healthwatch

NHS Long Term Plan

Engagement Report

An insight from people in Lancashire

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what would you do?

It's your NHS. Have your say.

Project Summary

This project provided feedback from the public about their views and recommendations on the NHS Long Term Plan. The Long Term Plan sets out what the NHS wants to do better, including:

- making it easier for people to access support closer to home and via technology
- doing more to help people stay well
- providing better support for people with specific or long term conditions including cancer, mental health conditions; heart and lung diseases; long-term conditions, such as diabetes and arthritis; learning disabilities and autism; for people as they get older and experience conditions such as dementia

This report details the findings from Healthwatch Lancashire based on feedback from those that identified as living in the Lancashire Integrated Care Pathway (ICP) footprint. Other reports are available that detail the findings from other Local Healthwatch that are within the Lancashire and South Cumbria footprint.

Each Healthwatch had a target to fulfil the following:

1. Gain feedback from 250 people in each area from two separate surveys. One generic survey gathering general views and one survey for people that have specific or long term conditions
2. Complete two focus groups in each Healthwatch footprint, one at a general group and one at a group for people with specific conditions

For the generic survey, respondents were asked to state how important different components of care were to them, in order to:

- Live a healthy life, such as being able to easily access good quality health care or having knowledge to prevent ill health
- Managing and choosing the support they need, such as making decisions jointly with professionals and choosing where to receive care
- Keeping their independence and ageing healthy such as being looked after at home for as long as possible or friends, family and communities having the knowledge to support them

For the survey which asked questions to people with specific conditions, respondents were asked a range of questions including:

- If the support they have received met their needs
- Their experience of getting help
- Seeking support for more then one condition at a time
- The amount of time to receive initial assessment, diagnosis and treatment

Overall, Healthwatch Lancashire gathered feedback from 225 people: 170 on generic feedback and 55 on specific conditions. The remaining 25 people did not state that they lived in Lancashire and so have been excluded from the findings of this report. Some questions were not answered by respondents and so the number is detailed underneath each chart.

Healthwatch Lancashire engaged with people in two focus group settings, which were a respite care service in Chorley and a friendship group tackling social isolation and loneliness.We also completed a number of more detailed case studies.

Key findings from the generic survey

For all of the questions where the respondent was asked to state how important each statement was to their care, a large majority in each question said that all were very important. Listed below detail those that scored the highest:

- Access to help and treatment when needed and being listened to by professionals when talking about concerns were considered the most important for people to live a healthy life
- Timely communications and choosing the right treatment with health professionals scored the highest for people to manage and choose the support they need
- Ensuring their family are supported if they care for them at the end of life and staying at home for as long as possible scored the highest for people to maintain their independence and age healthily
- In terms of interacting with the NHS, respondents said receiving results quickly scored the highest, followed jointly by having absolute confidence that their personal data is managed securely and being able to access services over the phone or computer
- The majority of respondents said they would use online sources and/or go to their GP/doctor to find out more information about staying well

Key findings from the specific conditions survey

We received over 70 free text comments during the completion of the specific conditions survey, of which there were themes throughout. These included:

- Respondents said they wanted to see more knowledgeable health professions as it was found that many felt they did not know enough about their specific condition to help
- Respondents felt their health condition was not taken seriously, resulting in conditions not being tested and diagnosed
- Carer’s not being offered support
- Difficulties getting results, logging in to the online service Patient Access and incomplete or missing information in medical records
- Health professionals not understanding specific conditions particularly understanding how different aspects of conditions coexist
- Having to travel too far or too often, particularly when their condition may mean their mobility is limited
- People not being informed
- Long waiting lists and inconsistent and vague information
- Support not being offered
- Delays in appointments due to cancellations and a lack of staff
- Having to do own research to find information about their condition and make their own appointments or request referrals to specific departments
- Help treatment and extra support not quick enough sometimes resulting in people paying privately to access care
- More awareness of what treatment is available and if people can self-refer
- More information and signposting to help themselves following treatment
- Inconvenience of appointment times

- Difficulties being taken seriously and being listened to, particularly when they had a diagnosis of another condition. This resulted in people not being offered tests and doing their own research to seek help or information
- People having to wait a long time to be referred or gain an appointment or test result

Most people found the initial support they received did not meet their needs (68% said it did not meet their needs or felt it only somewhat did).

Some people had more than one condition. Of these 17% said receiving support for more than one condition at a time made it more difficult to get the support they needed

Respondents told us that waiting times were slow; 34% said the length of time waiting for their initial assessment or diagnosis was either slow or very slow and 26% said the length of time waiting for treatment following an initial assessment or diagnosis was either slow or very slow. Of those that were offered and saw a specialist, 52% said the length of time waiting to see the specialist was slow or very slow

Half of our respondents said they found it difficult or very difficult to access ongoing support after being diagnosed or assessed and 77% said the support they received did not meet their expectations . 61% said that throughout the process of getting support, communication was inconsistent and slow

It was more important for respondents to see the same doctor when receiving treatment or long term support, rather than in the initial diagnosis or assessment when respondents were more willing to see anyone. However, a significant number wanted to see the same doctor throughout all.

The feedback gathered throughout both the generic and long term condition surveys and focus groups have raised a number of recommendations from the public about keeping well and changes they would like to see within the NHS.

Recommendations

1. Access to services was one of the main themes identified, including:

- Better use of digital technology to aid a convenient service, although ensuring people that do not have a computer or are unable to use a computer are not disadvantaged
- Shorter travel times
- Inclusive methods to communicate with services and book appointments
- Shorter waiting lists with GPs and specialists
- More eligibility of patient transport
- Care to be delivered at home where possible and for this to be a fast response
- Appointment booking systems to be less restrictive, such as being able to book in advance
- Patient Access to be easier to log in and to improve or expand its content
- Full awareness of treatment options including those available privately
- Improved online health services and information
- Improved, sustainable travel mechanisms, particularly in the ‘hard to reach’ communities
- Quicker access to mental health services for both children and adults

2. Improved outdoor facilities and green spaces to enhance a general sense of wellbeing and also to enable people to use these spaces for leisure activities and exercise

3. Health professionals and services to be more person-centred and caring, including:

- People’s concerns being listened to and respected during appointments
- More time in appointments to get information to look after themselves better
- Taking into consideration the difficulties faced by people with learning disabilities and / or autism when booking appointment and within the appointments, for example, appointment not to be booked at a busy time in a busy environment
- Services to be joined up with continuity of care where applicable, to aid effective transitions and communications
- Improved discharge system from hospital

4. Being aware of self referral options to mental health services, and for these services to be longer and more personalised. We also received comments on a need for more information made available on the mental health condition

5. Easily accessible/easy to understand diet and nutrition information and advice and exercise activities to be cheaper and at a range of times during the day, to support people that work during the day

6. Improved communications, including receiving results to be quicker, clearer and more joined up with other services and service users

7. More awareness on patient choice on where to receive care and for health professionals to support this

8. Improved communities for older people including:

- Access to care and health professionals in the community
- Meals on wheels
- Adapting homes so that people can stay at home safely for longer
- Support with household tasks and how to cook healthily
- Communities to be supportive of older people or people with more complex needs
- Information on support groups in the community individualised to the persons needs

9. More support for carers as well as financial support for families that have to give up work to look after someone. There were also comments about providing more financial support for people living within care homes to avoid spending their saving on necessary care

10. Activities within care homes to be more fun, for the image of care homes to improve and for care staff to be valued and paid accordingly

Background

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

The Government is investing an extra £20bn a year in the NHS. The NHS has produced a Long Term Plan, setting out all the things it wants health services to do better for people across the country. The NHS needs to hear from people about what those changes should look like in local communities.

The Long Term Plan sets out what the NHS wants to do better, including making it easier for people to access support closer to home and via technology, doing more to help people stay well, and providing better support for people with cancer, mental health conditions, heart and lung diseases, long-term conditions, such as diabetes and arthritis, learning disabilities and autism, and for people as they get older and experience conditions such as dementia.

Objectives

Long Term Plan Programme Objectives: The Long Term Plan sets out what the NHS wants to do better, including making it easier for people to access support closer to home and via technology, doing more to help people stay well, and providing better support for people with cancer, mental health conditions, heart and lung diseases, long-term conditions, such as diabetes and arthritis, learning disabilities and autism, and for people as they get older and experience conditions such as dementia.

Local Objectives: There are many areas of interest and development locally in Lancashire as well as the specific conditions set out in the long term plan surveys. Some of these areas include stroke, cancer, maternity, and respiratory.

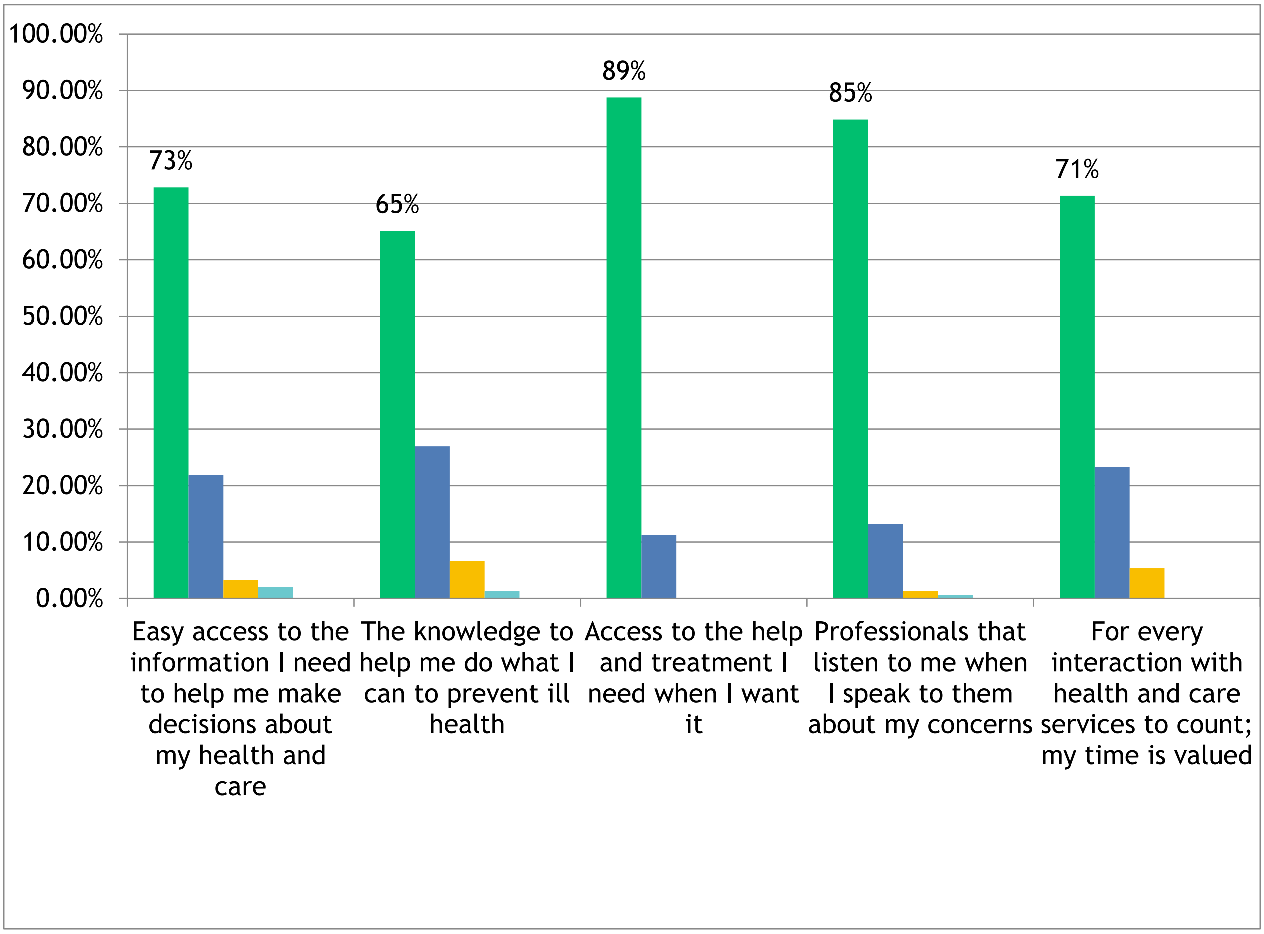
Findings: Generic Survey

We received 170 responses to the generic survey from people telling us they lived in Lancashire. All gave Healthwatch their consent prior to completing the survey. 93% of respondents provided feedback about their own views and experiences whilst the remaining 7% was on behalf of someone else.

The following show the questions asked by Healthwatch Lancashire and the answers provided.

We asked: "Please rate how important the following things are to you when it comes to living a healthy life"

The chart below shows that the majority of respondents felt all statements were very important for them to live a healthy life. Access to help and treatment when needed and being listened to by professionals when talking about concerns were considered the most important.



(153 respondents answered)

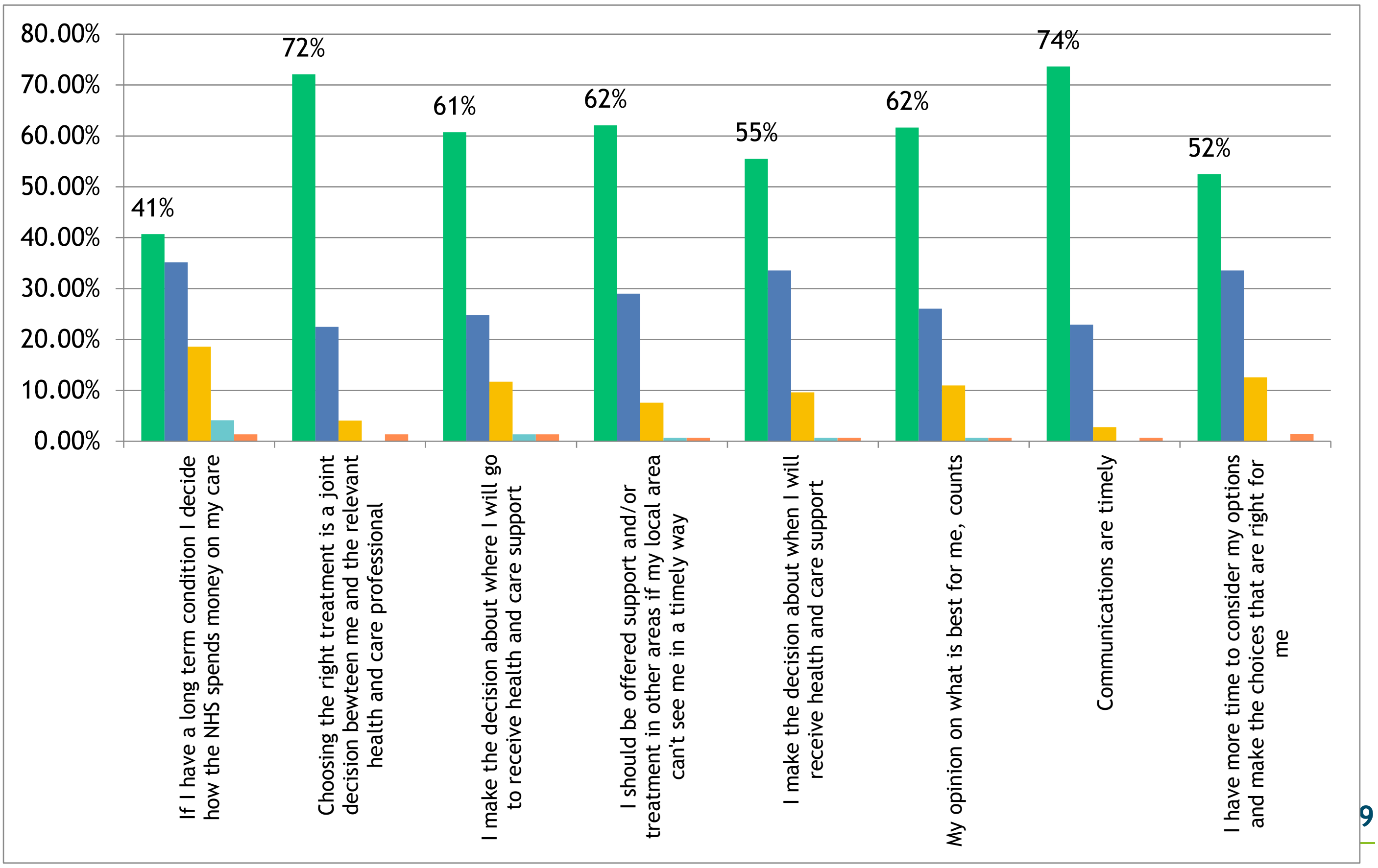
Following this question, respondents were asked if they had one choice which would be the most important: A large majority at 39% said *access to help and treatment I need when I want it*.

