

NHS Long Term Plan

Engagement Report

An insight from people in Lancashire & South
Cumbria

wh  **t**

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.

This project shows the findings from each respective Healthwatch within the Lancashire and South Cumbria ICP footprint, which are:

- Healthwatch Lancashire
- Healthwatch Blackburn with Darwen
- Healthwatch Blackpool
- Healthwatch Cumbria (Carnforth, Barrow, Kendal, Ulverston, Millom and Kirby Lonsdale)

Each Healthwatch had a target to fulfil the following:

1. Gain feedback from 250 people in each area on general views about the Long Term Plan or specific conditions (Healthwatch Cumbria was half of this at 125, as the other half falls under a different ICP area)
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 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 in Lancashire and South Cumbria gathered feedback from 969 people, 803 on generic feedback and 166 on specific conditions.

Each Healthwatch engaged with people in two focus group settings, including a day centre in Blackpool, a self advocacy group in Barrow in Furness, a respite care service in Chorley and a women's South Asian group in Blackburn with Darwen.

We also completed a number of more detailed case studies

The following report has identified some significant findings in relation to the NHS LTP and the views of the Lancashire and South Cumbria people regarding their existing services.

Key findings from the general 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. Those listed below detail those that scored the highest:

- Access to services and being listened to were considered the most important for people to live a healthy life.
- Choosing the right treatment with health professionals and timely communications 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 that having complete confidence that their personal data is managed securely was the most important followed by receiving results quickly. Interestingly, when asked to make once choice from this list, the highest score changed to being able to talk to a doctor or other health care professional wherever they are.
- The majority of respondents said they would go to their GP/doctor to find out how to stay well whilst consulting online sources was the second choice overall.

There is significant differences for individuals travelling the same care pathway in terms of diagnosis, treatment and support/ on-going support provided - this was identified in reference to those on a Dementia Care Pathway in Lancashire.

There was reference to the "inequality (of treating dementia) compared with other long-term condition, for example cancer".

The theme of alternative therapy was raised in all forums, face to face, specific and general groups, through general engagement and it was also apparent on the online survey.

It was highlighted that social prescribing would require a change in position both of cultural views and also a change in service provision for women from a South Asian background to be able to access this alternative form of support for example going forward, but that it would be welcomed.

Prevention and/ or early intervention was identified by more than 90% 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 area was also identified as being significantly important for those with existing heart and lung disease diagnosis including;

- *Support groups with health professionals in attendance*
- *Quicker appointments*
- *Provide Specialist health care practitioners*
- *Regular assessments and reviews*
- *Ongoing treatment with a consistent professional medical practitioner*
- *Regular check-ups to see if any change of condition*

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.

