

NHS Long Term Plan

Engagement Report

An insight from people in North Cumbria

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

Executive summary

This project is providing 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
- and 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.

Healthwatch Cumbria is contracted by Cumbria County Council to operate across the whole of the county of Cumbria. However, the county is now associated with two distinct Health and Care Partnerships or Integrated Care Systems (ICSs); the districts of Furness and South Lakeland are included in Lancashire and South Cumbria ICS and the districts of Copeland, Allerdale, Carlisle and Eden relate to the North Cumbria ICS.

Healthwatch Cumbria had a target to collect at least 250 responses from the whole of the county. These have been disaggregated so that responses obtained in the south have been included to inform the coordinated response for Lancashire and South Cumbria ICS and responses obtained from across the north have been used to inform this report for North Cumbria ICS.

Healthwatch Cumbria was also required to carry out two Focus Groups drawn from the whole county but we chose to increase this to two in the south and a further two in the north, one at a general group and one at a group for people with specific conditions. This assured more detailed insight for both reports.

This project report shows the findings from North Cumbria which consists of Allerdale, Carlisle, Copeland and Eden.

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 you need, such as making decisions jointly with professionals and choosing where to receive care
- Keeping your 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 than one condition at a time
- The amount of time to receive initial assessment, diagnosis and treatment

Overall, Healthwatch Cumbria gathered feedback from 224 people, 165 on generic feedback and 56 on specific conditions.

The following report has identified some significant findings in relation to the NHS LTP and the views of the North Cumbrian people regarding their existing services. The report is based on feedback from people who responded to our survey or attended one of our focus groups.

Overview of key findings;

There are challenges being raised regarding accessing the appropriate care and health services due to geographical challenges, lack of consistency of care and lack of service provision, demonstrated in this occasion with failure to provide assessment facilities in Cumbria for someone with Autism, out of county assessment required in this instance.

It was noted however that the introduction of video calls with GPs and the use of technology was identified as beneficial and could provide an opportunity to address some of the areas of challenge that were identified going forward.

The themes of accessing cheaper/free gym, exercise sessions, the provision of better detailed nutrition information/ diet plan availability was highlighted through general engagement and it was also apparent on the online survey to enable people to live a healthier life, supported by the NHS.

Clear and timely communication also featured as a prominent theme based on the feedback provided. It was highlighted that there was some experience of 'a disconnect' between health care providers and the service users in that one service user was having to follow up on surgical procedure appointment dates, scheduled thereafter with little notice to prepare.

Prevention and / or early intervention was identified by more than 50% of respondents as to the level of support the NHS could provide to help people stay healthy. This particular theme identified a range of areas including easy to access nutrition advice, holistic treatments, psychological and talking therapies, specialists to assist with diet and exercise. This particular feedback has provided an opportunity for NHS Cumbria to look at supporting the population to work and think differently with them to implement preventative measures.

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 North Cumbria as well as the specific conditions set out in the long term plan surveys. Some of these areas include stroke, cancer, maternity, and respiratory.

Recommendations

What matters most to people in North Cumbria?

During the local engagement, it was apparent that the method for delivering services varies quite considerably between age groups, geographical barriers and the service users past experience of NHS services in their area.

Largely there were three key themes identified throughout the engagement online and at the focus group sessions;

- 1. Areas that the NHS could improve upon going forward to engage with the service users**
 - *Improved, sustainable travel mechanisms, particularly in the ‘hard to reach’ communities.*
 - *Improved communications across the NHS and Multi-Healthcare network to ensure that the service user does not have to relay their story at every appointment i.e. shared access to service user files.*
 - *Improved waiting times and notice provided to the service user if an appointment has to be cancelled and re-arranged.*
 - *Incorporating the provision of holistic alternative treatments, where applicable, instead of traditional routes*
- 2. Areas that the NHS and Local Authority could work collaboratively on to enable service users to lead a healthier life**
 - *Provide easier/ cheaper access to gyms and exercise classes*
 - *Easily accessible/ easy to understand nutrition advice/ diet plans that are tailored to the individual*
- 3. Preventative measures that could be taken to enable the service user to make better/ healthier choices**
 - *Provide easy to understand nutritional advice*
 - *Access to/support from Healthcare professionals in a timely manner to avoid the need to be admitted to hospital*
 - *Quicker access to mental health services*
 - *Better mental health support for those living in small, rural communities*

In terms of identifying what is currently working well and what could be better, based on the feedback provided by respondents, improved communication between Hospital staff but also NHS and Social Care was a strong theme. When the communication is good and an appropriate care plan has been put in place, with the appropriate level of support the service user feedback is of the highest praise.

Healthwatch Cumbria carried out focus group sessions with the aim to capture what matters most to people living in North Cumbria regarding how they access health and social care services and how they want the NHS to support them to live a healthier life going forward.

In Focus: Diverse Communities



We visited a support group in the Eden District of Cumbria and spoke to 25 people who live in the most sparsely populated districts in the country. General issues in relation to health and social care were discussed and comments were taken on: ‘What keeps you fit and healthy in later life?’ and ‘what would help you to continue to live at home?’ Key themes included:

Public transport - The group informed us about the extreme limitations of public transport in their community “there is one bus, just three days per week”. One lady was referred to Whitehaven in West Cumbria for treatment, a round trip of 110 miles. The volunteer driver scheme is much appreciated for hospital visits but is generally oversubscribed. The patient transport service involves committing almost the whole day for what might be a short appointment and is only available based on strict eligibility. Clinics held in the local surgery were therefore highly valued.

Mental health - An individual told how it is particularly difficult to set up or be part of a mental health support group in a small remote village. Confidentiality was compromised by living in such a small community and people are not willing to self identify.

What support would be helpful?

- Community action groups are extremely important particularly in remote areas
- Personal alarm systems to call for help in an emergency
- Supportive GP services at the heart of the community
- More clinics in nearby towns or within the GP surgery itself would alleviate some of the transport difficulties that older people experience

In Focus: Diverse Communities

The 'My Community and Me' group are part of a six week course provided by Women's Community Matters. The course aims to increase the confidence of its participants and support them to become more integrated in their community. This course is for women only, but offered to all ages and of all abilities. The members of this group are also members of a group called the Swallows, which provides support and companionship for those who are widowed or have lost a partner.

