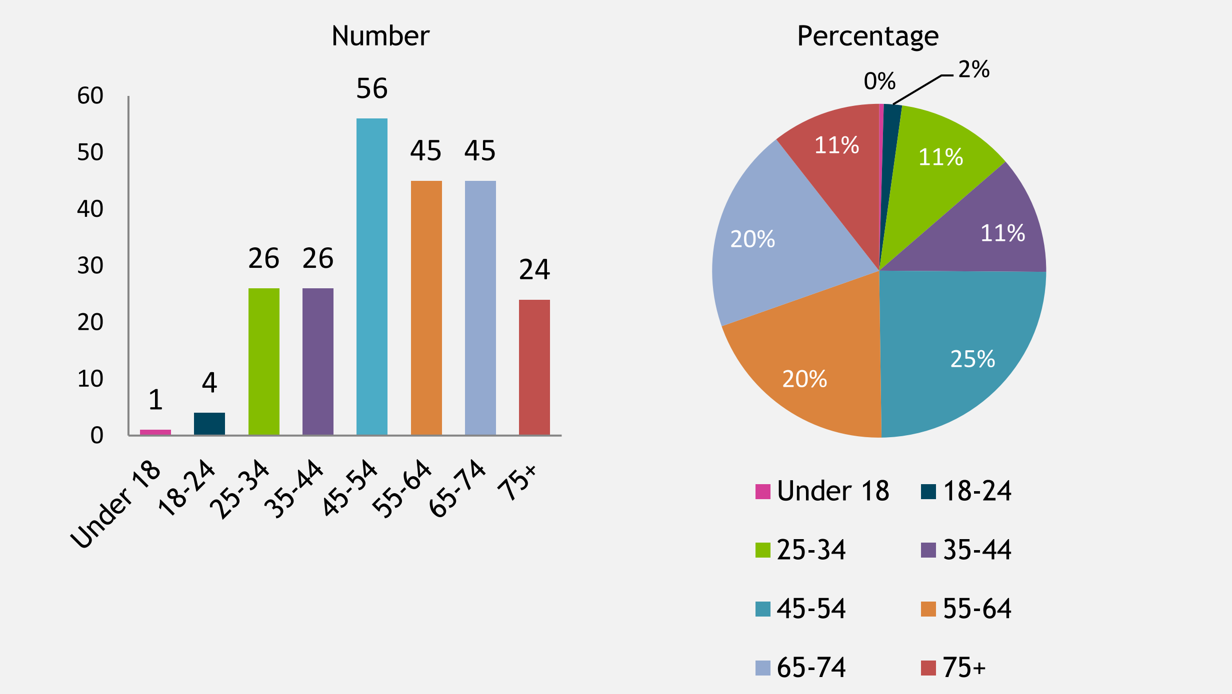
What level of support do you want the NHS to provide to help you stay healthy?