We received 93 comments and recommendations to this question. Below are the key themes identified:

- Many were in relation to accessing GP services including better access via digital technology and seeing the same doctor. We also received a significant number of people asking for shorter travel times to appointments and using more inclusive methods to contact services, particularly for people that struggle to get to appointments or services such as older people and physically disabled people.
- Shorter waiting lists to see GPs and specialist consultants
- More support for parents and children that have learning disabilities and / or autism.
- Improved outdoor facilities and green spaces
- More person centred care and people’s concerns and wishes being listened to and respected during appointments
- Some comments were about more access to mental health services including being aware of self referral options and help and treatment being longer and more personalised
- More information to understand diet and nutrition and having more access to exercise activities, particularly for people working through the day and therefore not able to access cheaper exercise programmes. Some of these comments also related to people having better access to eating disorder specialists

We asked: *“Please rate how important the following things are to you when it comes to managing and choosing the support you need”*

The chart below shows that the majority of respondents felt all statements were very important for them to manage and choose the support they need. Timely communications and choosing the right treatment with health professionals scored the highest.



(147 respondents answered)

Following this question, respondents were asked if they had one choice which would be the most important: A large majority at 42% said *choosing the right treatment is a joint decision between me and the relevant health and care professional.*

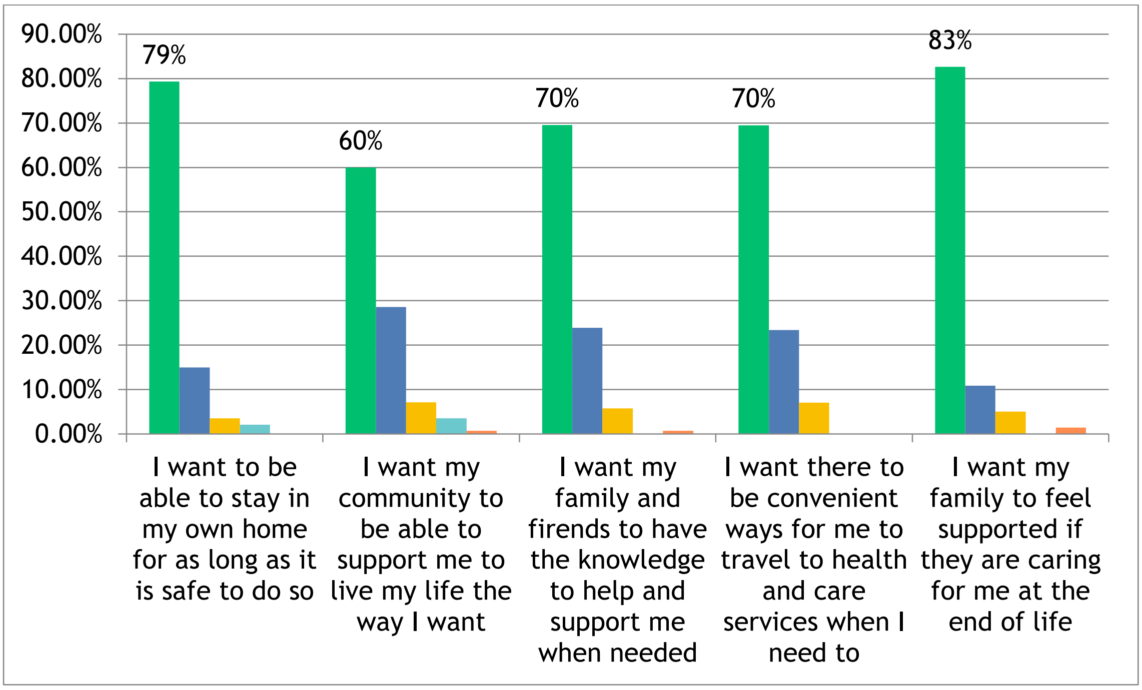
The next largest answer with 19% said *I should be offered care and support in other areas if my local area can't see me in a timely way*

We received 66 comments and recommendations. Below are the key themes identified:

- Communications to be quicker and clearer, both with service users and between health professionals, to enable a more joined up approach to individuals care
- Ensuring that people have full information allowing them to be involved in decisions with health professionals, understanding what tests are being carried out and why
- Easier access to book appointments and receive results that are simple and easy to understand
- Having more choice on where to receive care and health professionals supporting these choices and decisions
- Having more time in appointments to get the information needed to look after yourself
- Quick methods to ask a question about your condition, such as a text message
- More person centred care, including taking into consideration people with disabilities such as autism, that struggle to wait in clinic for their appointments
- Having communication between services and being assured that all people involved are understanding and active within treatment
- Closer places to receive care or more access to patient transport
- More empathy from health and care professionals

We asked: *"Please rate how important the following things are to you when it comes to keeping your independence and ageing healthy"*

The chart below shows that the majority of respondents felt all statements were very important for them to maintain their independence and age healthily. Ensuring their family are supported if they care for them at the end of life and staying at home for as long as possible scored the highest.



(141 respondents answered)

Following this question, respondents were asked if they had one choice which would be the most important: A large majority at 49% said *I want to be able to stay in my own home for as long as it is safe to do so.*

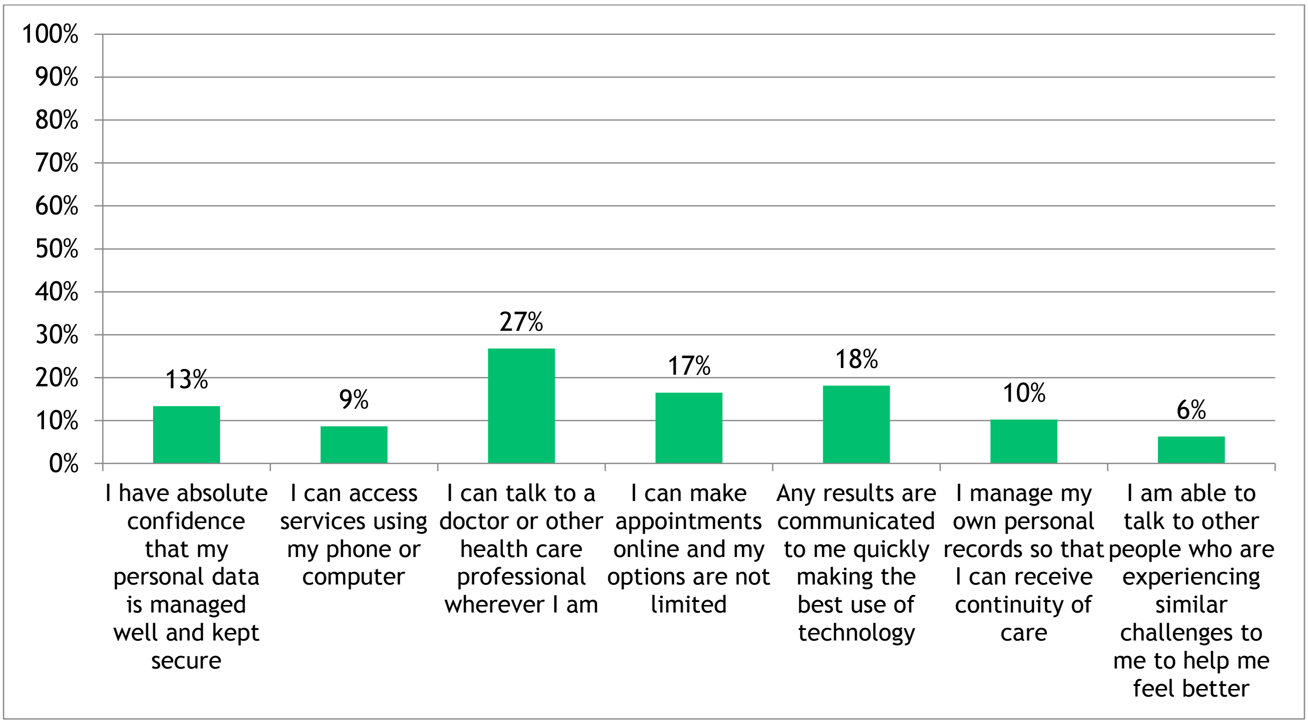
We received 56 comments and recommendations. Below are the key themes identified:

- Improved community care and access to relevant health professionals in the community
- Help and treatment to be delivered in people's homes and for these to be fast
- More services such as meals on wheels, helping people to cook healthily, and adapting homes to be safe and support with household tasks
- More support for carers including help financially when families have to leave paid work to look after family members
- Easily available information about what's already out there, such as exercise centre timetables, community transport phone numbers, social groups. Knowing what services are available and ensuring people use them by supporting
- Communities to be more supportive of older people and better support networks
- Continuity of care and ensuring people are checked up on following treatment

- For care home services to be to be more enjoyable and fun so that many people do not dread this option of care
- Care staff to be recognised as part of the health and care system, viewed as a more valuable resource and paid in accordance with this value. It was felt that care for older people and those with complex needs would improve with these changes
- More financial support for older people, in particular not having to spend most of their savings in order to receive care

We asked: *"What is most important to you when interacting with the NHS?"*

The chart below shows that the majority of respondents felt all statements were very important for them when interacting with the NHS. Receiving results quickly scored the highest, followed jointly by having absolute confidence that their personal data is managed securely and being able to access services over the phone or computer.



(138 respondents answered)

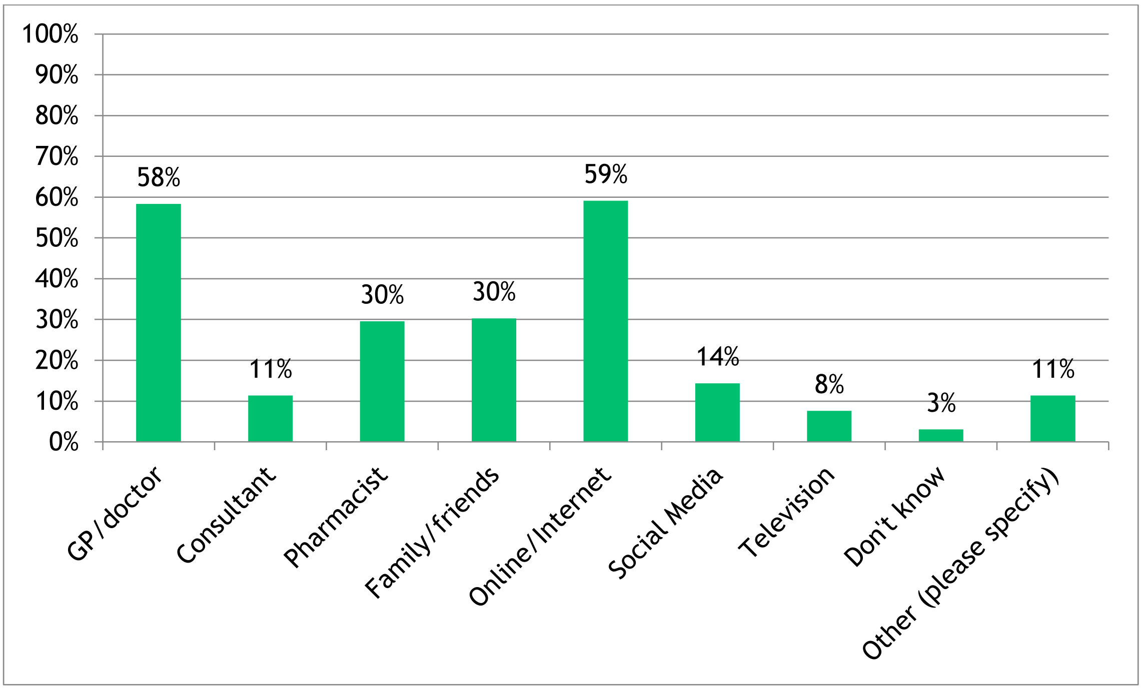
Following this question, respondents were asked if they had one choice which would be the most important: A majority at 27% said *I can talk to a doctor or other health care professional wherever I am.*

We received 61 comments in relation to this question. Below are the key themes identified:

- Better access for older people that do not have access to or are unable to use computers
- Supporting people to stay in their home
- Easier access to book appointments including fewer restrictions for example, only being able to book one week ahead and better online booking facilities.
- Being listened to by health professional and seeing the same doctor or ensuring continuity of care
- Better provision of mental health services and to talk more about mental health conditions
- Improved discharge system
- Patient Access to be easier to gain access/entry and to work more effectively. For this service to have all services including dental, health fitness, dietician
- Easier and quicker access to GP services including seeing the same GP
- Better communications between service user and health professional and between services
- Home visits for older people
- More accessible information on support groups that are relevant to people's individuals needs
- Having a full range of choice with regards to treatment including treatments that would have to be paid for
- More face to face care
- Improved online health services and information

We asked: *"Where or who would you go to, to find out more information about staying well?"*

The chart shows that the majority would use online sources and/or go to their GP/doctor to find out more information about staying well.



(132 respondents answered)

A few key differences from the overall results

Almost none of the respondents over 65 said they would use online services to access information. Staying at home for as long as possible was more important to older people.

Compared with the general findings, respondents that said they had a disability felt particularly strongly about professionals listening to them to enable them to live a healthy life. They also felt strongly about going to their GP to find out information to help them to stay well.

Respondents under 55 and particularly those aged 25-34, were more likely to want support to be offered in other areas if the local area is unable to see them in a timely way.

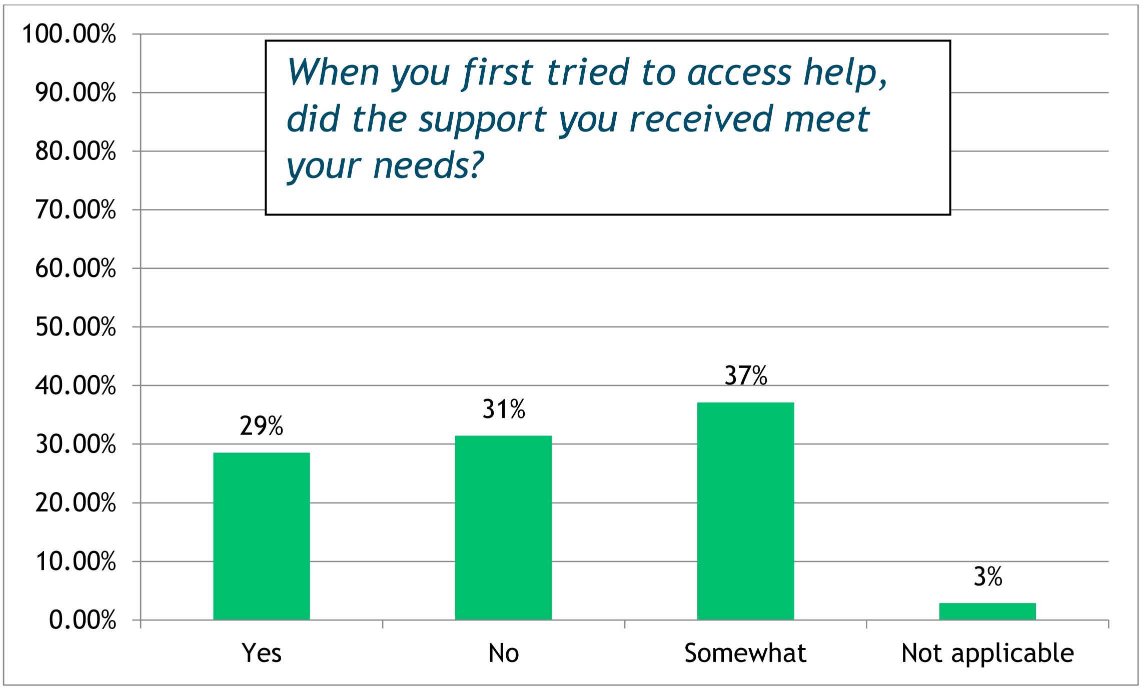
Specific or Long Term Condition in Lancashire

Summary

55 people responded to the NHS LTP specific conditions survey. Of those who told us about their condition; 13 people said they had a mental health condition, 11 said they had a long term condition, 6 had cancer, 3 had a heart and lung disease, 1 had dementia and 1 said they had a learning disability.