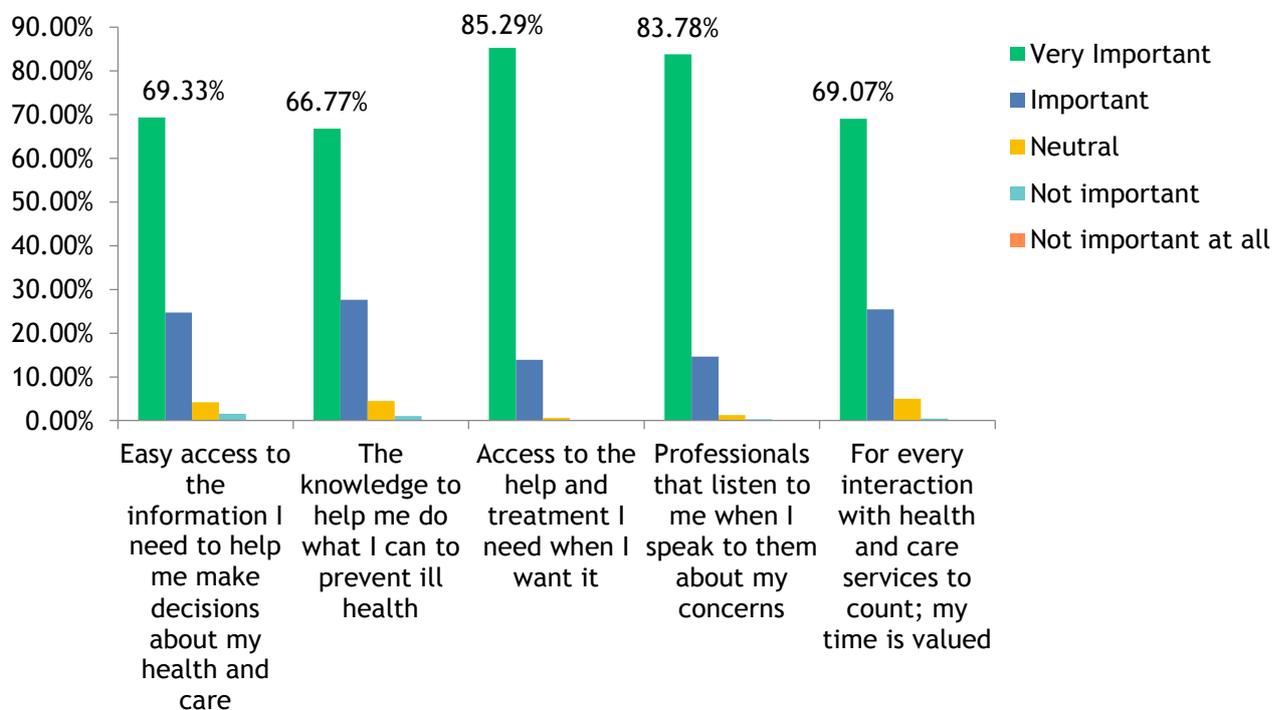
Local Objectives: There are many areas of interest and development locally in Lancashire as well as the specific conditions set out in the long term plan surveys. Some of these areas include stroke, cancer, maternity, and respiratory.

Summary of Findings:

We received 803 responses to the generic survey from people across Lancashire and South Cumbria. All gave Healthwatch their consent prior to completing the survey. 97% of respondents provided feedback about their own views and experiences whilst the remaining 3% 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”

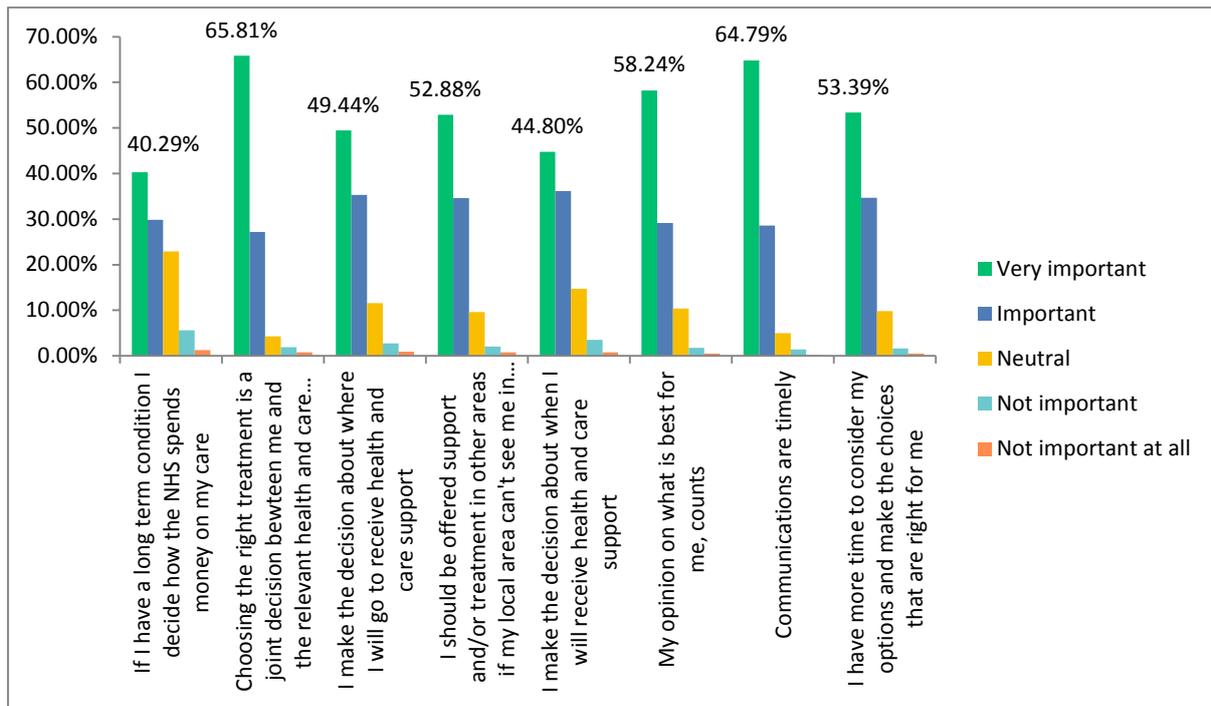
The chart below shows that the majority of respondents felt all statements were very important for them to live a healthy life. Access to services and being listened to were considered the most important.