How the focus group took place

The focus group began with an introduction to the NHS Long Term Plan and explaining some of the key areas of change that will be taking place. All members of the group were unaware of the plan and we discussed what the changes outlined in the plan were and what this might look like to them in some detail. The group was asked to complete a task called 'The good, the bad, the OK'. They were given the opportunity to discuss different experiences the group had with their health care in the past and group them within the three categories, this was completed as a group so that we could discuss people's opinions on each experience. After ensuring that each experience was added to the correct category the group were asked to choose an experience from the 'bad' category (which wasn't their own experience) and write a recommendation of how this could have been avoided or improved. Each member of the group was then asked to feedback their suggestions.



Some of the group's suggestions for service improvement are detailed below

Experience	How could the NHS improve this?
Continuity of carer, no familiar GP or 'family doctor' anymore.	More doctors available with smaller population to treat.
Travelling long distances for out of county treatments.	Commission more specialist services in Cumbria.
Have to wait weeks to see a GP for non-urgent appointments.	More medical professionals available, more 'drop-in' appointments and same day appointments available. Could people with similar conditions or older people be seen in groups or specialised clinics to make better use of the professionals time?
No NHS Dentists available	Partly subsidise private dentists so that treatment costs are low. Provide more NHS dentists in the area.

Specific Conditions Identified in North Cumbria

Summary

In total, 56 people responded to the NHS LTP specific conditions survey. Of those who told us about their condition; 14 people said they had a long term condition, 9 had cancer, 3 people had a heart and lung disease, 3 had dementia, 3 said they had a learning disability, 2 people identified as having autism and 2 had a mental health condition.

Of those who responded in this category, 55% advised that they had experienced a very positive or positive journey when seeking help. 21% of people that responded advised that they had experienced a very negative or negative journey when seeking help.

Of those comments provided as being a negative/very negative experience, many told us they had experienced lengthy waiting times for appointments and did not receive helpful information about their conditions and communication from health professional were poor.

Implementing cancer health and care services

Summary

We heard from 9 people in total, with 78% of those being patients spoke about their own experience of accessing cancer care services whilst 22% was on behalf of someone else.

Generally the feedback we gathered around assessment, diagnosis and treatment was predominantly positive, however, a small number of comments referred to lack of information received and waiting times for appointments.

The feedback highlighted a need for better communication and readily available information for patients. In addition, people expressed some concerns around the lack of face to face communication as their support was primarily provided over the phone due to the geographical challenges.

Assessment, diagnosis and treatment

- 56% of those who responded advised that they felt that the support that was provided to them met their expectations. The most prominent themes that arose were the lack of communication between the Healthcare staff across the organisations and the distance that needed to be travelled for appointments and treatment.

"From concerns to diagnosis to treatment I can not fault the care and support that I got. Apart from Christmas delaying things a bit, everything from biopsies, operation to treatment happened quickly and efficiently. The one thing that could be better is not having to travel 1000's miles during the course of treatment. Radiotherapy an hour drive away for example."

Of those people who responded, 38% felt that the time that they had to wait between their initial assessment and diagnosis was fast or very fast

- 63% felt that the time they had to wait between diagnosis and treatment was fast or very fast
- Of those people who responded, 63% confirmed that they were offered access to further health and care support after being diagnosed or assessed

Prevention and/or early intervention

Of the 8 people who responded, all said they would like support from the NHS to enable them to stay healthy, with 38% saying they would like a lot of support.

Some of the recommendations to help manage their condition included implementing regular check-ups, treatment closer to home and good and bad test results to be communicated in detail. The two following comments were received about information/education:

“Reassurance that the way I cope/treat the varying problems that have arisen since treatment is appropriate and if not advice on how to proceed.”

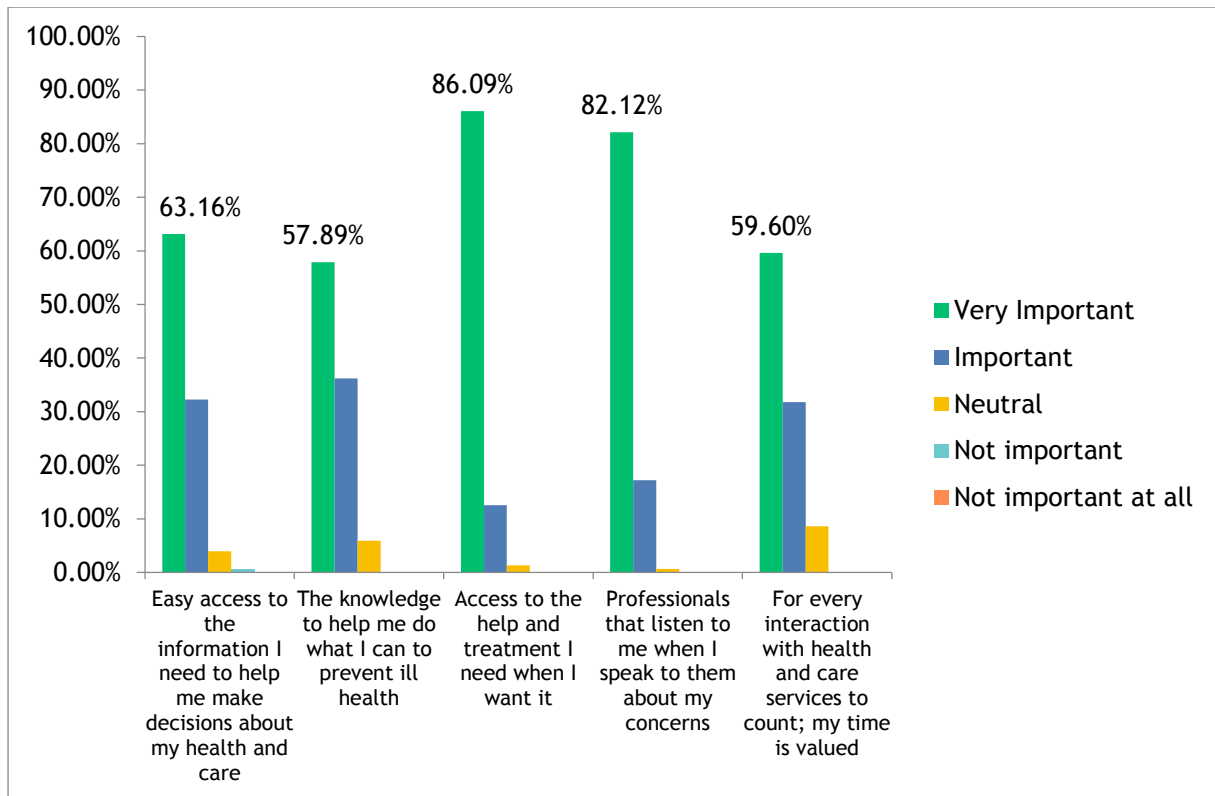
“I don’t know how to choose which problem is the most important to take to the doctor and when I go with a list it is not welcome.”