We asked the respondents if the support they received met their needs when they first tried to access help. The chart below shows the results, Most people found the initial support they received did not meet their needs (68% said it did not meet their needs or felt it only somewhat did).

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



(35 respondents answered)

Some people had more than one condition. Of these 17% said receiving support for more than one condition at a time made it more difficult to get the support they needed

Waiting times

34% said the length of time waiting for their initial assessment or diagnosis was either slow or very slow

26% said the length of time waiting for treatment following an initial assessment or diagnosis was either slow or very slow

Of those that were offered and saw a specialist:

- 52% said the length of time waiting to see the specialist was slow or very slow
- 50% said they found it difficult or very difficult to access ongoing support after being diagnosed or assessed
- 77% said the support they received did not meet their expectations

61% said that throughout the process of getting support, communication was inconsistent and slow

Travel to services

57% of our respondents used their own car to get to appointments whilst 27% said they received lifts from others

To get a quick and accurate diagnosis:

- 23% would travel less than 30 minutes
- 40% would travel between 30 minutes to one hour
- 13% would travel one to two hours
- 23% would travel over two hours

To receive specialist treatment and support:

- 17% would travel less than 30 minutes
- 41% would travel between 30 minutes to one hour
- 17% would travel one to two hours
- 24% would travel over two hours

Support and treatment

It was more important for respondents to see the same doctor when receiving treatment or long term support, rather than in the initial diagnosis or assessment when respondents were more willing to see anyone. However, a significant number wanted to see the same doctor throughout all.

57% said they would like the NHS to provide them with some support to stay healthy whilst 23% said they would like a lot of support.

Findings: From respondents with specific conditions

We received 55 responses to a survey about experiences of specific conditions. All gave Healthwatch their consent prior to completing the survey. 80% of respondents provided feedback about their own views and experiences whilst the remaining 20% was on behalf of someone else.

29% said their condition has started in the last three years whilst 71% saying they had their condition for longer than three years.

The following show the questions asked by Healthwatch Lancashire and the answers provided.

In Focus: Day services for people living with long term conditions in Lancashire

We visited Genesis Care, a small not for profit organisation which provides well-being and respite care services. We spoke to 15 people on our visit.

Genesis Care told us: "Older people deserve respect and dignity as they move towards the end of their lives. For many, dementia comes along and changes everything. A loss of identity, thoughts and word; faces become unrecognisable and friends may not always be around as they once were. For the person who cares for them it is often hard for them to find someone to stay with their relative, to go out and have some respite."

"Our aim is to provide person-centred care within a homely environment, focusing on strategies for maintaining life skills, building self-confidence and self-esteem."

Denise's Story

Five years ago my Mum had an episode of delirium where she thought people were damaging her plants and trying to break in to her house. One evening when I was working nights the Police contacted me as Mum had called and thought someone was trying to break in. The next day Mum thought the burglars were at the Magistrates court. I went to the GP with Mum and she was prescribed medication.

Mum went in to hospital with an infection and following her stay went in to Broadfield House in Leyland for rehabilitation to support her return home.

We made adaptations at home such as installing a key safe, Mum's medication being put in to blister packs and Mum received 6 weeks of crisis care from Housing 21 on her return home.

Two years ago there was a concern with the safety of Mum's medication, so with support from a social worker and a carer's assessment from n-compass a care package of domiciliary care was put in place and other adaptions made at home, to support Mum's independence.

Through n-compass there was a referral to the Royal British Legion Admiral Nurses, as my Mum had been in the services. They said the "Admiral nurse was my lifeline". There needs to be support for carers and families.

My Mum is 99 next week and is now living at The Lodge in Buckshaw Village, where I visit regularly.

I am now a volunteer with Dementia UK to help families who face dementia. I would like the Admiral Nurses Dementia Helpline to be promoted right across health and social care services so that carers and families know there is support available.

Eric and Tarnia's Story:

"There was just nothing after the diagnosis. We haven't heard anything in 6 months.

A pack would have been great 6 months ago. We didn't know about Genesis Care until yesterday. We haven't known who to speak to.

It's quite frightening at first, you are just anxious.

We have now gone out and sought support, we were assessed and we've applied to Primrose Gardens which is a supported living scheme, we are waiting so aren't making any changes at home. It's a new development it should have opened in March, so we're a bit in limbo.

It's reassuring today to hear that others can help.

Tarnia has recently joined a choir and said “It’s really important to be with people, I felt relaxed as soon as I got there.”

Pam and Alan’s Story

You have to work out “the balance” and it’s taken a while.

When we go for appointments for Alan I give them an hour at the hospital, I will give them an hour and then have a word, there’s no point shouting. The longer you are in the system the more skilled you become. I keep a notebook of conditions you need to have the facts on and this will help the carers.

You have to fight for the person you love; otherwise you won’t get anywhere. You need the facts when you do this. Carers save the community lots of money.

It’s been hard for me to see the change in Alan but a great leveller.

The Parkinson’s nurses were great especially when first diagnosed and spoke in “plain English”. The diagnosis was so impersonal; it’s the specialist nurses that give the real everyday support.

If Alan is admitted to hospital I ring the Parkinson's nurses and they go to the ward to support Alan.

n-compass assessment is really important. As a carer I've signed up to n-compass Peace of Mind 4 Carers, just in case anything happens to me.

Summary of feedback

When you first accessed help, and received diagnosis, did the support meet your needs?

Our initial discussion focused around referral from GPs to Charnely Fold which is the Lancashire Care NHSFT Memory Assessment service for Central Lancashire.

Referral waiting times were not highlighted as an issue and the main concern after diagnosis was being left in "limbo", "being left on their own to just get on with it", "We haven't known who to speak to."

A lack of communication,for example being prescribed medication by Charnley Fold and then told there would be a GP follow up but nothing, no phone call. You're in a "whirl" coming to terms with this diagnosis, you need support then.

The Community Fire Officer who regularly attends the homes of people with a recent diagnosis stated "people feel very on their own,there should be someone to follow up with people". One of the attendees had received help with her partner post diagnosis from the Alzheimer's Society and advised that an appointment was made at the time for a home visit with a support worker who provided on going support.

Could it be improved and how?

A referral there and then to n-compass who will arrange a dedicated carer's support worker to visit and complete a carer's assessment and put in place a Peace of Mind 4 Carers plan and information about the Carer's Hub to support carers in their caring role. This information needs to be provided as a matter of course.

An information pack to be given out at Charnley Fold with contacts for organisations who can support, for example Genesis Care, n-compass, Dementia UK, social services. A named person to follow up with a pre-arranged phone call.

"Information can be a bit of an overload. A person to speak to is more important"

"People need to be supported at their own pace"

After assessment /diagnosis were you offered access to health and care support:

Experiences of the impact of other medication mixed with dementia medication and the contra indications were highlighted as a real concern. Guidance from the diabetes team regarding diet though very good was not with dementia medication, for example having grapefruit and cranberry juice.

"Medical professionals are tunnel visioned for their particular care pathway"

Food and medication balance is so important for people, it is critical for people with Parkinson's

Regular medication reviews with either the pharmacist or GP.

In terms of further feedback people shared their experiences of social services, their concerns were the waiting times to speak to a social worker, it can take up to 3 weeks to get a response and so much can change in that time.

"You never get to speak to the same person" This was also the experience of the Lancashire Fire and Rescue who refer through to Social services and can speak on behalf of their clients.

"It's that inbetween time from diagnosis and when people hit crisis"

"There seems an inequality compared with other long-term conditions for example cancer - you need some one now not in 3 weeks time or somewhere we can go"

Many people do not go to the Memory Assessment Service until their dementia is quite developed, and depending on what type of dementia they have symptoms can change quite rapidly.

Support for carers was also raised as a priority and being made aware of organisations who can provide support for example Genesis, ncompass, the Alzheimer's Society, Age concern central lancashire

"Experience of cancer treatment was very different with regular follow ups"

Could it be improved and how?

The promotion of Genesis care together with other partner organisations to provide a one stop shop, for example a monthly hub similar to the Bay Dementia Hub or the weekly Carer's café on a Wednesday.

Key in the delivery of the above is communication, to ensure people know what's going on in their local area

Respite support – carers have long stints with their loved ones

Document every condition so that you can reference this when talking to healthcare professionals.

Using the local Dementia Action Alliances as a "voice" for People Living with Dementia and their carers to influence change. The local Parkinson's group exampled the very positive experience of the Parkinson's nurses providing a drop-in at Chorley hospital rather than having to travel to RPH.

A suggestion from the Dementia UK volunteer: "Is there an opportunity for a group of Admiral Nurses to do drop in centres across the locality"

How easy did you find it to access ongoing support?

"People with Parkinson's struggle with communication. Patients weren't eating and drinking because they couldn't be understood, I helped feed a patient because there was no-one to help".

"There was no information that my friend had dementia, so hospital porters don't know a person's needs and whether they can communicate".

"My friend had a water infection and was admitted to a room with 3 other ladies, they didn't know she had dementia, it was very upsetting"

"Volunteers aren't allowed to touch patients – if no response leave them".

The hospital expect patients to feed themselves and to be "independent" however many are too weak and need help to build their strength up

The problems of texture and thickness of drinks in cups and clingfilm not being removed was another issue raised as a reason why patients weren't eating

Menu/ food options that take into account the needs for diabetic patients

Hospital staff ask people living with dementia questions however don't understand their capacity. Carers and family members need to be made aware so they can support and explain.

Reference was made a number of times to ncompass and the Peace of Mind 4 Carers plan, a plan for carers in the event of an emergency with an option of upto 72 hours free replacement care from a care provider in the case of emergencies.

Could it be improved and how?

Training – All staff at Chorley hospital to have an understanding of dementia, including RVS volunteers

"Dementia is a different discipline, they are not looking at the person " you can't put a bandage on it"

The Butterfly scheme is adopted in many hospitals for example Clifton Hospital in Lytham St Annes, this is a whole-hospital care response to people with dementia, but also supports people with other forms of cognitive impairment. The Dementia Champion at Healthwatch Lancashire is supporting the hospital to deliver Information sessions across the healthcare team.

Use of hospital passports, life journals

Identifying patients living with dementia – either butterfly/forget me –not

Regular Dementia Hubs across Chorley and Leyland where information and support is available from health and local authority and Partner organisations for people living with dementia and their families and carers

Support for care homes who don't have available transport to take patients out need people to come in to support activities, volunteers.

In Focus: Friendship group tackling social isolation and loneliness in Fylde ad Wyre

We visited the group Just Good Friends in Lytham St Annes, a group that aims to combat loneliness, isolation and bring people together in friendship. Over 30 people attended

Just Good Friends told us: *We make sure that no-one is ever on their own again. It's about being there for each other, making new friends, enjoying life and each other's company. Special friendships are formed and someone recently has met a Best Friend. They would never have known each other had it not been for Just Good Friends. Loneliness is a terrible problem which we at Just Good Friends are trying hard to change. It's about changing loneliness to*

happiness, it's about laughter and fun and being there for each other"

The age of participants ranged from 55 to 80+ years and there were a higher number of women (70:30 split) in attendance. 39% of the group reported having a disability and 42% a long-term condition with 23% reporting living with multiple conditions. 12% of the group considered themselves to be a carer.

The workshop was fairly informal with Healthwatch Lancashire colleagues joining smaller groups (6 – 8 people) at different tables throughout the morning session. We collected a combination of individual feedback and group comments using the NHS Long Term Plan questionnaires on general health.

Having what I need to live a healthier life

In terms of general feedback on this theme, the main issue for the group from discussions involved having easier access to GP appointments, both from the point of view of availability of appointments and also the difficulties of getting to the GP practice.

On the availability of appointments, the main concern highlighted was around getting urgent (on the day) appointments. There were concerns about phoning, not getting through to anyone or when they do get to speak to the receptionist they find the urgent appointments have usually gone. Others reported being unhappy about queuing first thing in the morning outside the surgery ("in all weathers") and still not always getting an appointment. As a group there seemed to be a re-occurring theme of wanting to see a GP; often a named GP, rather than another health care professional, for instance a nurse practitioner.

Specific needs around accessing appointments online were identified by people in the group with visual appointments. "I am reliant on phoning the GP practice and would love to be able to find out how I could access the system online".

On the transport front some people mentioned that certain GP practices had now merged and new practices were further away and not on a public transport route. Others were concerned that they might in the future be losing their current GP practice and that this might involve having to travel more as well as losing the more personal support from a known GP. These comments were balanced by the responses from others who felt the benefits of a larger health centre that provided a wider range of services (for instance blood tests, audiology and physiotherapists services were referenced).

In response to further support to living a healthy life, many people highlighted the provision of exercise opportunities to help them stay healthy. Other themes that emerged included access to a garden (having downsized to a flat), being isolated from loved ones and getting access to other wellbeing support (healthier eating).

When asked to choose which statement was most important to *having what I need to live a healthier life* the highest number of the group identified “having access to the help and treatment I need when I want it" (35%) along with “professionals that listen to me when I speak to them about my concerns” (35%) as their main priorities.

Managing and choosing the support I need

Communication was the most significant area of feedback from the group on what would help them manage and choose how the NHS supports them. One of the concerns related to how different parts of the NHS work together - as there was a feeling that there was a disconnect between services. Another concern quoted was "better communication about what tests are being carried out and why". Someone else highlighted "listening to my input and seeing it as an important contribution". Other communication themes shared included keeping it simple, "I find it frustrating with long lists of options when I ring up - I need to speak to a person". Whilst people highlighted the importance of timely communications there was also an emphasis that these need to be understandable too and not full of jargon.

When asked to choose which statement was most important *to managing and choosing the support I need*, 42% of participants identified “choosing the right treatment is a joint decision between me and the relevant health and care professional" as their priority.

Keeping my independence and ageing healthily as I get older

In terms of feedback on maintaining independence and ageing healthily, the group really valued the 'Just Good Friends' service - it has been a life line for some individuals who had been becoming more isolated and lonely. They valued the group gatherings but also the support that the service had previously provided to initially get them involved - this was a service that is no longer funded. In terms of the group meetings, it was evident that individual friendships had evolved which enabled meeting up for other social activities beyond the main session. This was particularly important as some of the group highlighted that they had less communication with family than they would have liked but now more contact with friends.

Some of the group identified that there might be additional support needed now to help them stay independent. This included exercise to help them maintain their mobility and the provision of strength and balance exercise programmes may have been timely and beneficial. One person stated "I at the moment live in a private rented property and although it's okay I am not sure that I will stay there long term but I do not feel ready to go into a home as yet". Two other people highlighted the need for home support and medical visits at home (for a housebound individual). The importance of listening to individual concerns and choices was emphasised again during discussions around this theme.

When asked to choose which statement was most important *to keeping my independence and ageing healthily as I get older*, 56% of participants identified "I want to be able to stay in my own home for as long as it is safe to do so" as their priority.