Following this question, respondents were asked if they had one choice which would be the most important: A large majority at **42%** said *access to help and treatment I need*.

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

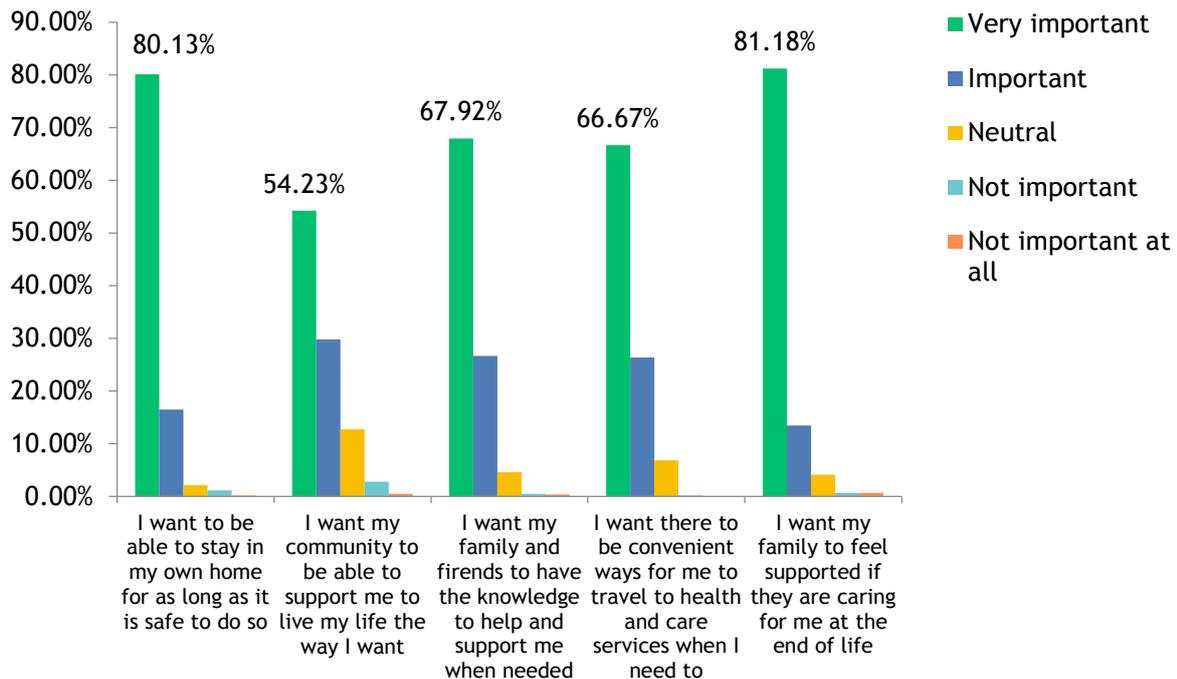
The chart below shows that the majority of respondents felt all statements were very important for them to manage and choose the support they need. Choosing the right treatment with health professionals and timely communications scored the highest.