Local Survey Responses and General Themes Identified

We received 165 responses to the generic survey from people in North Cumbria. All gave Healthwatch Cumbria their consent prior to completing the survey. 95% of respondents provided feedback about their own views and experiences whilst the remaining 5% was on behalf of someone else.

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

The following chart shows that the majority of respondents felt all statements were very important for them to live a healthy life. Access to services for help and treatment and being listened to by professional were considered the most important.



Following this question, respondents were asked if they had one choice which would be the most important: A large majority at **48% said *access to help and treatment I need when I want it.***

There was a key theme throughout the responses that accessing Healthcare professionals was a considerable problem in North Cumbria. When asked about how people could be supported to live healthier lives through accessing help and treatment that is needed the following response was conveyed;

“Access to appointments at the GP’s. It takes too long to access an appointment, ringing at 8 a.m. daily is not always appropriate when at work, the GP app does not always work and patient access only releases 1 minute before 8 a.m. It is not acceptable that you have to fight to get an appointment with a GP.”

“Appointments being available. I have previously been referred for treatment and when I logged on to the NHS site no appointments were available so I was asked to leave a message. Nobody has contacted me and it has been over two weeks.”

Another key theme that emerged from this area of discussion was those respondents who have more than one condition but have described having to ‘pin point’ one or two symptoms to receive treatment, which does not provide an accurate diagnosis or indeed provide the patient with the relevant care and treatment that they require;

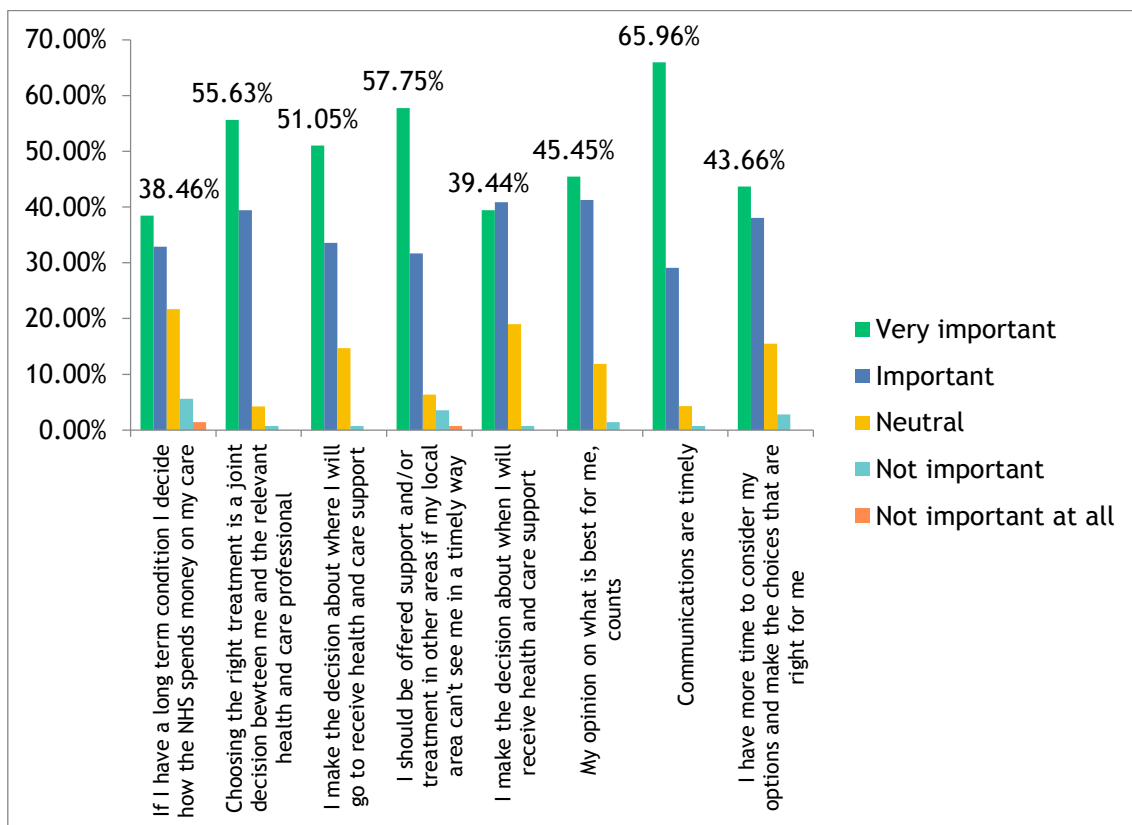
“I would like to be supported by having a health care practitioner listen to me if I have more than one symptom, having to pin your symptoms down to one or two can have an effect on the overall diagnosis and they will not see the “big picture” or see any relevance by limiting what they let me complain about.

It was raised that there also appears to be a lack of communication regarding the care that is provided to the patient in that they are required to explain their situation repeatedly and that there is a lack of ‘joined up’ thinking between those who are providing health/ social care services. Feedback provided indicated that the service provision did not focus on the patient but indeed highlighted the lack of person-centred care;

“Joined up thinking, planning and actions between health and social care professionals. A lead person from the most appropriate discipline working with the ‘patient’. Currently it appears that numerous health and social care professionals want ‘a piece’ of the patients’ time, which is confusing and adds to multiple meetings/contacts, many seem to be an unnecessary duplication.”