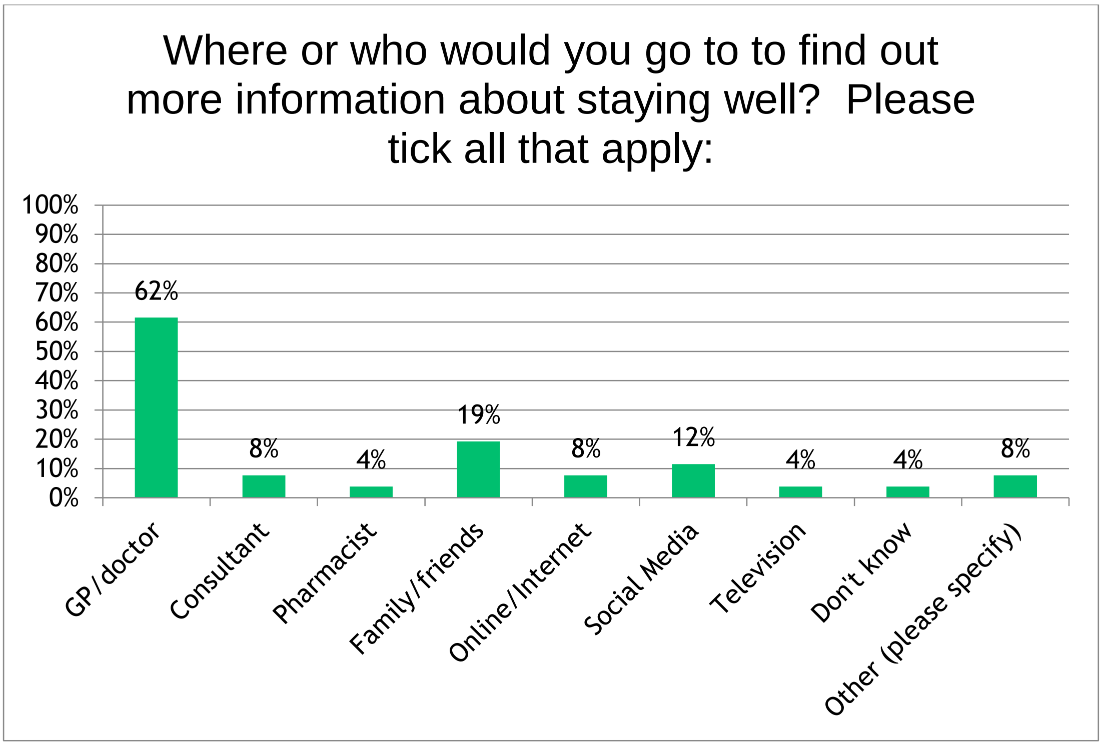
How you interact with the NHS and what is important for you

In terms of feedback on this theme access to and availability of services was again highlighted as the main concerns. There was interest from the group in knowing if alternative services were available closer to home - rather than travelling to hospitals or walk-in centres that were also some distance away. In terms of other feedback increased access and availability to GP appointments was highlighted with suggestions to "open more doctors' surgeries to ensure the community are able to receive appointments as soon as possible" and "no restrictions on appointment booking". For two of the responders the use of technology was critical for them in staying healthy and interacting with the NHS (e.g. Synaptic for visual impairment). This differed from feedback from other group members - one of whom stated "when is someone going to acknowledge that many elderly people do not have computers and phones". The importance of a joined up approach between different parts of the health and care system, and with individuals was also highlighted as an area that needed improving.

When asked to choose which statement was most important *in how you interact with the NHS and what is important for you,* 43% of participants identified “I can talk to a doctor or other health care professional wherever I am” as their priority.

Finding out information about staying well

When asked about where or who would you go to find out more information about staying well the overwhelming majority of respondents identified their GP or doctor as their main choice.



Implementing Mental health and care services

Summary

We heard from 13 people in Lancashire that said they had a mental health condition, more than 69% of those being people with a first hand experience of accessing support services for their mental health condition. 58% of these people told us their conditions started more than three years ago. We found that 13% of this group had other additional conditions.

The feedback we received was mixed, with 25% saying their overall experience was very positive, whilst the remainder felt their experience of receiving support has been average or negative. People told us about their disappointment with waiting times, difficulties with accessing support after diagnosis or assessment, inconsistent and lengthy waits with communications.

Some comments from people with a mental health condition:

Having spoken to other people I think that it's easy to sweep us under the carpet because our issues aren't obvious (i.e. physical pain) and it's impossible to keep chasing things around because we haven't got the energy. I know people who have finally got an appointment at the Mount and got there to find the person wasn't available and they hadn't been informed until they got there. That didn't do much good to their mental health

I was offered CBT, and went for my second session to be told that the therapist was no longer there as he was off sick, and there was no one else who could help me. I had not *been contacted about this, and I was not contacted afterwards for an alternative therapies*

There were long waiting lists, very vague information, and was certainly not consistent. I have recently access counselling via minds matters, but I had to wait several months and was only given a limited amount of sessions, which I do not feel are enough, and I feel as though I still need more support

The doctor listened and seemed to understand. He said he would refer us to MH support services. Nothing came through. I went to the doctors again and it was a different one, and he said MH services are very busy and I could help myself by reading books about it. Having finally accepted that I needed help it was all discouraging. I needed someone to talk to quickly; that would have been the improvement

I decided to use a service that I paid for privately, to avoid the painful journey of having to persuade a GP to refer me. I also wanted to do it as quickly as possible, so not to change my mind

The fear of having to wait to long or not being referred was what made me pay privately. I did not even check with my GP first. I have since found that I could have self-referred. This may have changed my decision, but I was unaware of it at the time, and either way, I do not regret paying, getting treatment is on of the best decisions I have made about my future.

Self-referral was very important for me when accessing a psychologist. I have spent around £1500 on this service, but I am now equipped to deal with life and am not on any medication for mental health. I was previously. If this is available now without a cost, people should be made more aware of it, as it has changed my life. People should also be made aware of services they might have to pay for, in case the NHS cannot provide it for free. Choices need to be made available and people should be believed and listened to. This should be assumed and should be the minimum standard.

Implementing Long Term Conditions and care services

Summary

We heard from 11 people in total, all of which had a first hand experience of accessing support services for a long term condition (for example, diabetes or arthritis). More than 73% of these people told us their conditions started more than three years ago. We also found that more than 38% of these people had other additional conditions.

The feedback we received was mixed, with 13% saying their overall experience was positive, whilst the remainder felt their experience of receiving support has been average or negative. Some told us about difficulties with waiting times resulting in them choosing to pay privately, although more told us the waiting times were ok or fast. Waiting times experienced were slower when waiting to see a specialist. A majority told us they found it difficult or very difficult to access ongoing support after their diagnosis or assessment and that the support they did receive did not meet their expectations. Almost all said that communications were inconsistent and slow.

Some comments from people with a long term condition:

I was trailing round from Hospital to Hospital being pregnant and with a prospective breech baby and having to go to anti natal clinic and diabetic clinic and the GP anti natal clinic not enough coordination/communication and my notes never caught up either. I was exhausted when I should have been resting

No one took my chronic pain seriously. With the first doctor I saw telling me it could just be 'one of those things'

It's been over 4 years and still no one has any idea what's wrong

Lack of Neurology cover in Preston meant that my appointment was delayed by more than 12 months. Local Specialist nurses are swamped with work - would be very helpful to have regular contact with them.

I paid for private health care to get an answer/diagnosis for the ongoing issues

Recommendations

1. Access to services was one of the main themes identified, including:

- Better use of digital technology to aid a convenient service, although ensuring people that do not have a computer or are unable to use a computer are not disadvantaged
- Shorter travel times
- Inclusive methods to communicate with services and book appointments
- Shorter waiting lists with GPs and specialists
- More eligibility of patient transport
- Care to be delivered at home where possible and for this to be a fast response
- Appointment booking systems to be less restrictive, such as being able to book in advance
- Patient Access to be easier to log in and to improve or expand its content
- Full awareness of treatment options including those available privately
- Improved online health services and information
- Improved, sustainable travel mechanisms, particularly in the ‘hard to reach’ communities
- Quicker access to mental health services for both children and adults

2. Improved outdoor facilities and green spaces to enhance a general sense of wellbeing and also to enable people to use these spaces for leisure activities and exercise

3. Health professionals and services to be more person-centred and caring, including:

- People’s concerns being listened to and respected during appointments
- More time in appointments to get information to look after themselves better
- Taking into consideration the difficulties faced by people with learning disabilities and / or autism when booking appointment and within the appointments, for example, appointment not to be booked at a busy time in a busy environment
- Services to be joined up with continuity of care where applicable, to aid effective transitions and communications
- Improved discharge system from hospital

4. Being aware of self referral options to mental health services, and for these services to be longer and more personalised. We also received comments on a need for more information made available on the mental health condition

5. Easily accessible/easy to understand diet and nutrition information and advice and exercise activities to be cheaper and at a range of times during the day, to support people that work during the day

6. Communications, including receiving results to be quicker, clearer and more joined up with other services and individual patient.

7. More awareness on patient choice on where to receive care and for health professionals to support this

8. Improved communities for older people including:

- Access to care and health professionals in the community
- Meals on wheels
- Adapting homes so that people can stay at home safely for longer
- Support with household tasks and how to cook healthily
- Communities to be supportive of older people or people with more complex needs
- Information on support groups in the community individualised to the persons needs

9. More support for carers as well as financial support for families that have to give up work to look after someone. There were also comments about providing more financial support for people living within care homes to avoid spending their saving on necessary care

10. Activities within care home to be more fun, for the image of care homes to improve and for care staff to be valued and paid accordingly

Next steps

Response from Lancashire and South Cumbria Integrated Care System:

Lancashire and South Cumbria Integrated Care System is a partnership of NHS, local councils, voluntary sector and community organisations working together to support the 1.7 million people who live in this part of North West England. We call this partnership Healthier Lancashire and South Cumbria.

This report from the collaboration of local Healthwatch organisations provides valuable insight from more than 900 people across our area and we would like to thank Healthwatch for their work in capturing this feedback and for presenting this in a way which will contribute to improving services across our integrated care system.

The NHS Long Term Plan states that each ICS must produce a five year strategy which will cover both operational and long-term priorities. The effectiveness of the ICS partnership will be judged by our ability to join up health and care services, to listen to the priorities of our communities, local people and patients and to tackle some of the biggest challenges we are all facing. We can only do this by making sure patients are at the centre of everything we do as a partnership.

We are committed to involving local people, patients, staff and partners in the development of our shared five year strategy. We are already working with partners across our system to capture feedback from each of these groups which will contribute to the development of this strategy and this report will help to make sure local people’s views are used to shape plans for working together and delivering safe and sustainable services. The feedback in this report has already been shared with teams working on specific areas referenced in the report along with those in each of our five areas which make up Lancashire and South Cumbria.

We are pleased that the collaborative of the four local Healthwatch in Lancashire and South Cumbria is continuing to support engagement with local people over the coming weeks to make sure local people have contributed to a strategy for our integrated care system. This engagement will see a programme of focus groups delivered within each of our five areas which are supporting local priorities.

For more information on the development of our five year plans please visit healthierlsc.co.uk

Methodology

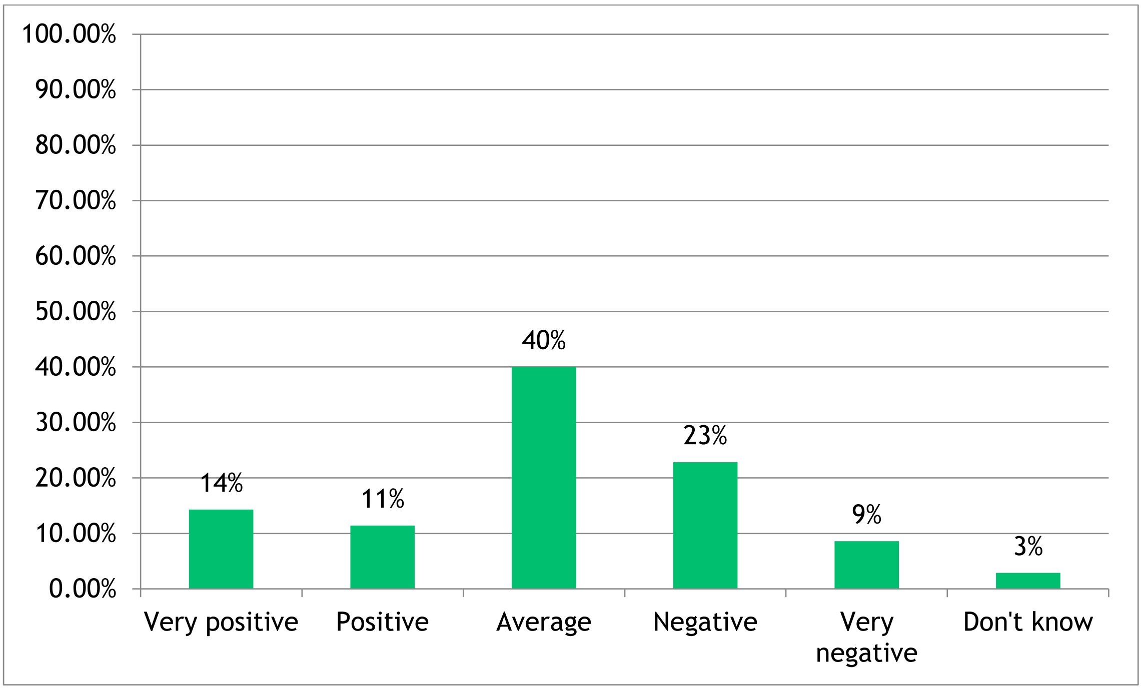
The methodology used to collect and collate this report for the people of Lancashire adheres as closely as possible to the guidance contained within the research quality framework. Prior to engagement commencing a local engagement plan was created that would look to engage with the population of Lancashire to identify what really matters to them as part of the response to the NHS Long Term Plan and how improvements could be made during local service transformation. This was undertaken by various methods including local online surveys looking at those in the population who have a long term condition(s) already diagnosed and also by engaging with the wider population. There were also Focus Groups and general engagement undertaken to ascertain this information.

Acknowledgements

With many thanks to all who have contributed to making this report possible:

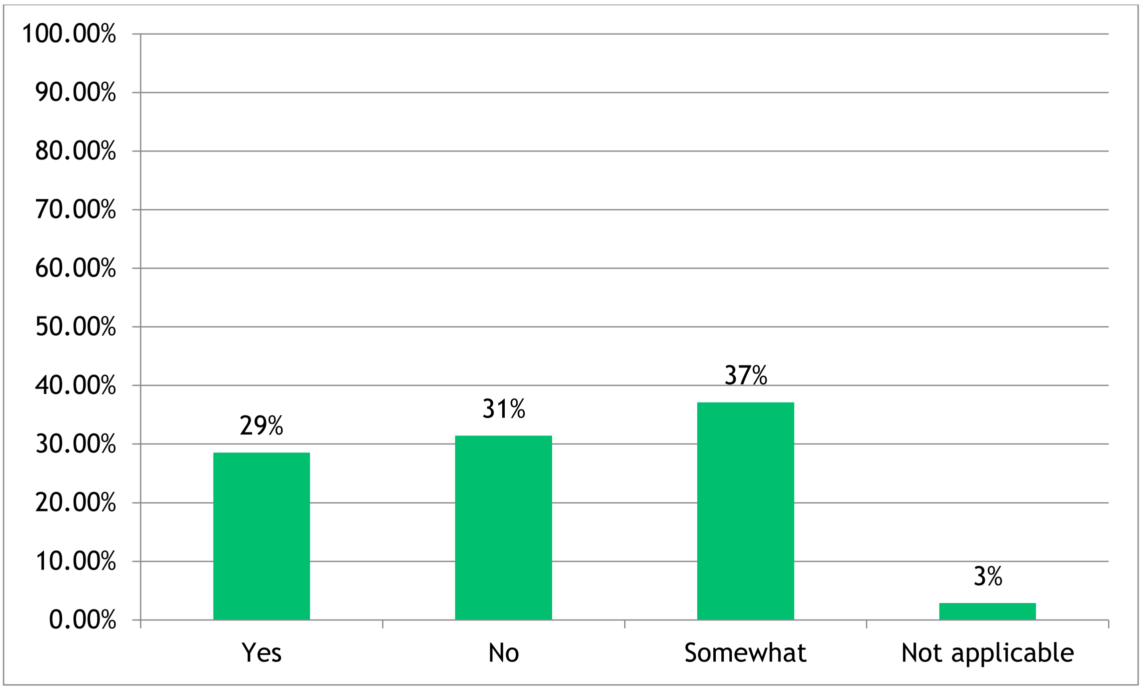
- *To all of the service users of Lancashire who have engaged with us either online or in person.*
- *Genesis Care in Chorley*
- *Just Good Friends in Lytham St Annes*

We asked: *How would you describe your overall experience of getting help?*



(35 respondents answered)