Following this question, respondents were asked if they had one choice which would be the most important: A large majority at 40% said *choosing the right 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”

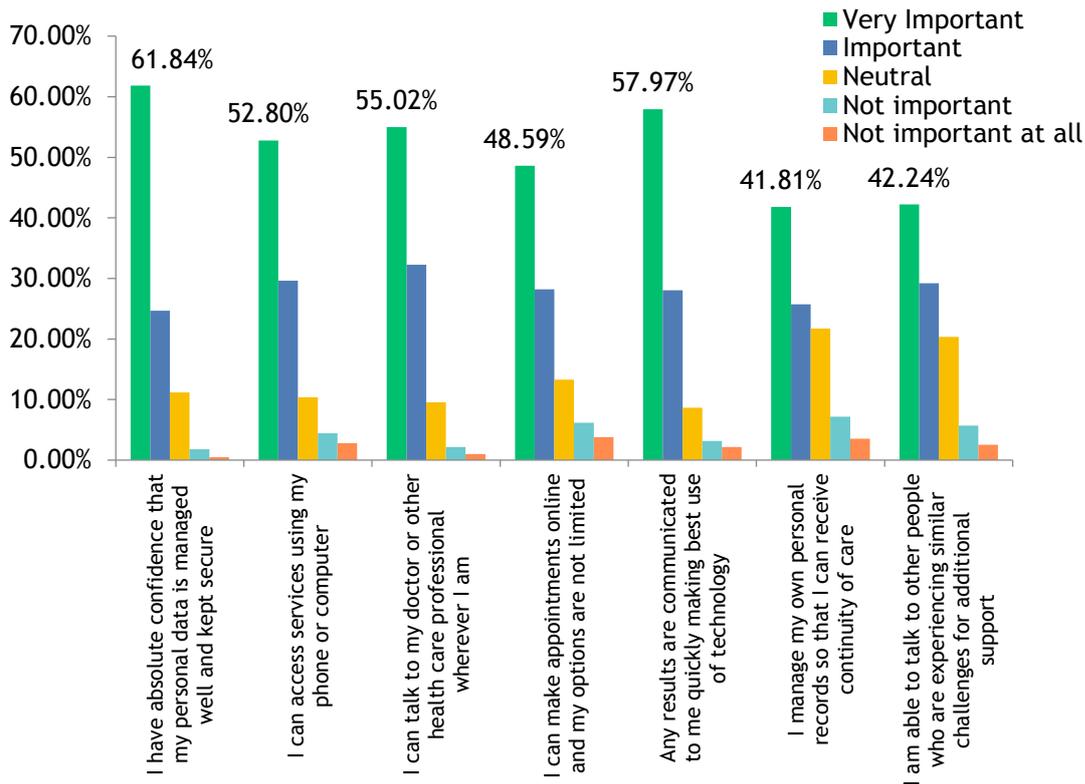
The chart below shows that the majority of respondents felt all statements were very important for them to maintain their independence and age healthily. Ensuring their family are supported if they care for them at the end of life and staying at home for as long as possible scored the highest.



Following this question, respondents were asked if they had one choice which would be the most important: A large majority at 58% 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?”