Known responses: 209

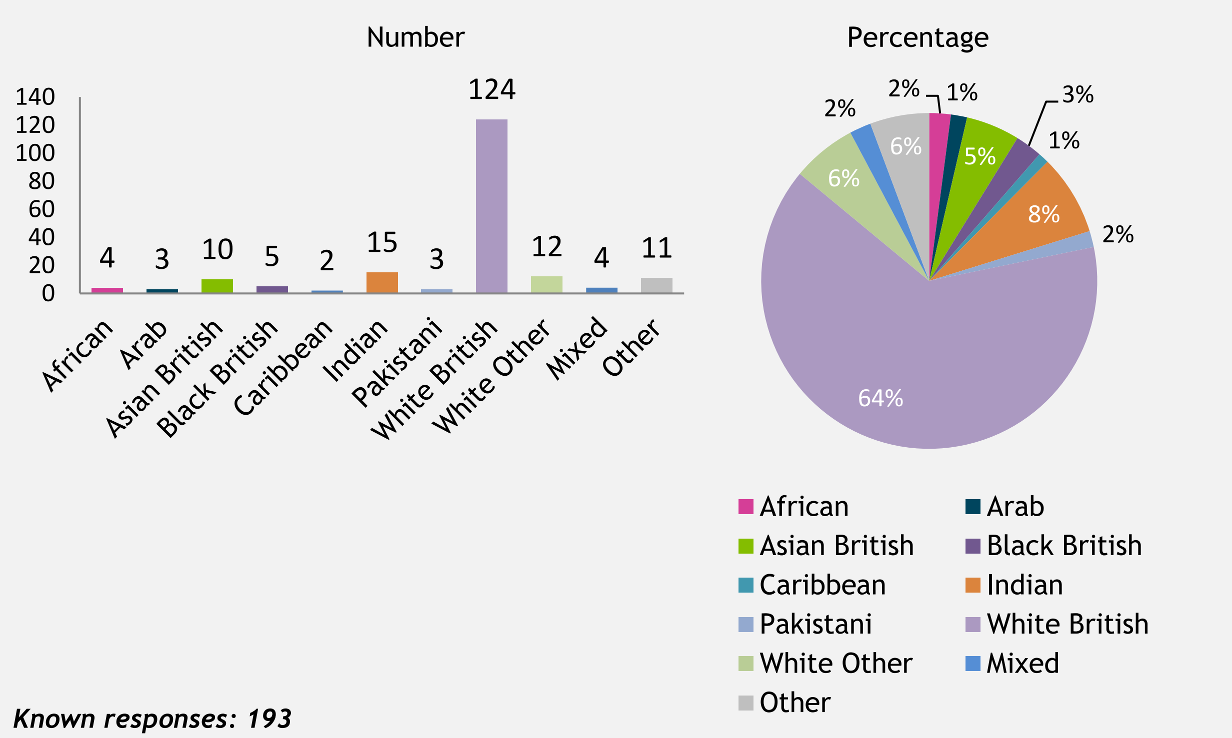
Demographics

Age



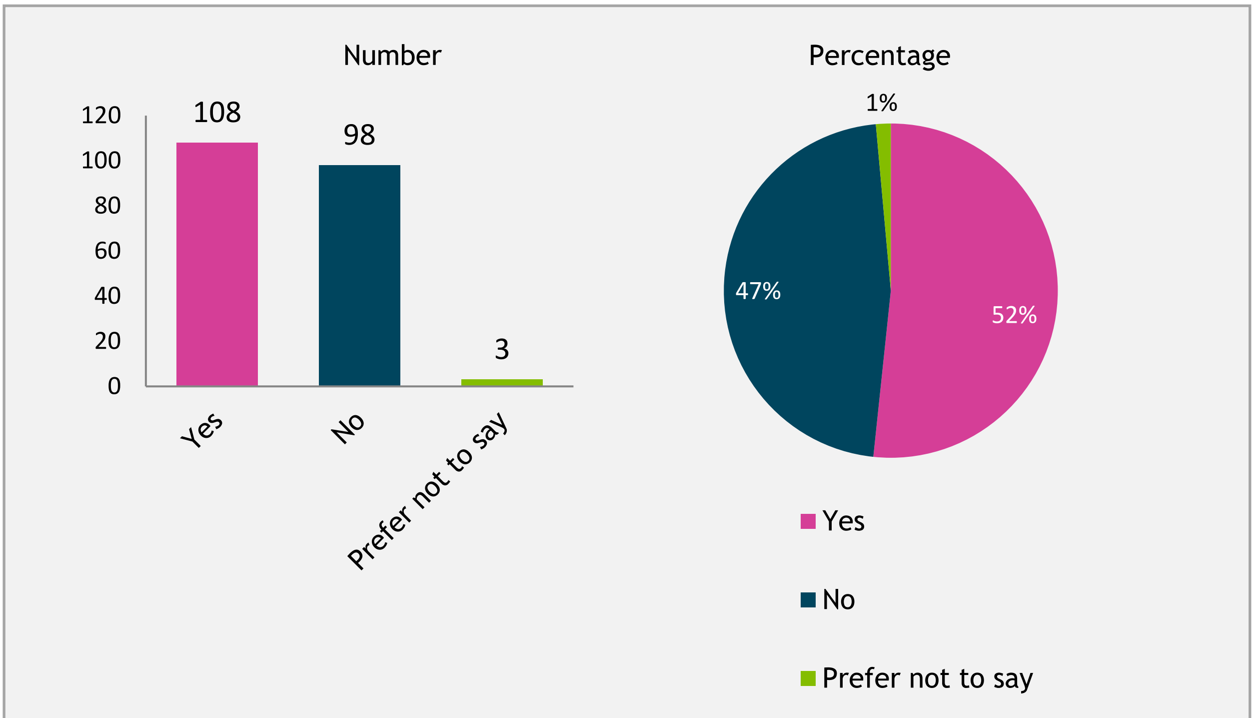
Known responses: 227