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

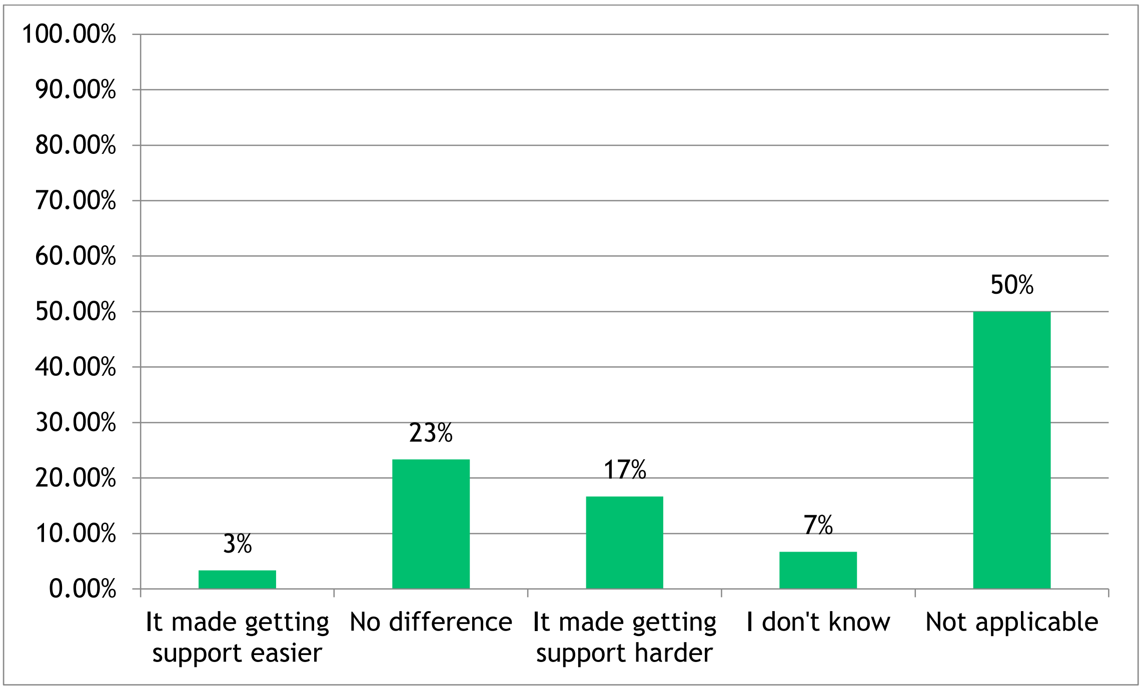


(35 respondents answered)

Following this question respondents were asked to provide further comments and information. We received 17 comments and recommendations about the following:

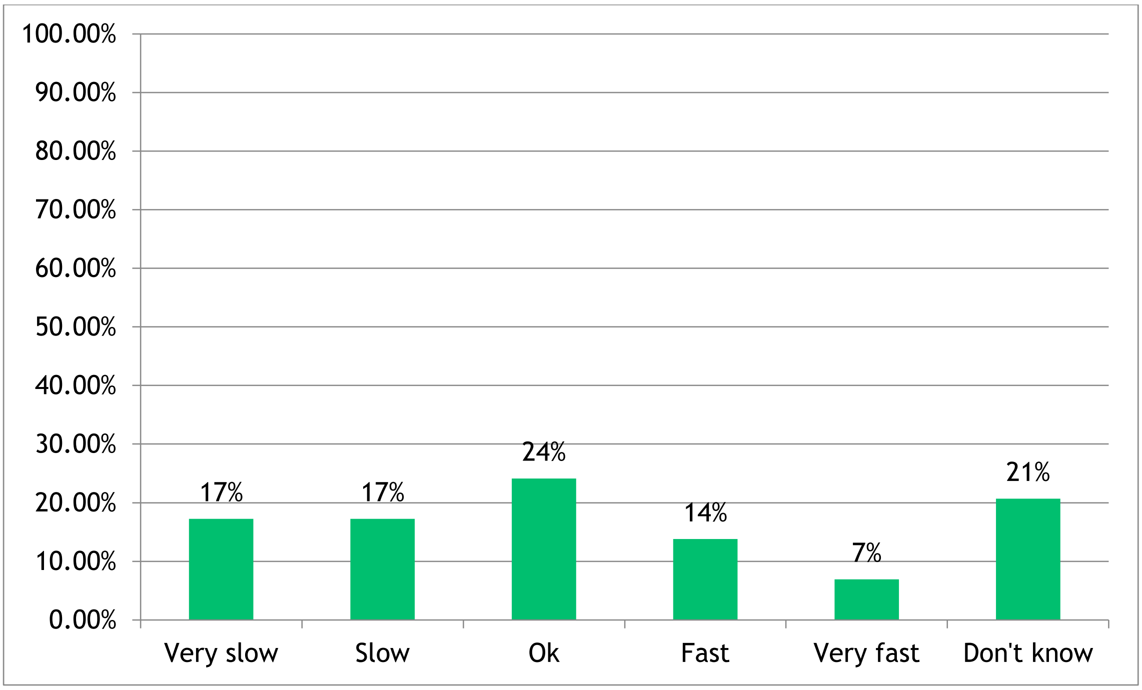
- Not being offered support
- Lack of information and clarity from services on specific conditions
- Inconvenience of appointment times
- Difficulties being taken seriously and being listened to, particularly when they had a diagnosis of another condition. This resulted in people not being offered tests and doing their own research to seek help or information
- Having to wait a long time to be referred or gain an appointment or test result. One respondent did not hear anything after being referred. They returned for another appointment but saw a different doctor who advised them to read self help books instead as mental health services were too busy. Others paid privately to get a diagnosis after their appointments were repeatedly cancelled. Another person chose to pay privately so that they received a quick appointment and did not change their mind

We asked: *If applicable, how would you describe the experience of seeking support for more than one condition at a time?*



(30 respondents answered)

We asked: *How would you describe the length of time you had to wait to receive your initial assessment or diagnosis?*

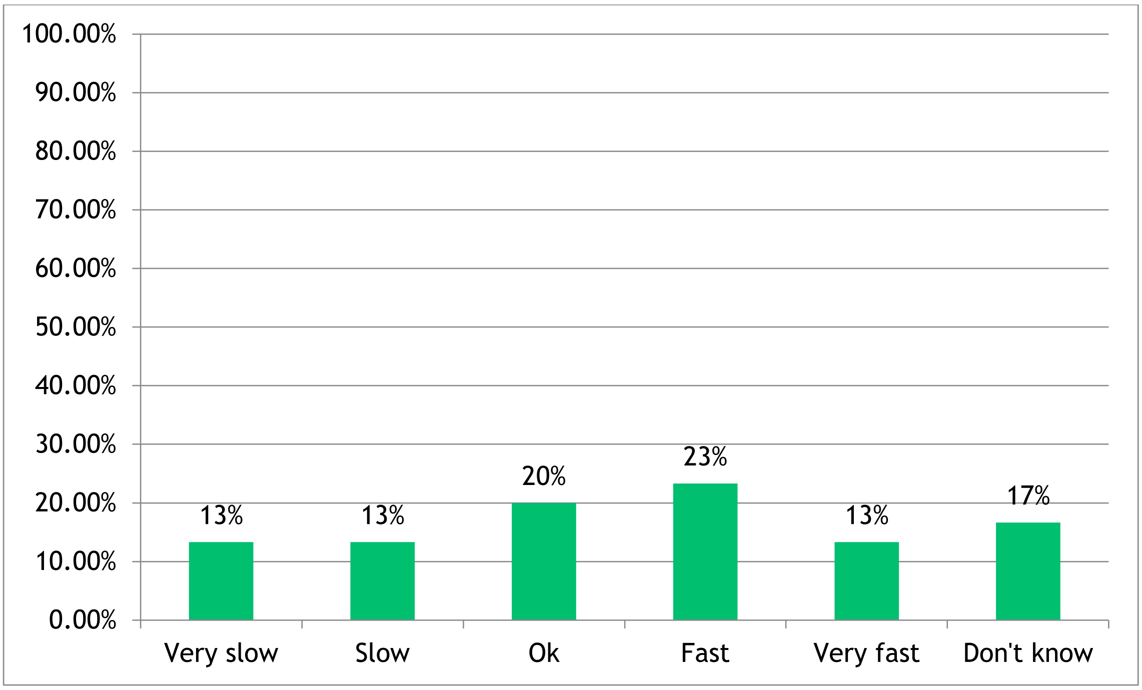


(29 respondents answered)

Following this question respondents were asked to provide further comments and information. We received 18 comments about the following:

- People talked about significant waiting to get an assessment or diagnosis from two weeks to six years
- Paying privately to access care
- People doing their own research to find information

We asked: *How would you describe the length of time you had to wait between your initial assessment/diagnosis and receiving treatment?*

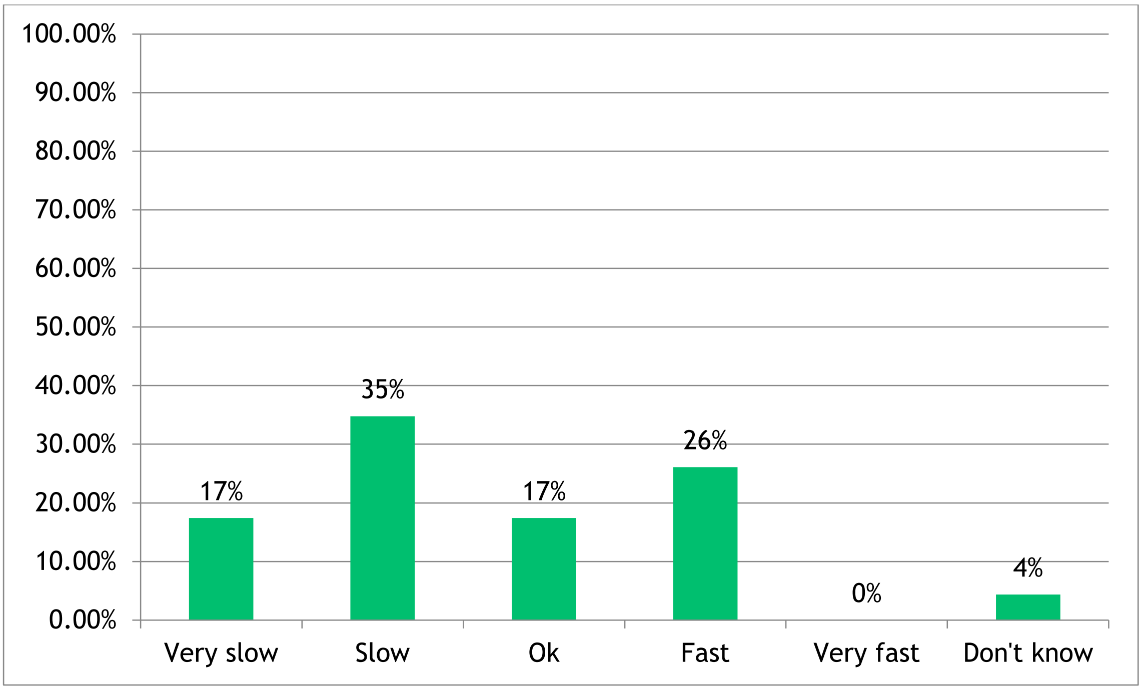


(30 respondents answered)

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

55% said they were not offered further health and care support. Of those that were offered further health and support, 71% were referred to a specialist.

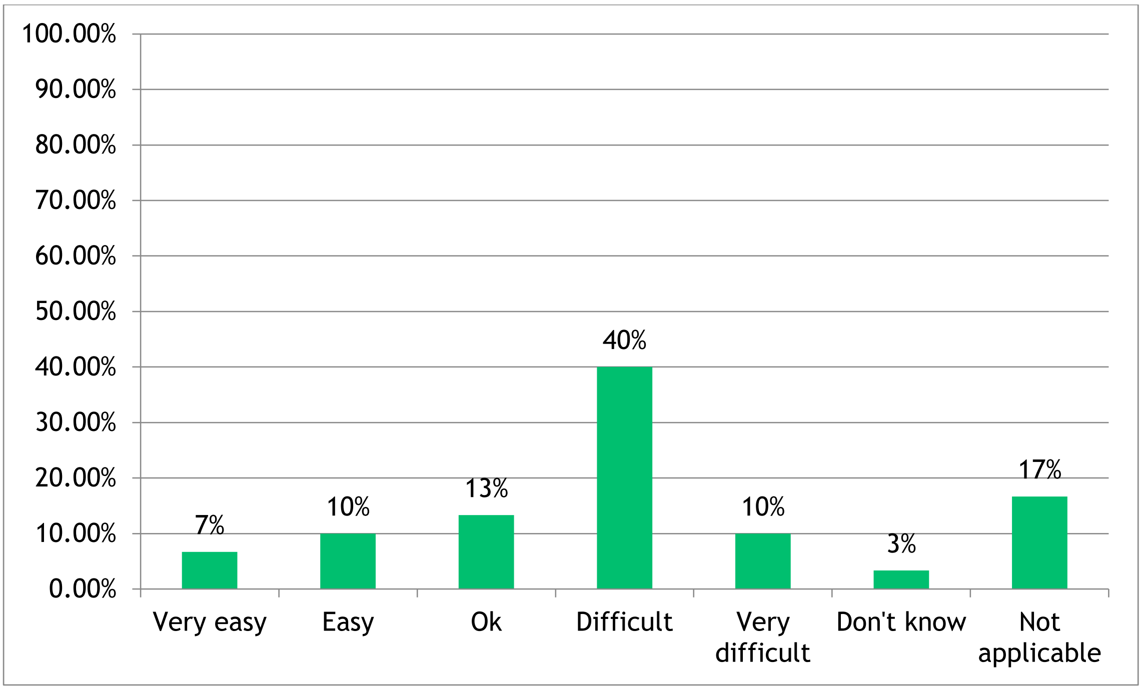
We asked those that said they saw a specialist: *How would you describe the time you had to wait between the initial appointment and seeing the specialist?*



(23 respondents answered)

Following this question respondents were asked to provide further comments and information. We received 14 comments about people paying privately to receive help and or treatment, long waiting times and delays in appointments. We received a recommendation of more awareness of what treatment is available and if people can self-refer

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



(30 respondents answered)

We asked: *Did the support option you were offered meet your expectations?*

77% said the support did not or only somewhat met their expectations.

Following this question respondents were asked to provide further comments and information. We received 14 comments about support not being offered, lack of knowledge from staff, delays in appointments due to cancellations and lack of staff, having to do own research to find information about their condition and make their own appointments or request referrals to specific departments. There was a recommendation for support to be received quicker.

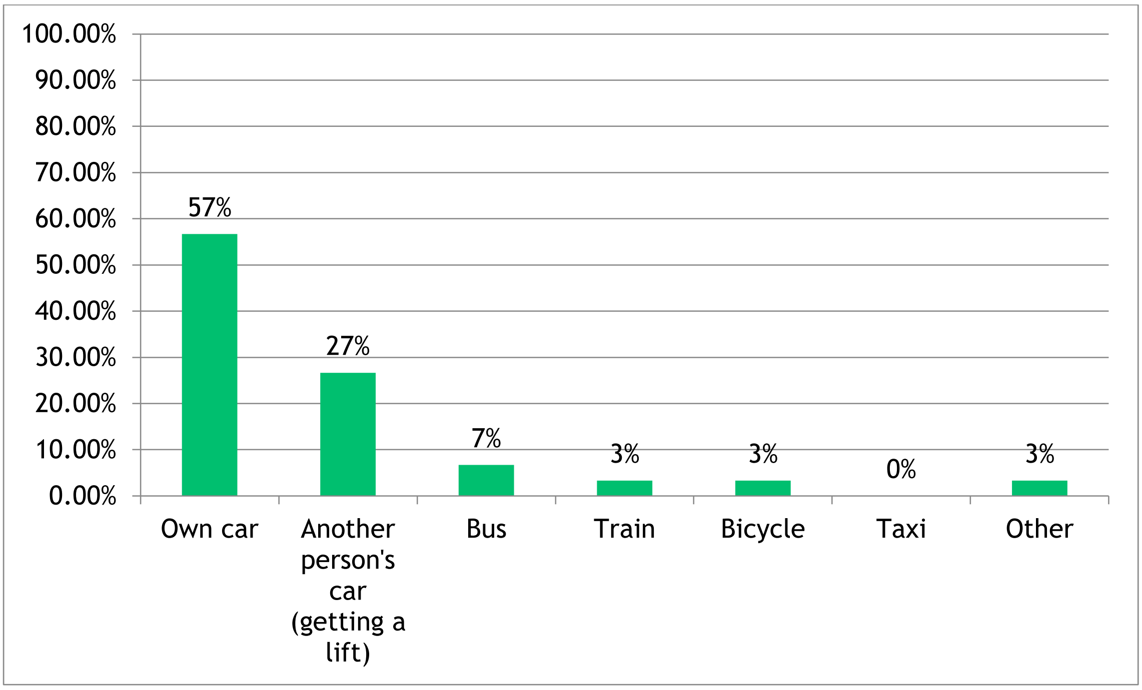
We asked: *During your whole experience of getting support did you receive timely and consistent communication from all of the services that you came into contact with?*

50% said they did not receive timely and consistent communications from all services they came into contact with and 11% said they somewhat did.