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 scored the highest whilst the second highest was being given the choice to be treated in a different area in the event that this can not be provided in their local area in a timely way.



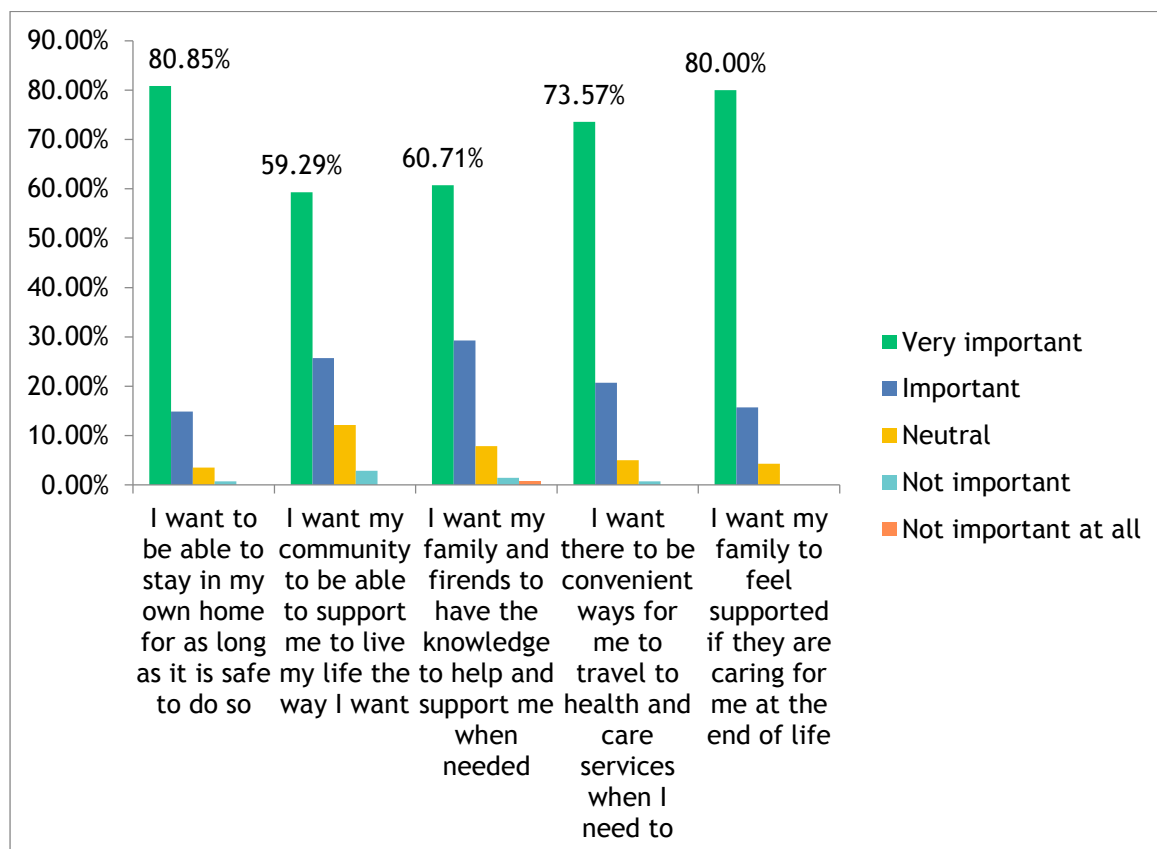
Following this question, respondents were asked if they had one choice which would be the most important: A large majority at **41% said choosing the right**

What would you do?

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

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

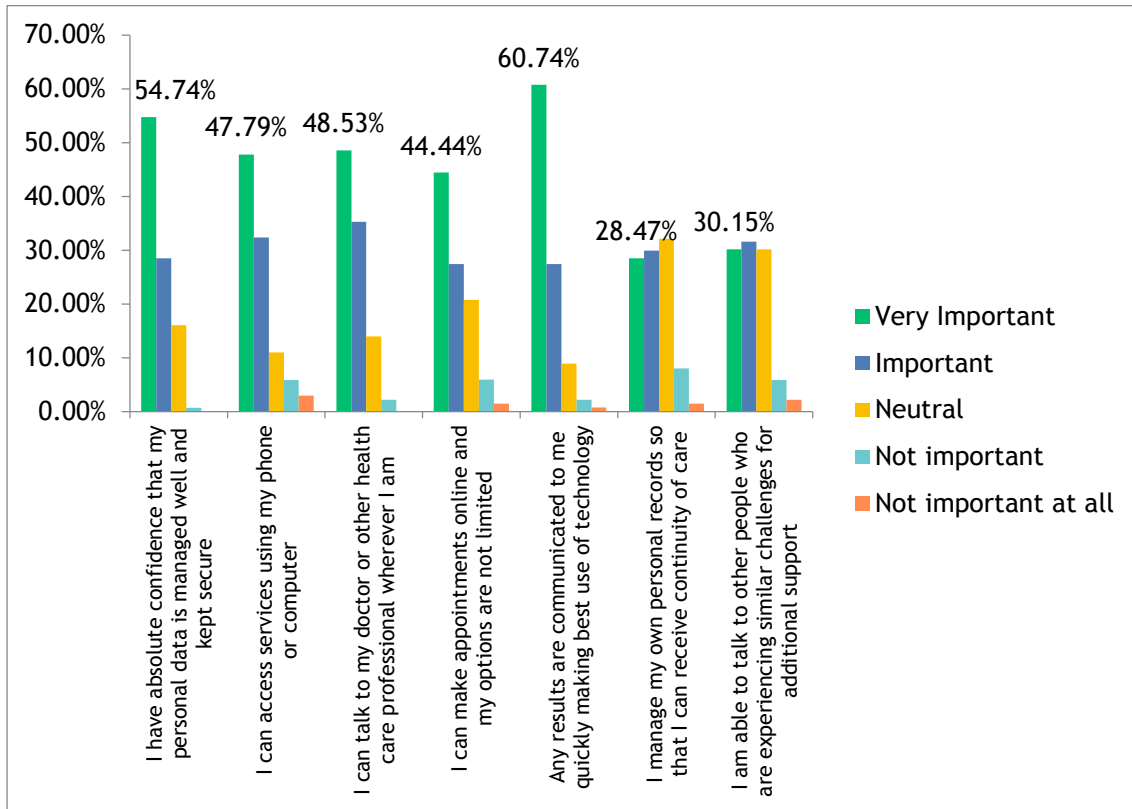
The chart below shows that the majority of respondents felt all statements were very important for them to maintain their independence and age healthily. Ensuring their family are supported if they care for them at the end of life and staying at home for as long as possible scored the highest.