Ethnicity



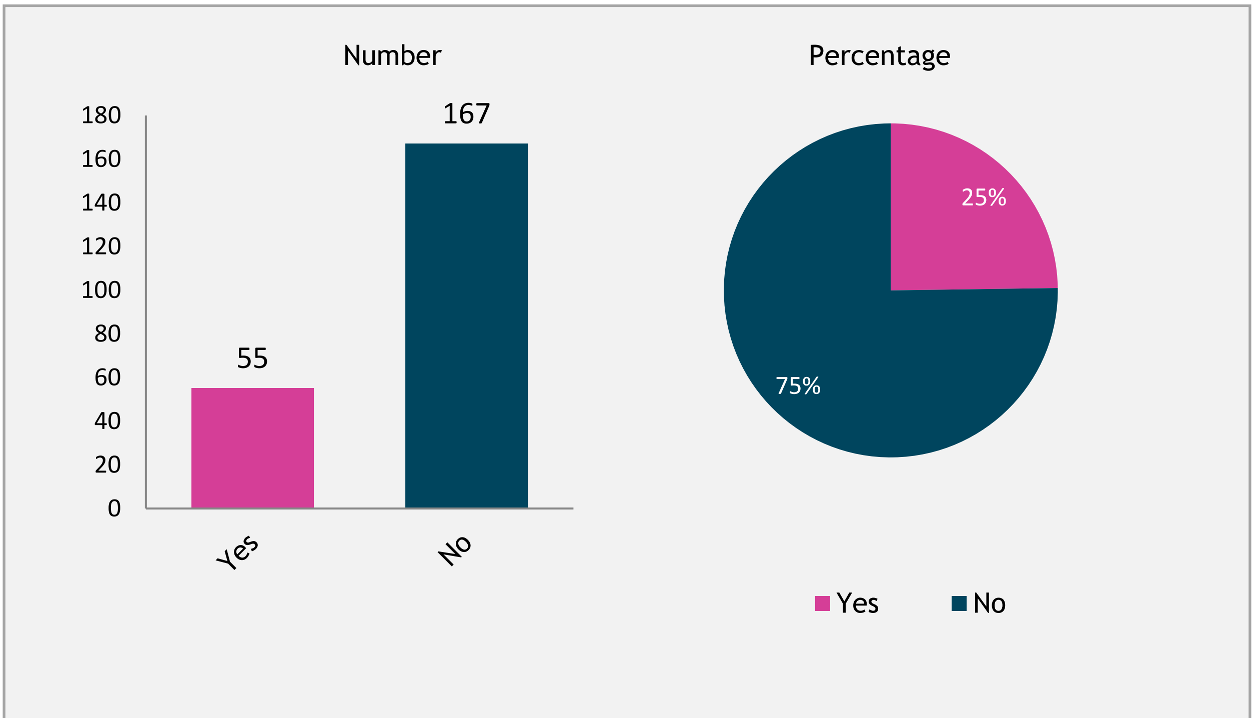
Known responses: 193

Do you consider yourself to have a disability?