Following this question respondents were asked to provide further comments and information. We received 12 comments about the following:

- People's health condition not being taken seriously resulting in conditions not being tested and diagnosed
- Carer's not being offered support
- Difficulties getting results, logging in to the online service Patient Access and incomplete or missing information in medical records
- Health professionals not understanding specific conditions particularly understanding how different aspects of conditions coexist
- Having to travel too far or too often, particularly when their condition may mean their mobility is limited
- People not being informed
- Long waiting lists and inconsistent and vague information

We asked: *What is your main means of transport?*



(30 respondents answered)

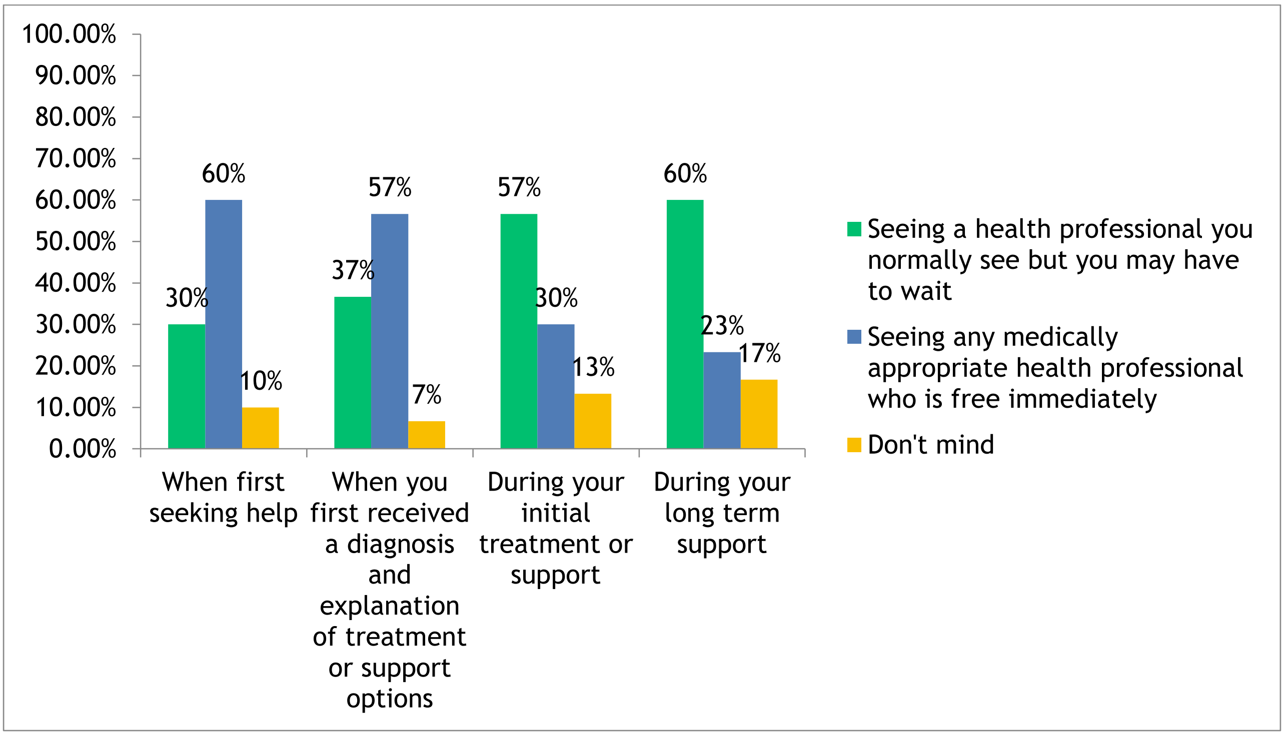
We asked: *How much time would you be willing to travel for to receive a quick and accurate diagnosis?*

- 23% would travel less than 30 minutes
- 40% would travel between 30 minutes to one hour
- 13% would travel one to two hours
- 23% would travel over two hours

We asked: *How much time would you be willing to travel for to receive specialist treatment or support?*

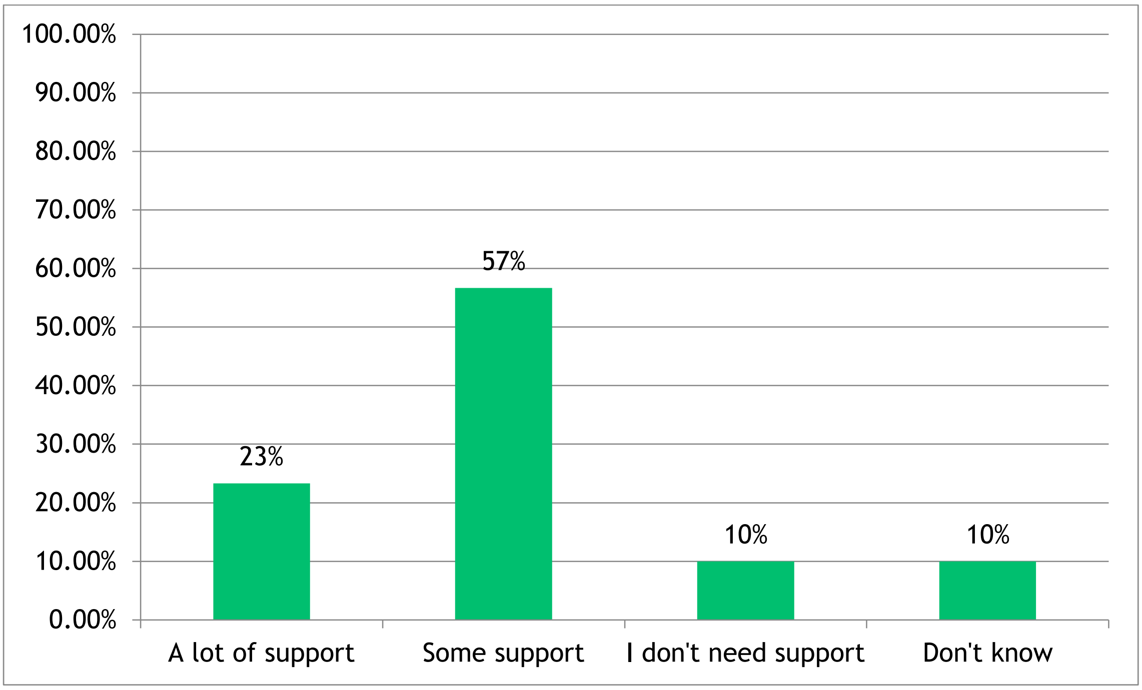
- 17% would travel less than 30 minutes
- 41% would travel between 30 minutes to one hour
- 17% would travel one to two hours
- 24% would travel over two hours

We asked: *What is most important to you?*



(30 respondents answered)

We asked: *What level of support do you want the NHS to provide to help you stay healthy?*



(30 respondents answered)

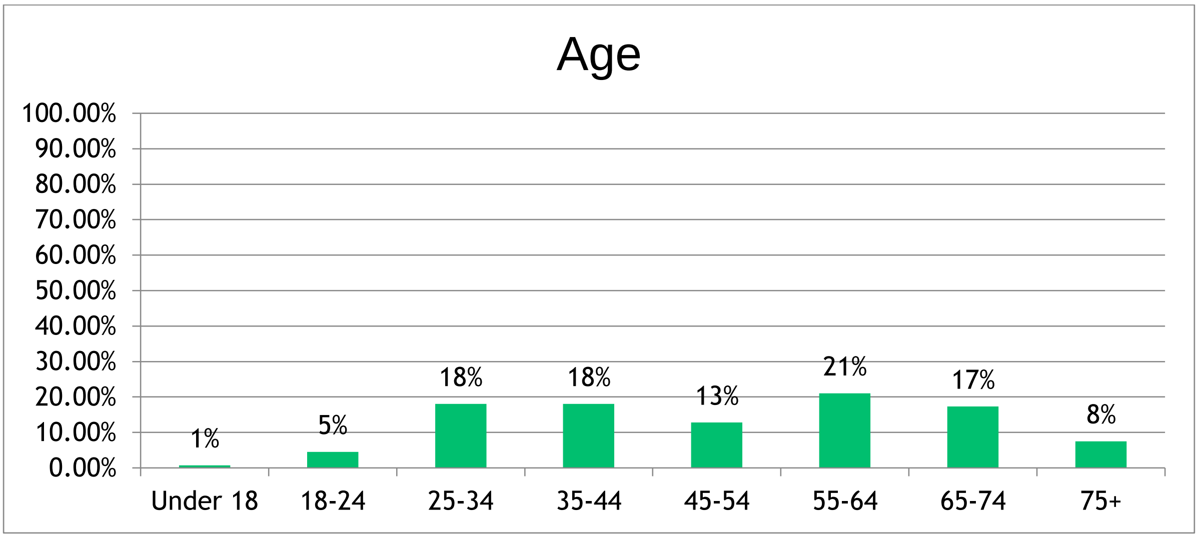
We received over 70 free text comments during the completion of the long term condition survey, of which there were themes throughout. These included:

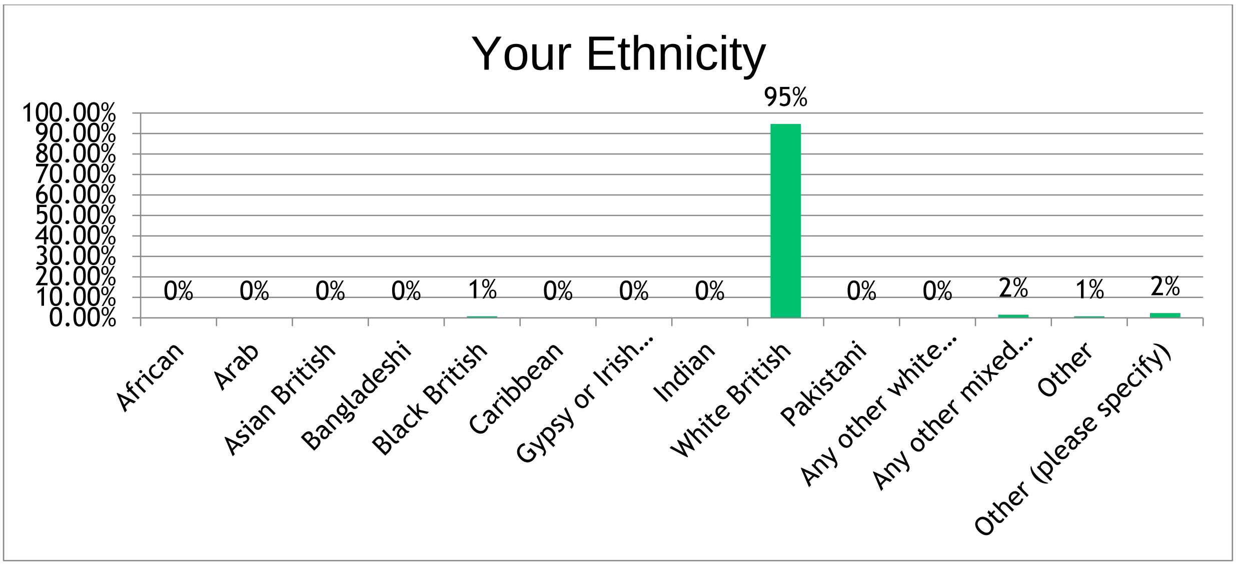
- Respondents said they wanted to see more knowledgeable health professions as it was found that many felt they did not know enough about their specific condition to help
- Respondents felt their health condition was not taken seriously, resulting in conditions not being tested and diagnosed
- Carer's not being offered support
- Difficulties getting results, logging in to the online service Patient Access and incomplete or missing information in medical records
- Health professionals not understanding specific conditions particularly understanding how different aspects of conditions coexist
- Having to travel too far or too often, particularly when their condition may mean their mobility is limited
- People not being informed
- Long waiting lists and inconsistent and vague information
- Support not being offered
- Delays in appointments due to cancellations and a lack of staff
- having to do own research to find information about their condition and make their own appointments or request referrals to specific departments
- Help treatment and extra support not quick enough sometimes resulting in people paying privately to access care
- More awareness of what treatment is available and if people can self-refer

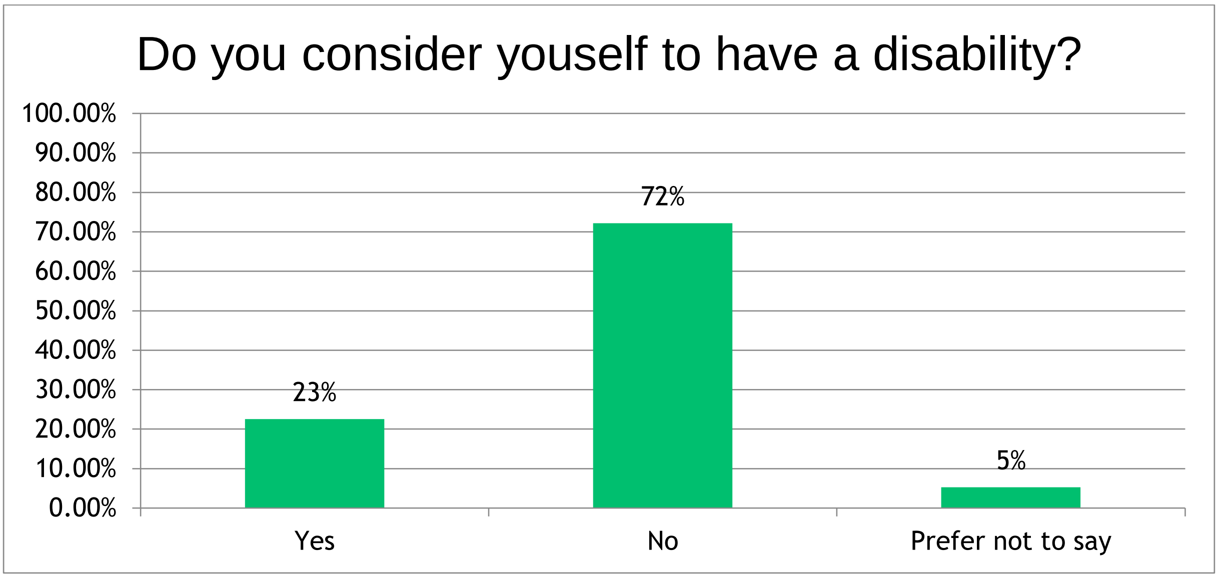
- More information and signposting to help themselves following treatment
- Inconvenience of appointment times
- Difficulties being taken seriously and being listened to, particularly when they had a diagnosis of another condition. This resulted in people not being offered tests and doing their own research to seek help or information
- People having to wait a long time to be referred or gain an appointment or test result