Following this question, respondents were asked if they had one choice which would be the most important: A large majority at 48% said *I want to be able to stay in my own home for as long as it is safe to do so.*

We asked: “What is most important to you when interacting with the NHS?”

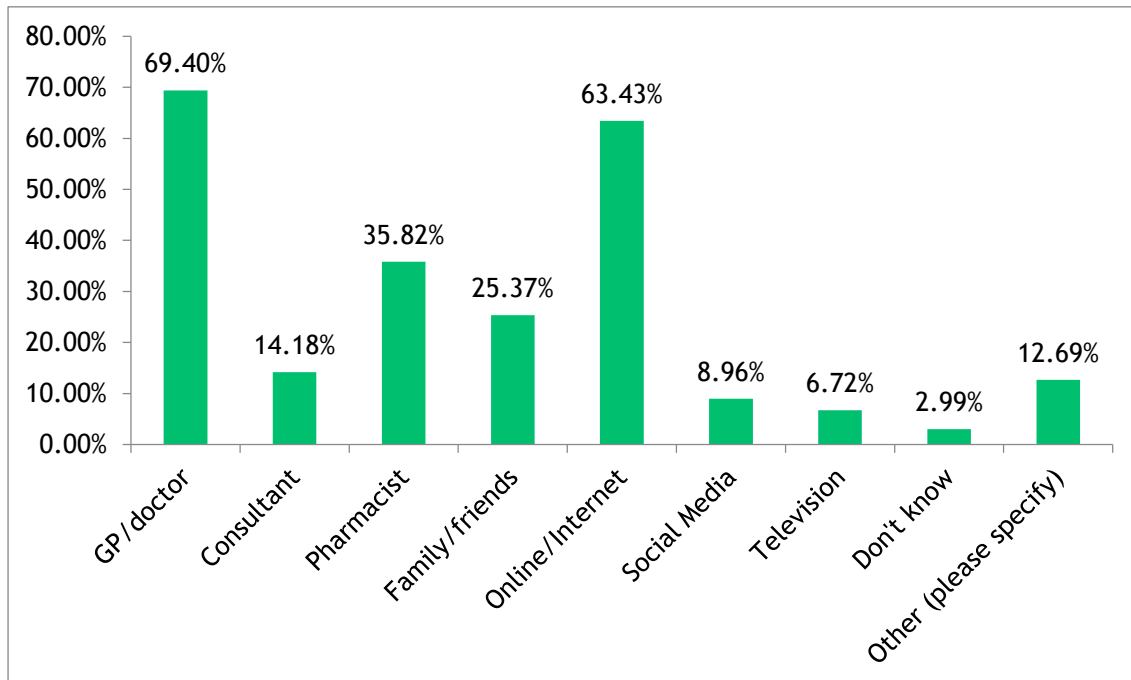
The chart below shows that the majority of respondents felt most statements were very important for them when interacting with the NHS. Receiving results quickly scored the highest followed by having complete confidence that their personal data is managed securely



Following this question, respondents were asked if they had one choice which would be the most important: A majority at 37% said *I can talk to a doctor or other health care professional wherever I am.*

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

The chart shows that the majority would either go to their GP/doctor or by consulting online sources with similar results for each.



Of the comments received there were mixed responses regarding online access to support; however, given that there are challenges in the geographical barriers, perhaps a stronger online support presence and education in how to optimise it would be welcomed by the people of North Cumbria.

The Positives identified in using online/ new technology

“More on line access to my records and treatment and appointments etc. Options to have video conference calls to GPs and consultants or email options.”

“Technology to 'check' when I am 'in trouble' in my home. (pendants etc are OK but not the full answer and other available technology could be applied. eg a check on whether the lavatory had been flushed, any 'power' items switched on such as a kettle, whether lights had been switched on or off, a bed side mat with a sensor to record movements etc.)”

“I am currently expecting my first baby, an app would be better than green notes. Something interactive and something that helps you write your birth plans.”

The Negatives in using online/ new technology

“Technology great for younger generation, however part of the elderly generation are reluctant to use it and may benefit from leaflet indicating where they can access support/ help when required.”

In April 2019, a maternity app was introduced to remove the need for paper notes in North Cumbria. To date there has been 100% take up of the app.

“Sometimes technology can get in the way of really good personal relationships built on trust and consistency of support - I would like some reassurance that opportunities to have this in place won't be lost.”

“Not being pushed to use computers to book appointments and get repeat prescriptions. More time should be given to assist people to make these changes.”

Next steps

Response from North Cumbria Health and Care System

North Cumbria Health and Care System (NCHCS) welcomes the Healthwatch NHS Long Term Plan engagement report findings.

Our thanks go to Healthwatch partners and engagement colleagues for their hard work in this important piece of work.

We are delighted that Healthwatch was able to hold engagement sessions in a range of areas including in rural Eden and with those with long term health conditions. This is a very helpful addition to work we have been doing with staff, partners and other specific community groups including, young people.

It is reassuring that the feedback reflects the areas we know are challenged - especially around mental health services and travel for some specialist treatment - and also that it shows an appetite for more support to stay well, prevention and early intervention, areas we are focusing on.

We recognise and value having peoples' voices at the very heart of all we do and remain committed to actively listening whilst taking into consideration these views wherever possible. We also believe that to improve care for people, health and care services need to work more closely together and improve the way the health system and patients communicate.

We want to know more about the experience of people living with multiple long term conditions and we are pleased that Healthwatch Cumbria will be working with two groups to provide some detailed information about the experience of these patients.

We would also like to invite Healthwatch Cumbria to present their report, and the feedback from the two focus groups, to our System Leadership Board on the 5th September 2019.