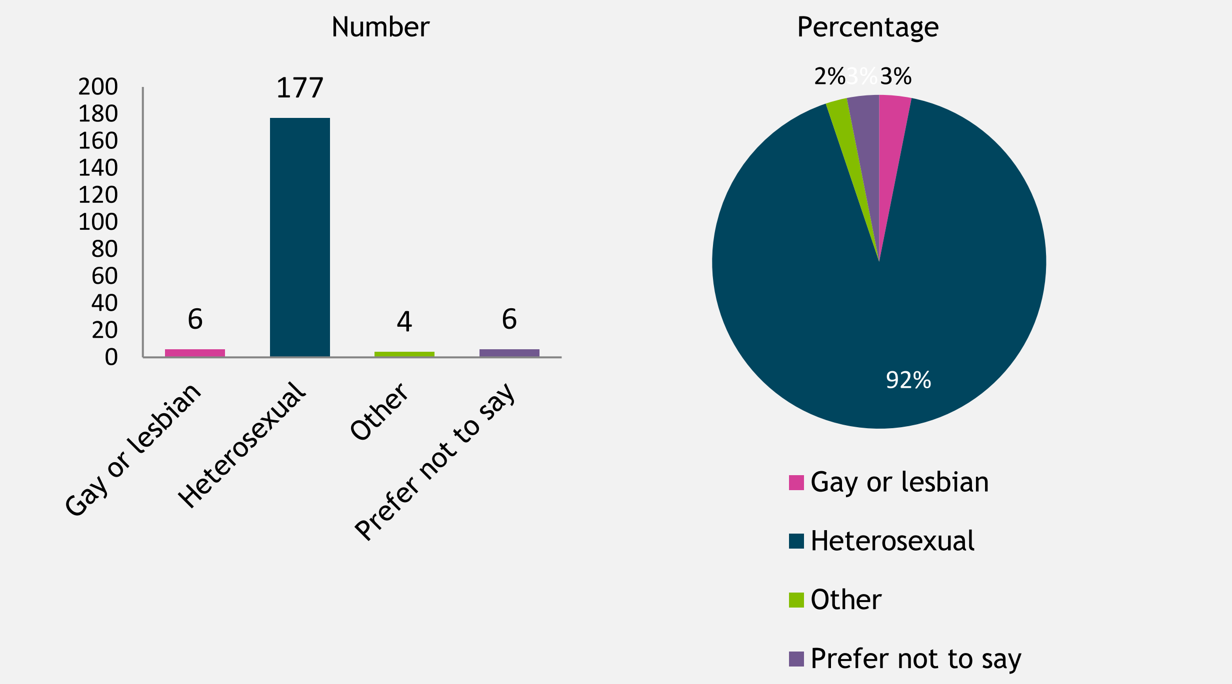
Known responses: 209

Are you a carer?