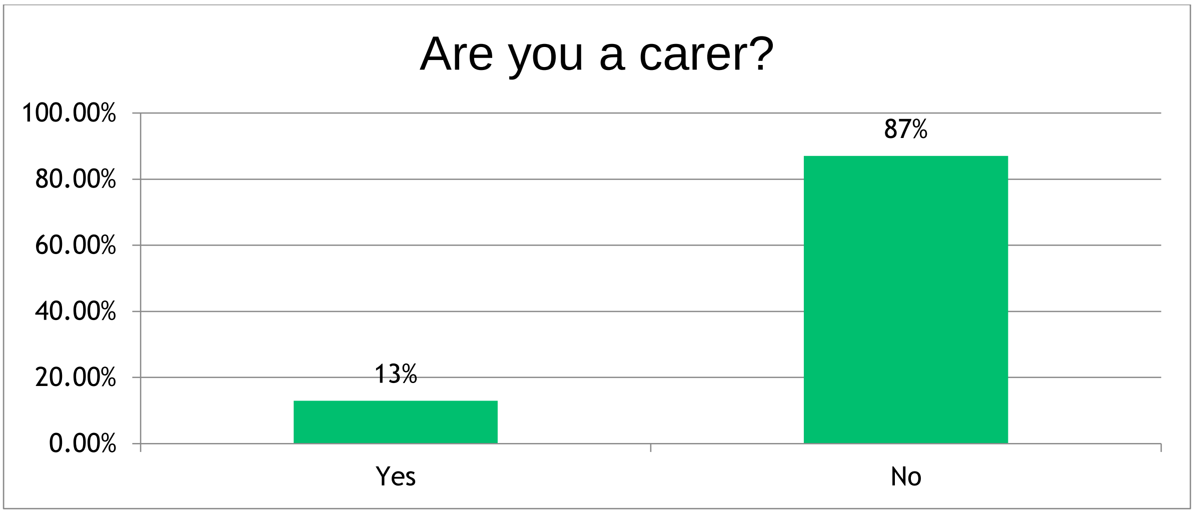
Appendix1 Demographics

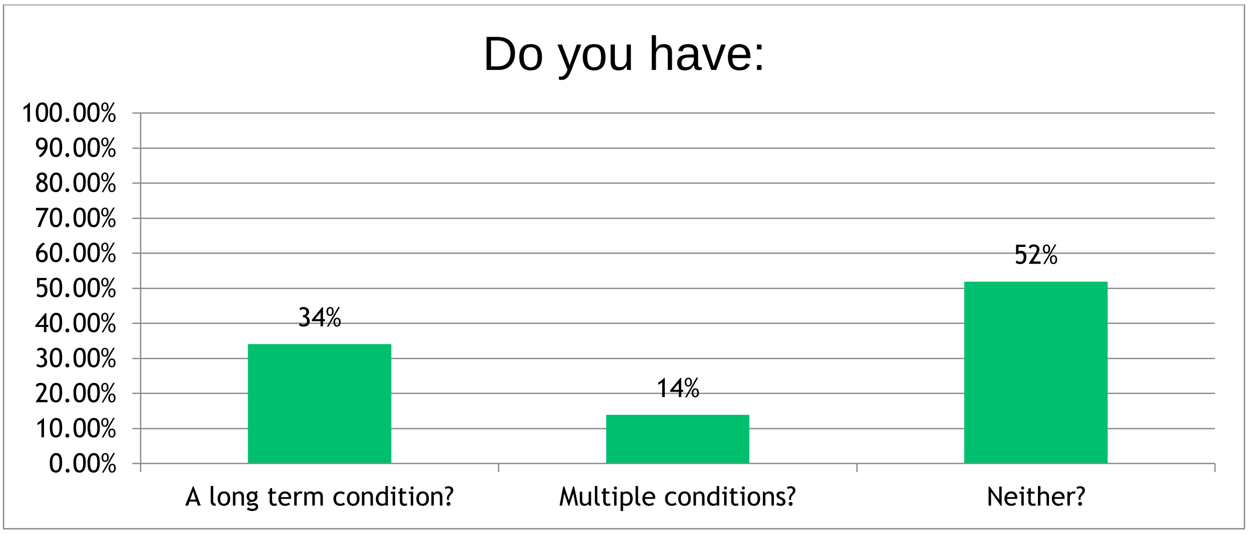
Below detail the demographic characteristics of respondents of the generic survey

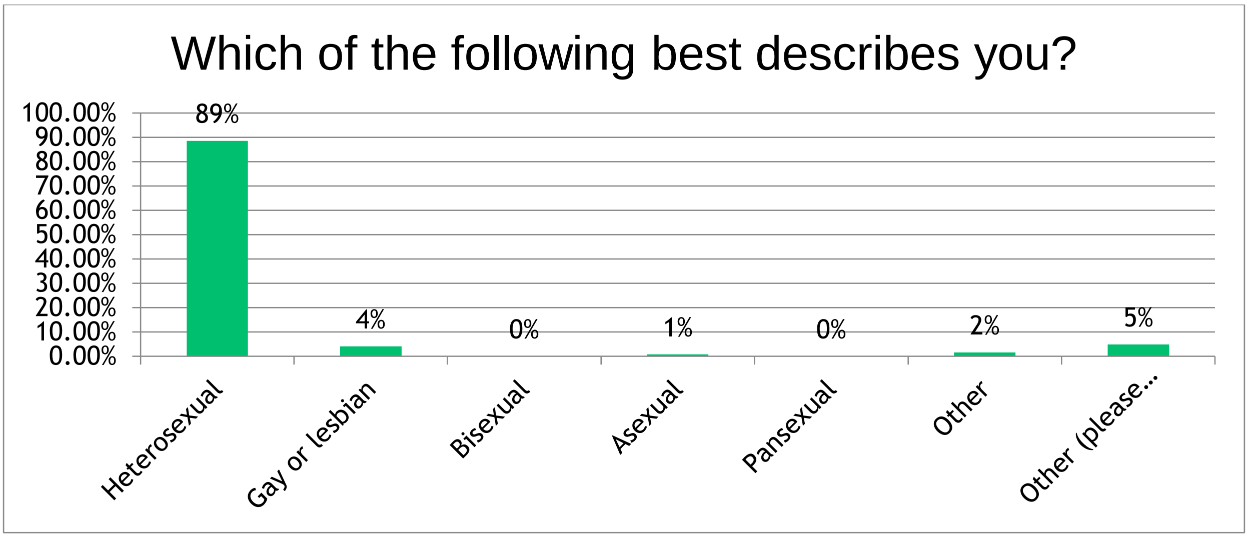


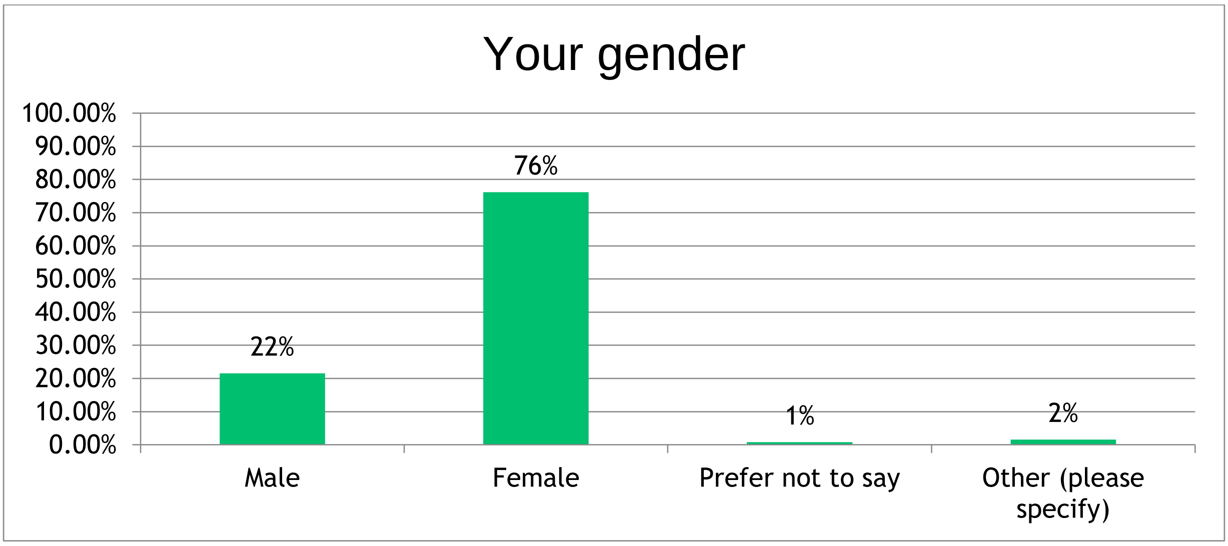

Your Ethnicity
100.00%
90.00%
80.00%
70.00%
60.00%
50.00%
40.00%
30.00%
20.00%
10.00%
0.00%
0%
0%
0%
0%
1%
0%
0%
0%
95%
0%
0%
2%
1%
2%
African
Arab
Asian British
Bangladeshi
Black British
Caribbean
Gypsy or Irish…
Indian
White British
Pakistani
Any other white…
Any other mixed…
Other
Other (please specify)

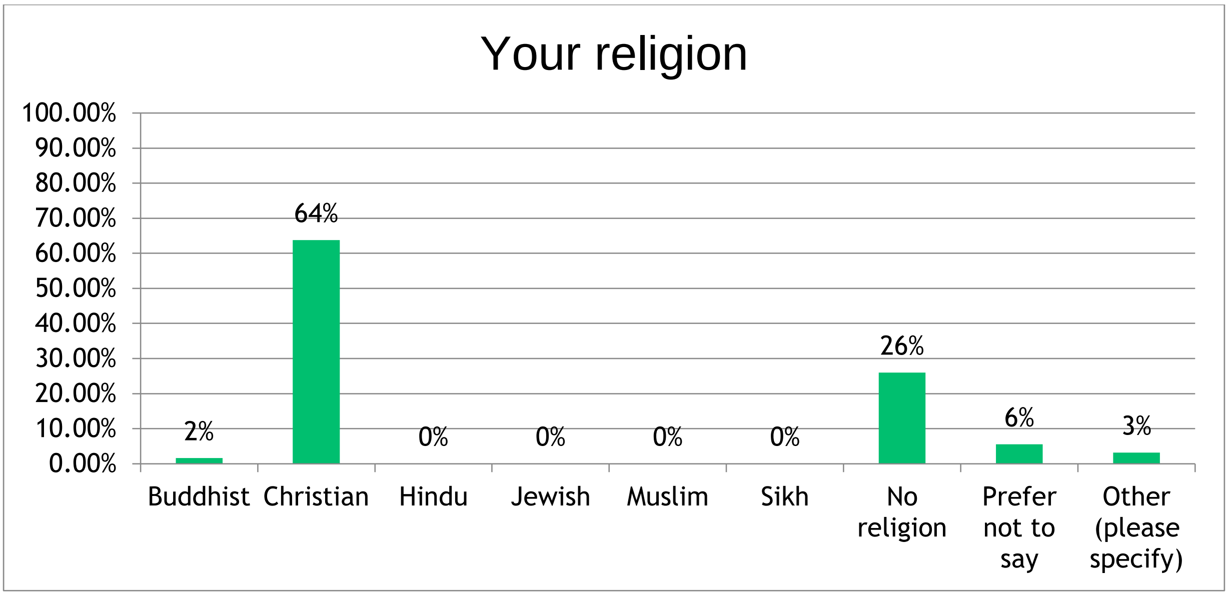

Do you consider youself to have a disability?
100.00%
90.00%
80.00%
70.00%
60.00%
50.00%
40.00%
30.00%
20.00%
10.00%
0.00%
23%
72%
5%
Yes
No
Prefer not to say


Are you a carer?
100.00%
80.00%
60.00%
40.00%
20.00%
0.00%
13%
87%
Yes
No

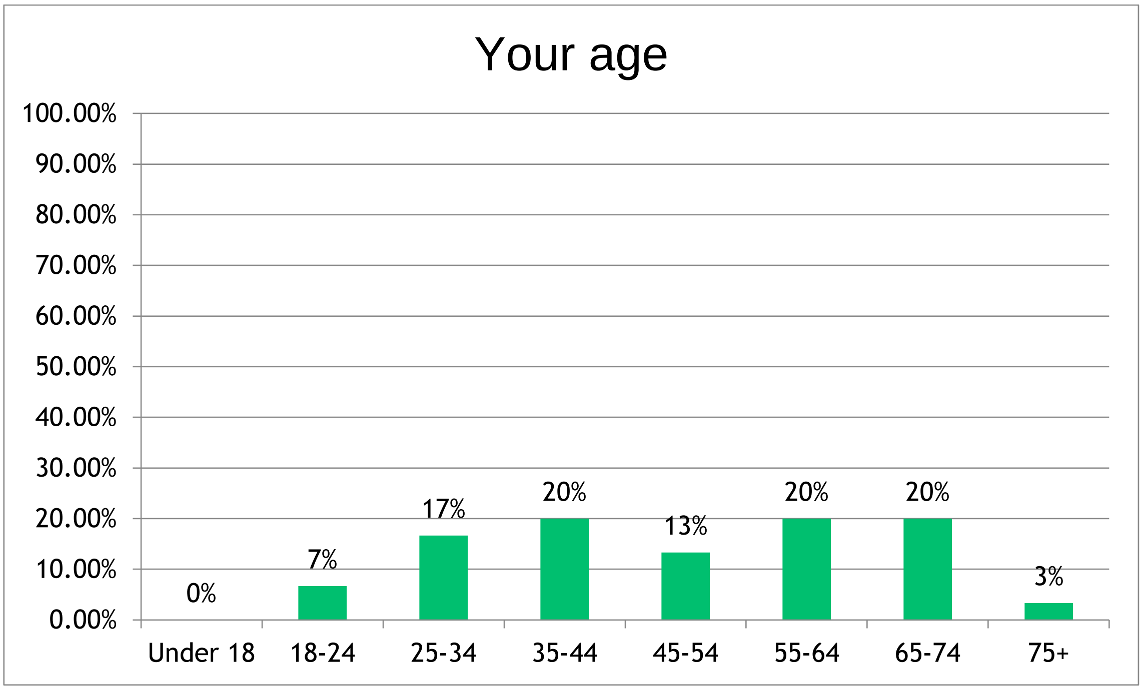

Do you have:
100.00%
90.00%
80.00%
70.00%
60.00%
50.00%
40.00%
30.00%
20.00%
10.00%
0.00%
34%
14%
52%
A long term condition?
Multiple conditions?
Neither?

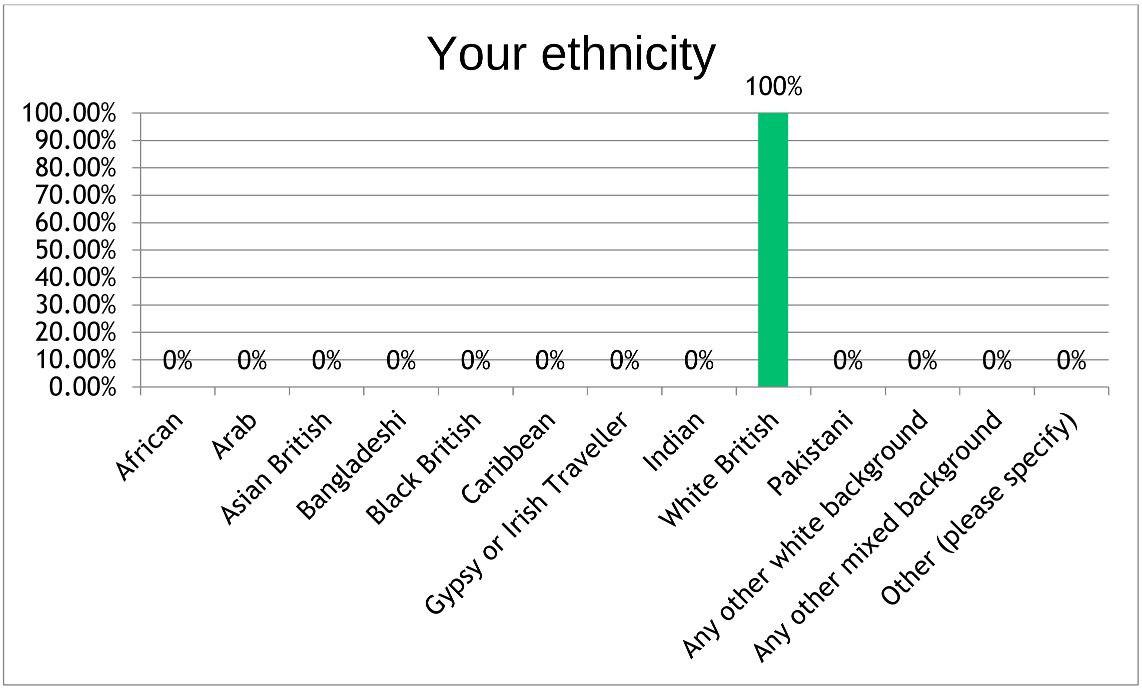

Which of the following best describes you?
100.00%
90.00%
80.00%
70.00%
60.00%
50.00%
40.00%
30.00%
20.00%
10.00%
0.00%
89%
4%
0%
1%
0%
2%
5%
Heterosexual
Gay or lesbian
Bisexual
Asexual
Pansexual
Other
Other (please...