Methodology

The methodology used to collect and collate this report for the people of North Cumbria 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

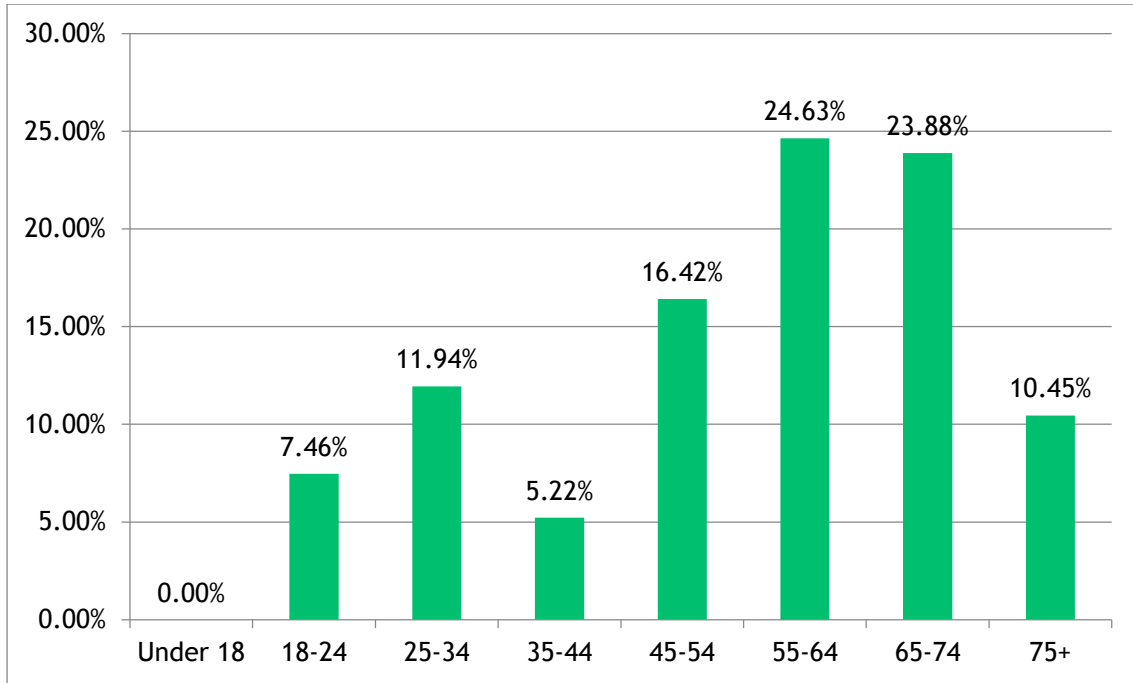
With many thanks to all who have contributed to making this report possible:

- To all of the service users of North Cumbria who have engaged with us either online or in person.*
- Cuppa and Company, for making us welcome to chat within their group and gather their feedback*
- My Community and Me, for making us welcome to chat within their group and gather their feedback*
- Healthwatch Cumbria Engagement Team*