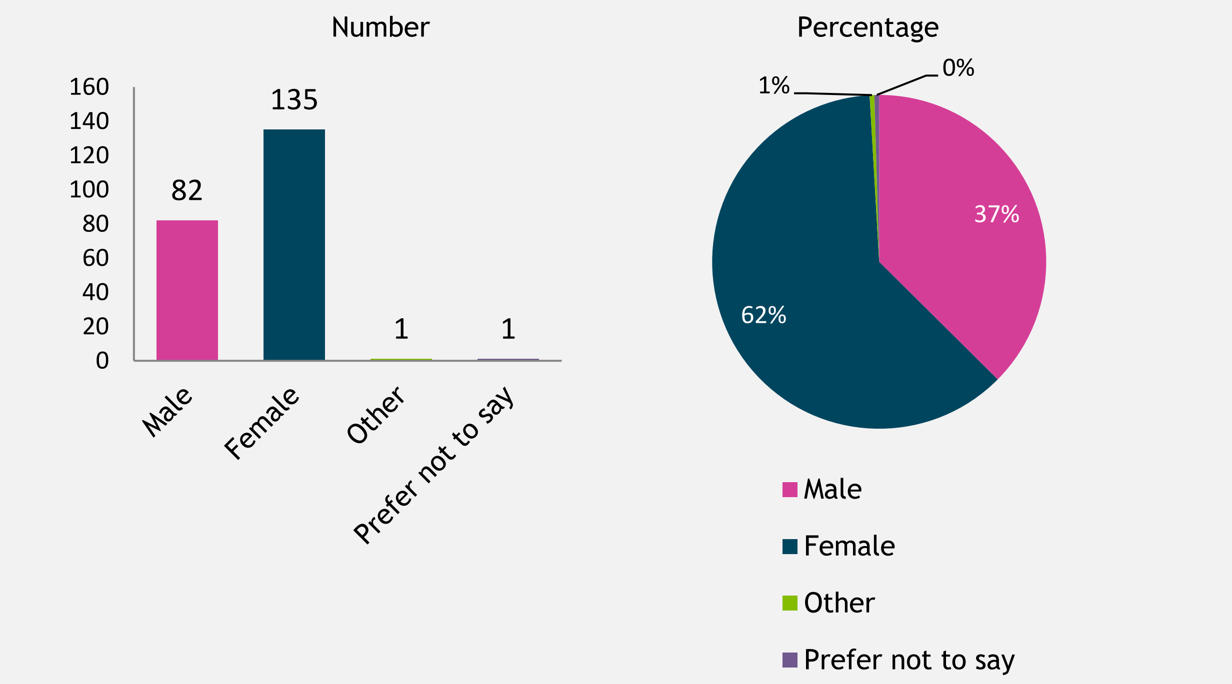
Known responses: 222

Sexuality



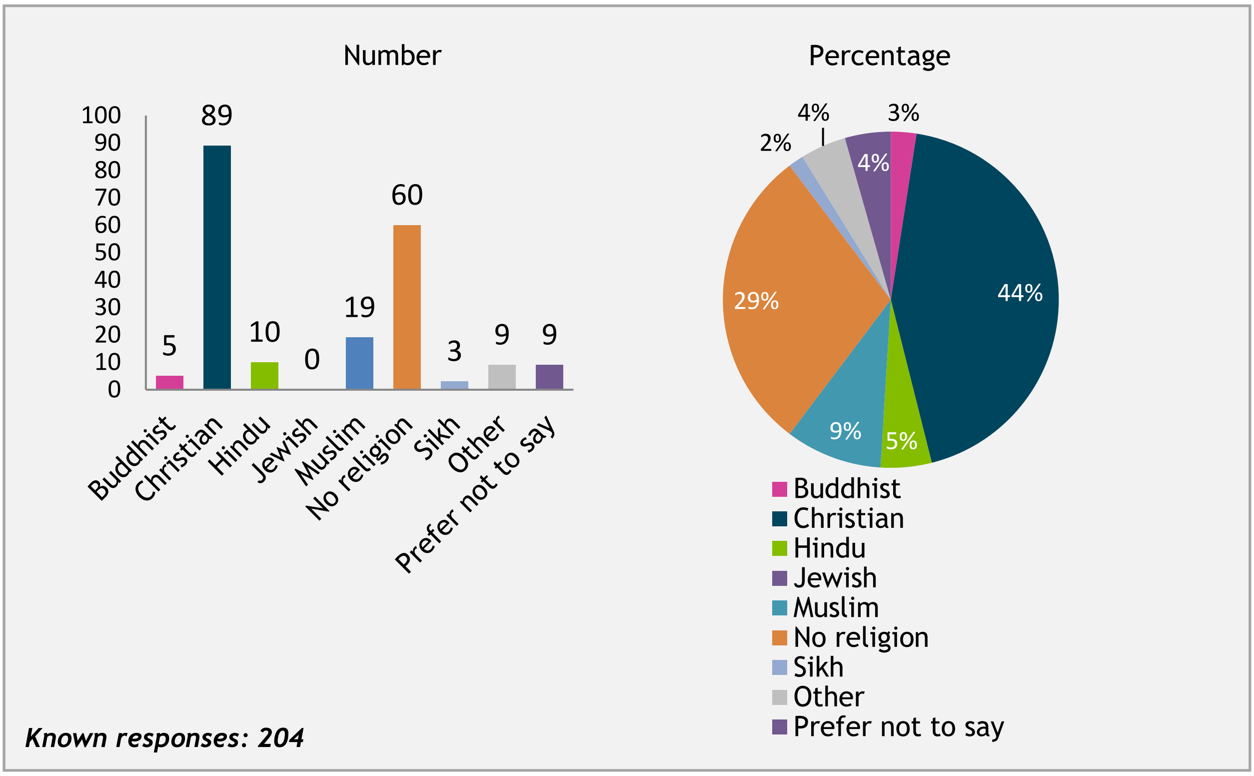
Known responses: 193

Gender



Known responses: 219

Religion



Known responses: 204