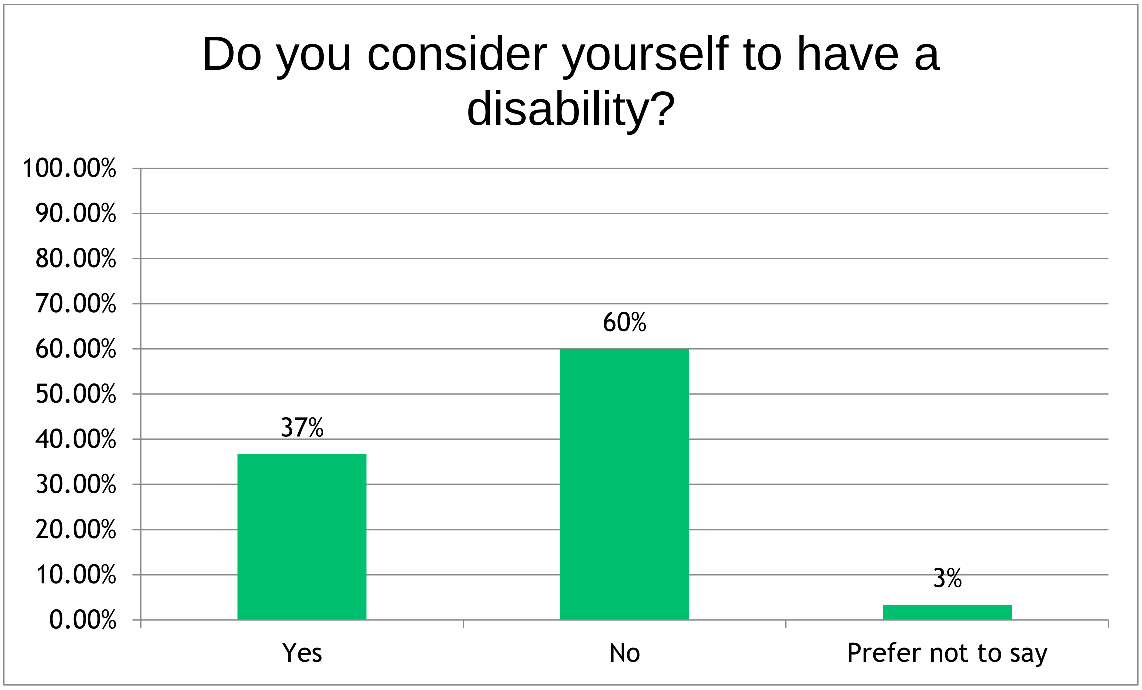

Your gender
100.00%
90.00%
80.00%
70.00%
60.00%
50.00%
40.00%
30.00%
20.00%
10.00%
0.00%
22%
76%
1%
2%
Male
Female
Prefer not to say
Other (please specify)

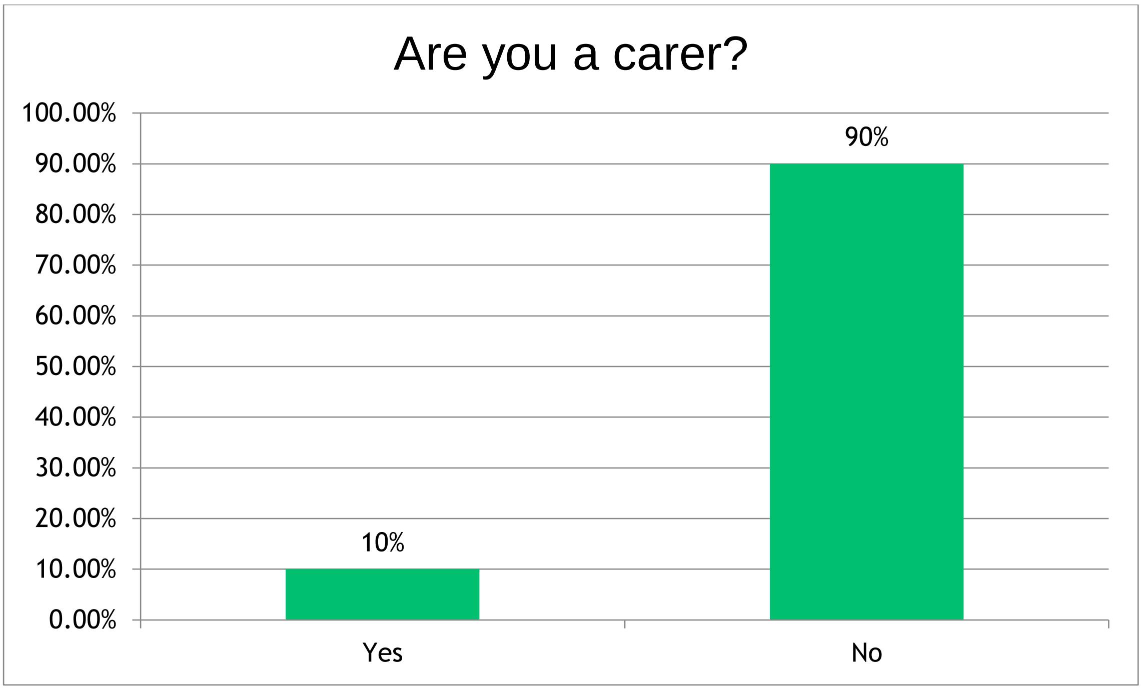


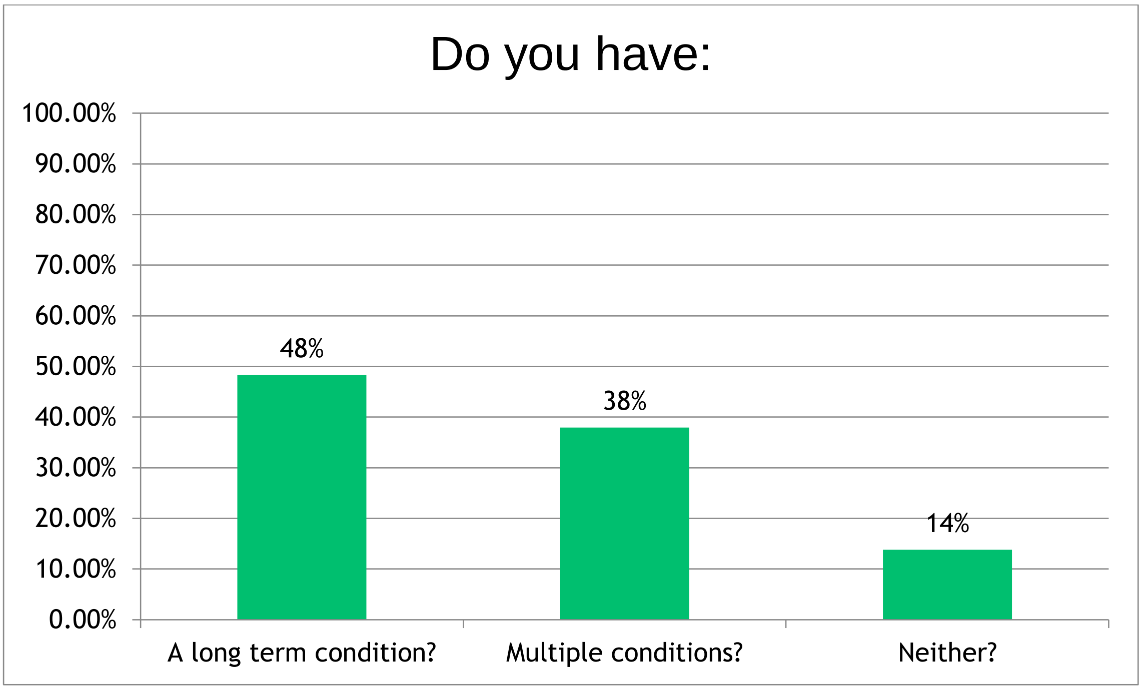
Below detail the demographic characteristics of respondents of the survey for people with specific conditions

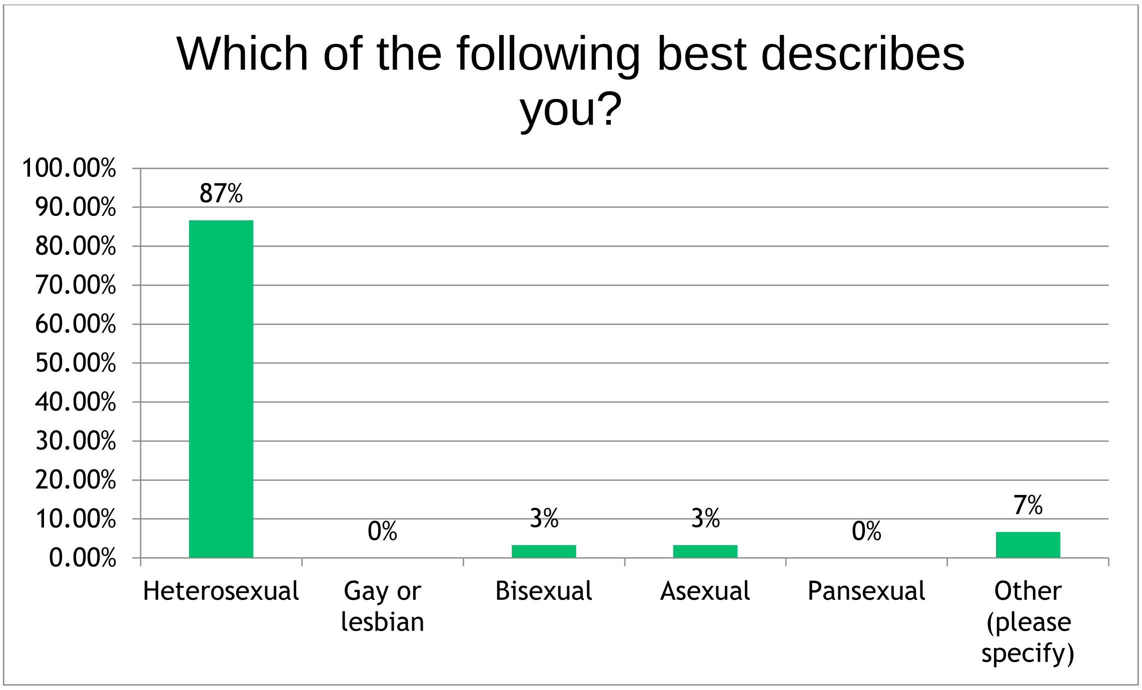


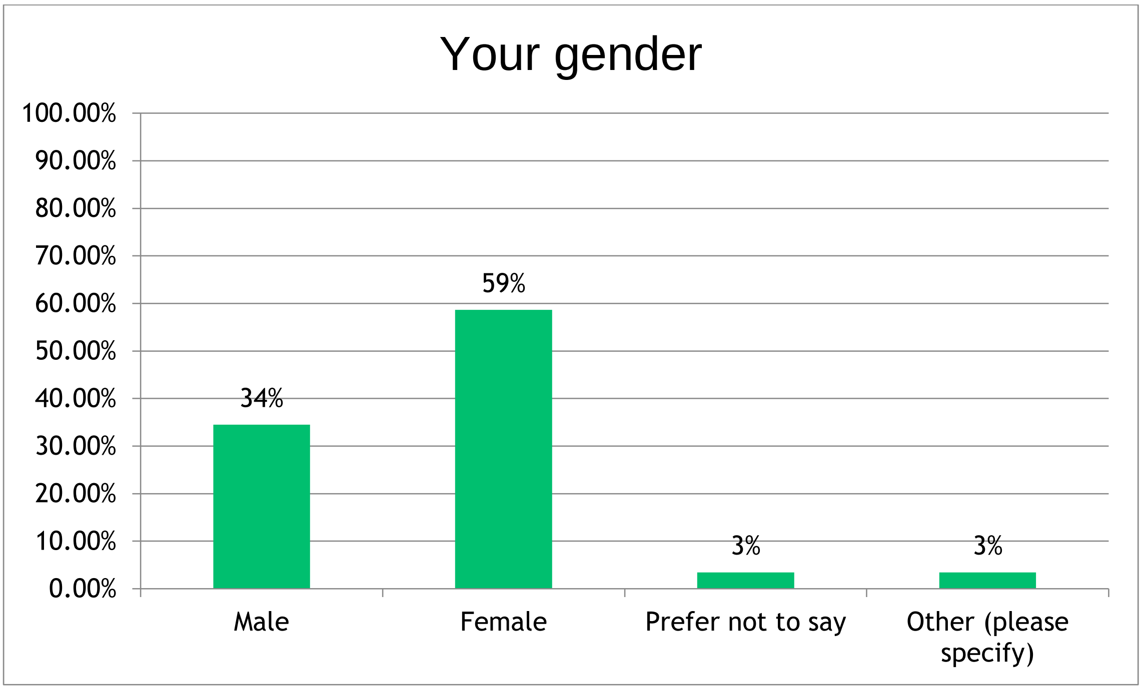

Your ethnicity
100.00%
90.00%
80.00%
70.00%
60.00%
50.00%
40.00%
30.00%
20.00%
10.00%
0.00%
0%
0%
0%
0%
0%
0%
0%
0%
100%
0%
0%
0%
0%
African
Arab
Asian British
Bangladeshi
Black British
Caribbean
Gypsy or Irish Traveller
Indian
White British
Pakistani
Any other white background
Any other mixed background
Other (please specify)

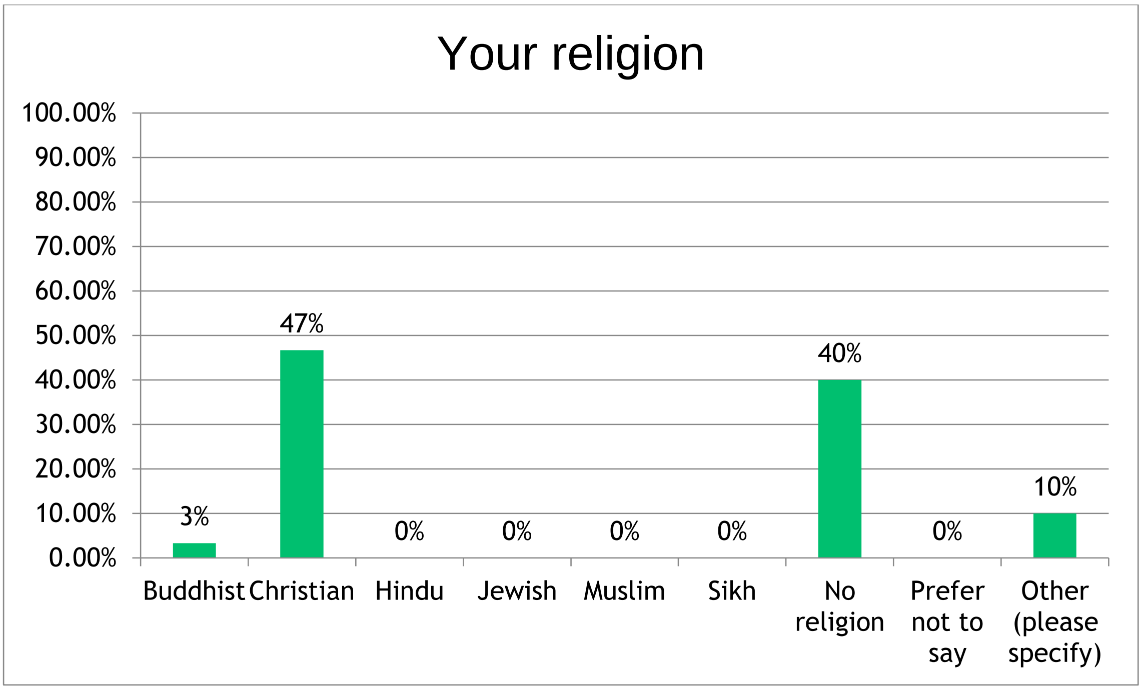

Do you consider yourself to have a disability?
100.00%
90.00%
80.00%
70.00%
60.00%
50.00%
40.00%
30.00%
20.00%
10.00%
0.00%
37%
60%
3%
Yes
No
Prefer not to say


Are you a carer?
100.00%
90.00%
80.00%
70.00%
60.00%
50.00%
40.00%
30.00%
20.00%
10.00%
0.00%
10%
90%
Yes
No


Do you have:
100.00%
90.00%
80.00%
70.00%
60.00%
50.00%
40.00%
30.00%
20.00%
10.00%
0.00%
48%
38%
14%
A long term condition?
Multiple conditions?
Neither?


Which of the following best describes you?
100.00%
90.00%
80.00%
70.00%
60.00%
50.00%
40.00%
30.00%
20.00%
10.00%
0.00%
87%
0%
3%
3%
0%
7%
Heterosexual
Gay or lesbian
Bisexual
Asexual
Pansexual
Other (please specify)


Your gender
100.00%
90.00%
80.00%
70.00%
60.00%
50.00%
40.00%
30.00%
20.00%
10.00%
0.00%
34%
59%
3%
3%
Male
Female
Prefer not to say
Other (please specify)


Your religion
100.00%
90.00%
80.00%
70.00%
60.00%
50.00%
40.00%
30.00%
20.00%
10.00%
0.00%
3%
47%
0%
0%
0%
0%
40%
0%
10%
Buddhist
Christian
Hindu
Jewish
Muslim
Sikh
No religion
Prefer not to say
Other (please specify)