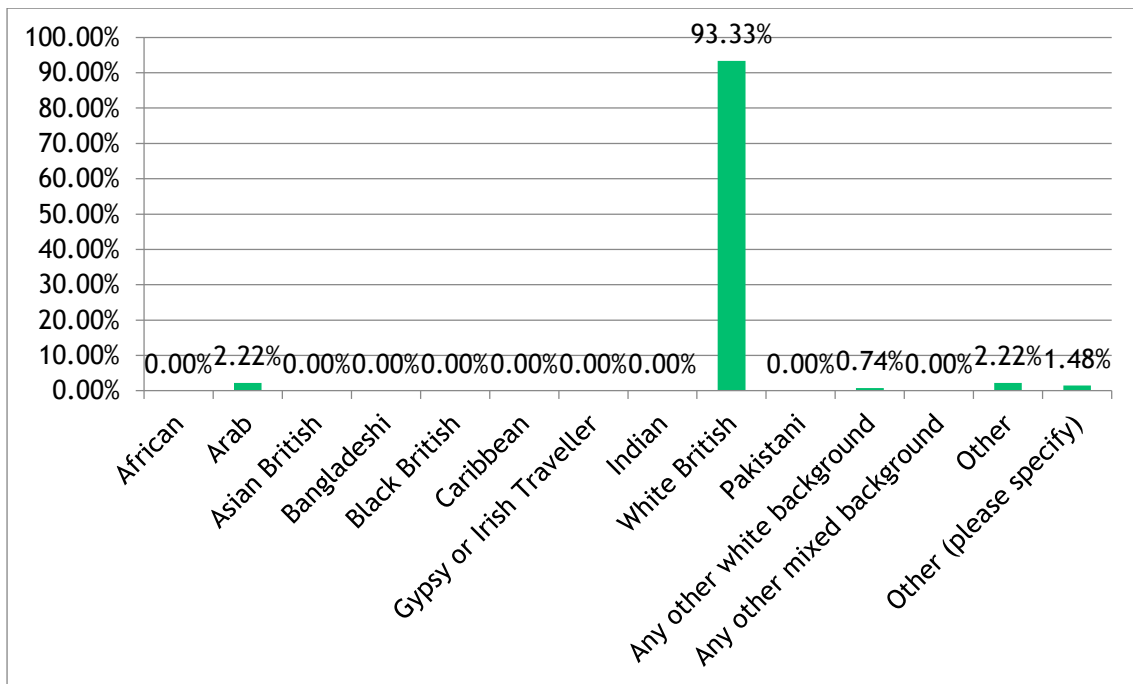
Appendix1 Demographics

Below detail the demographic characteristics of respondents across North Cumbria

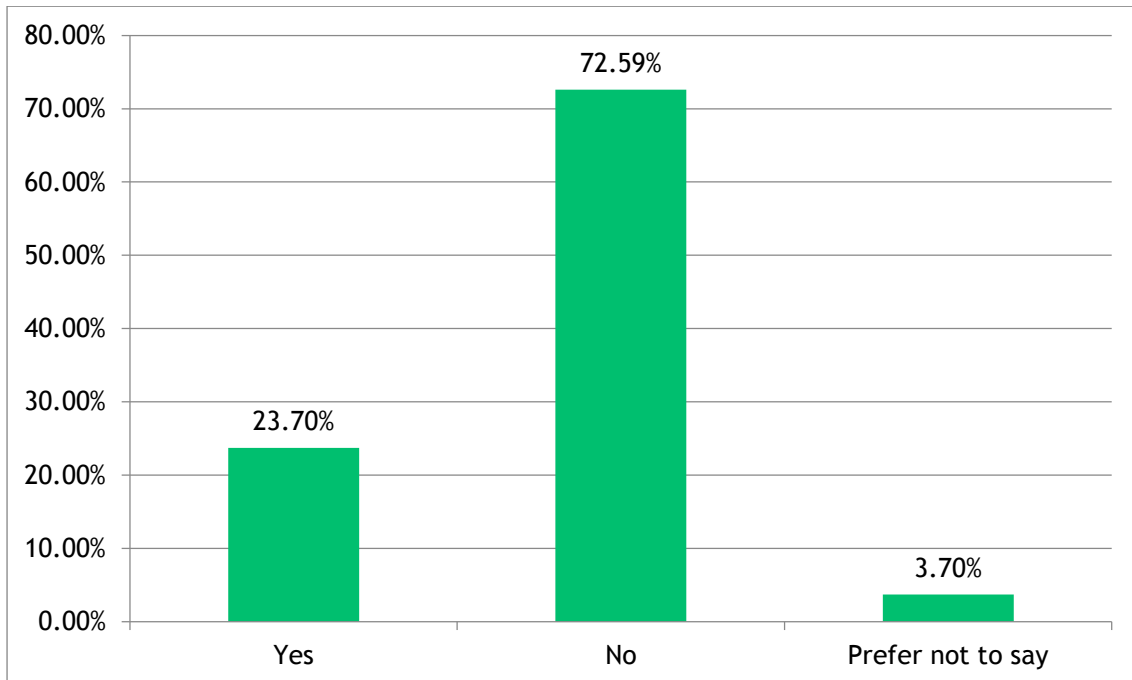
Age



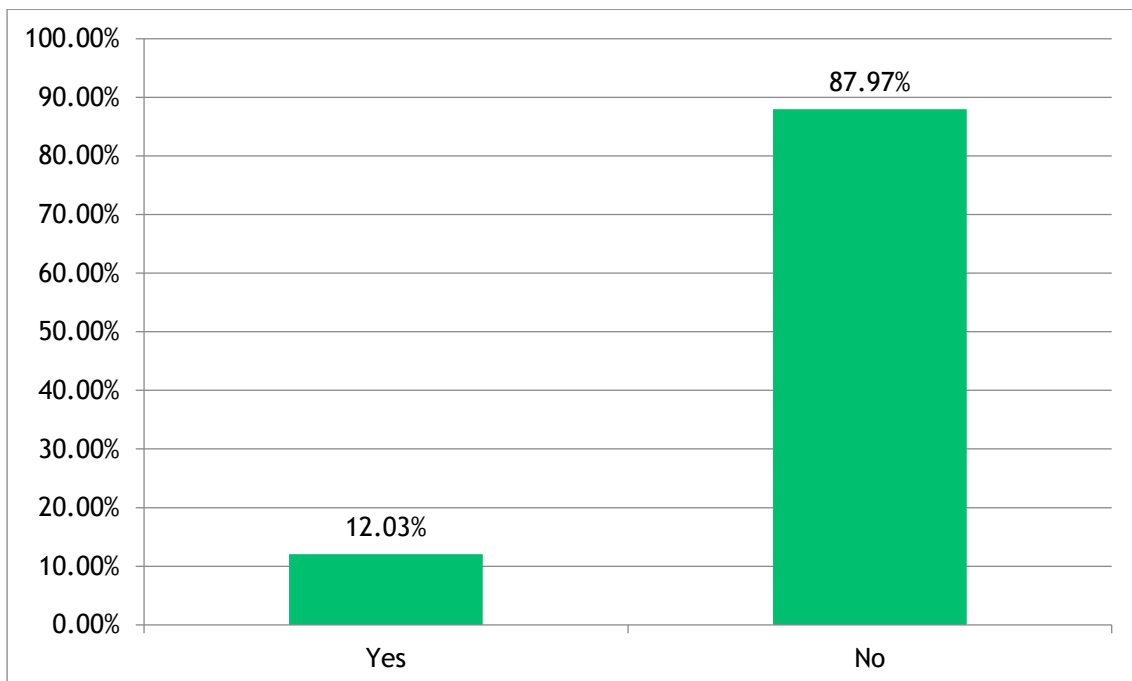
Ethnicity



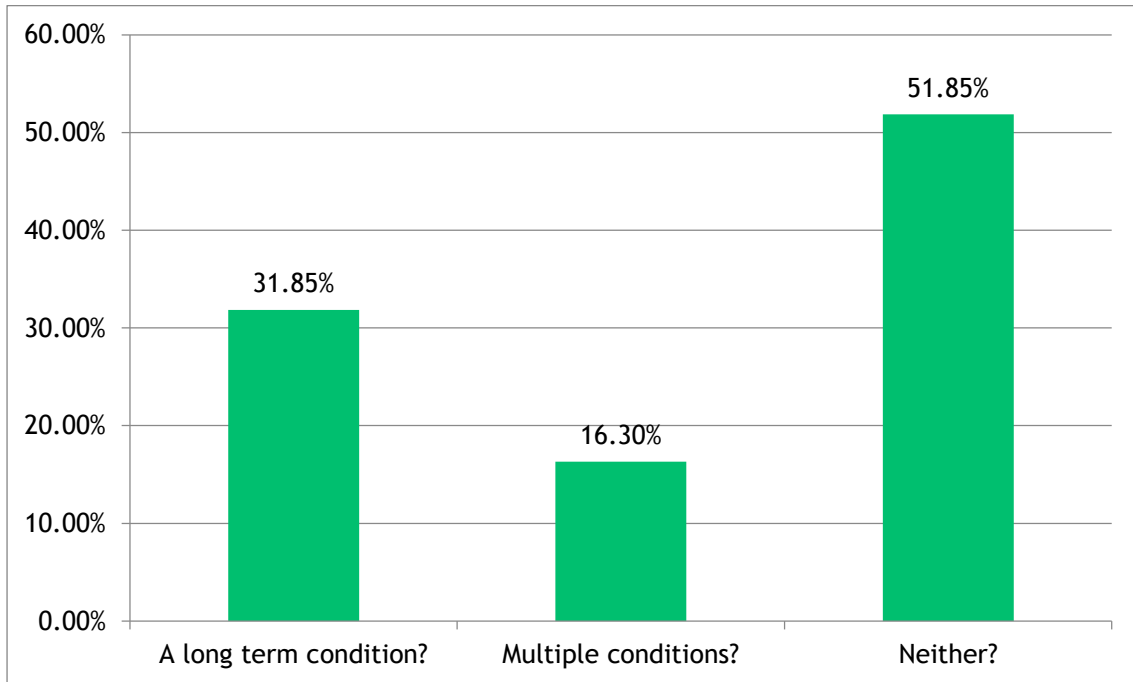
Do you have a disability?



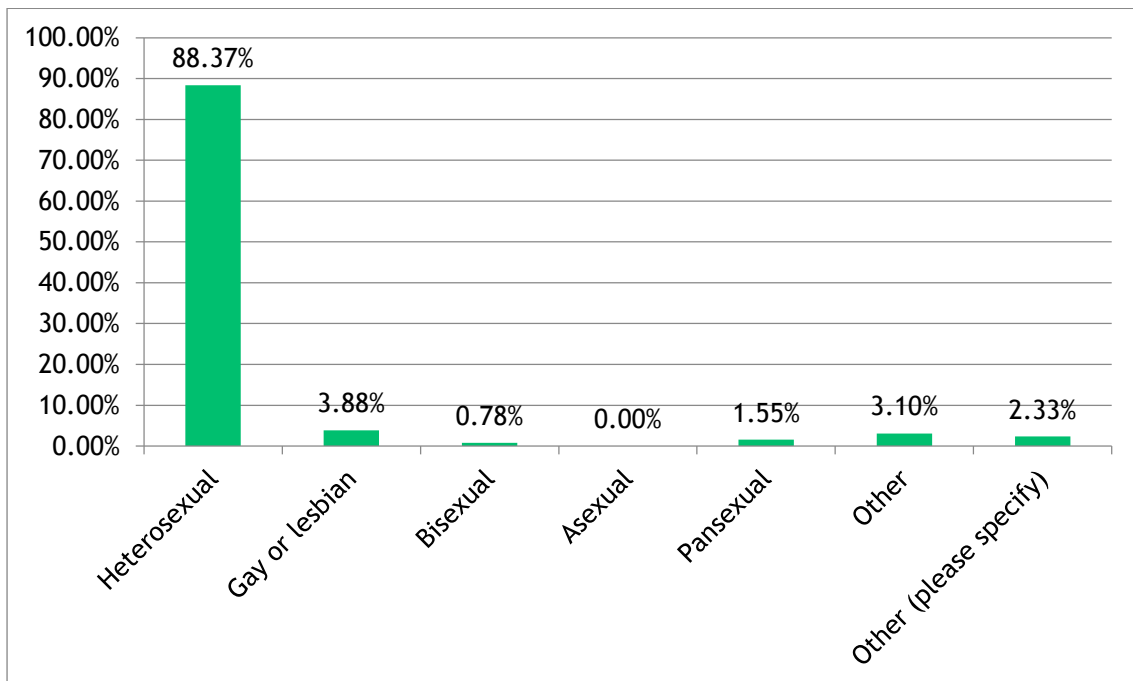
Are you a carer?



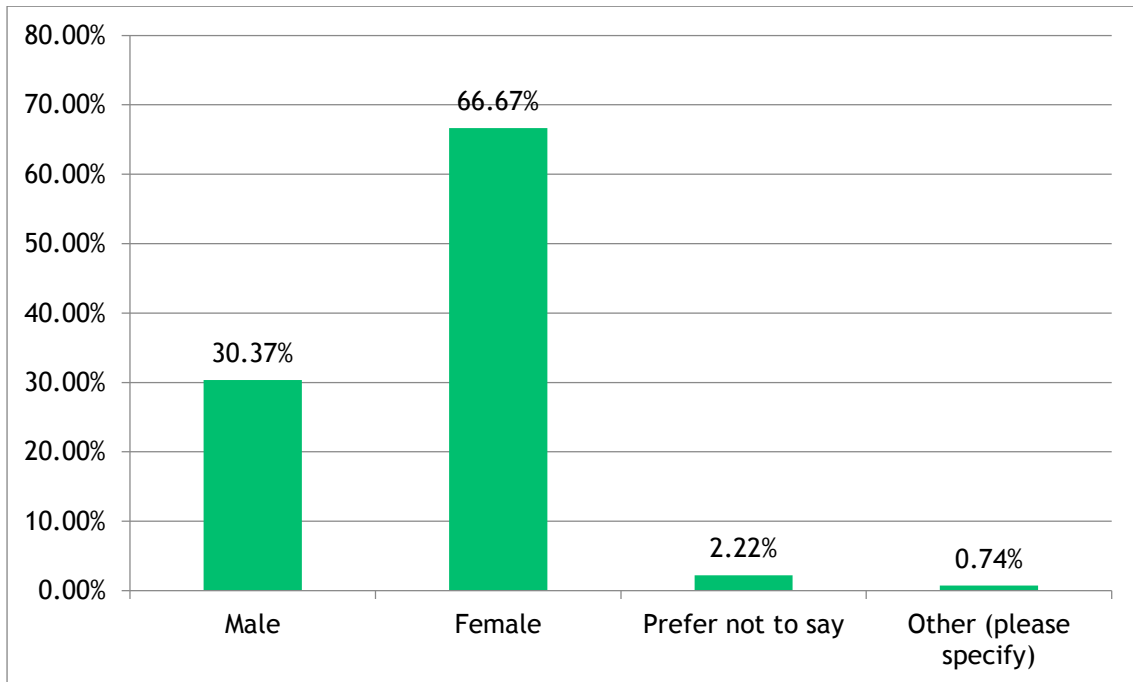
Do you have a long term condition?



Sexuality



Gender



Religion