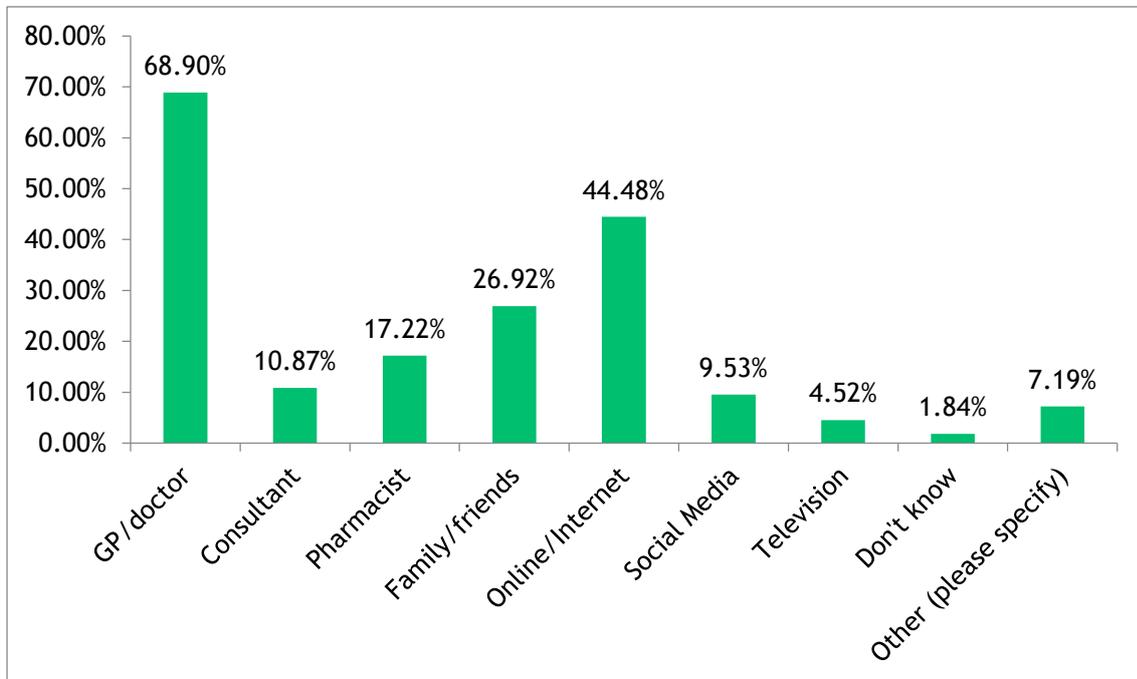
The chart below shows that the majority of respondents felt all statements were very important for them when interacting with the NHS. Having complete confidence that their personal data is managed securely scored the highest followed by receiving results quickly.



Following this question, respondents were asked if they had one choice which would be the most important: A majority at 33% 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 go to their GP/doctor followed by consulting online sources.



What matters most to people in Lancashire and South Cumbria?

During the local engagement, it was clear to see that there were significant differences in how the local people wanted services to be delivered to them depending on the age groups that we engaged with, the location of the groups that we facilitated (geographical barriers were identified in some areas) and the service users past experience of NHS services in their area.

The preferred way in which people wanted to engage with the health services regarding how to get information on how to stay well was face to face with their GP/Health Professional with 97% of those who responded stating that they would still want to speak to someone face to face. This is in stark contrast to those who stated that they would look for information online or via a social media platform, 44% and 10% respectively.

Recommendations

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
 - Providing workshops to service users on how to cook healthy, nutritious food on a budget.
- 3. Preventative measures that could be taken to enable the service user to make better/ healthier choices**
 - Provide easy to understand nutritional advice that goes beyond the Eat Well plate, including vitamins and minerals and how these work to keep us healthy
 - 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 for both children and adults to avoid being admitted to

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 between the NHS and Social Care services was a prominent 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 a highly positive nature. However, as identified in the focus group sessions, when this is not the case, although individuals may be using the same services, their experience is significantly varied.

In Focus: Diverse Communities



We met 7 women of South Asian (both Indian and Pakistani) background who attend the Kiran Women's Group at Bangor Street Community Centre in Blackburn. The topics discussed with the group focused on their experiences of accessing Primary Care and Community Services, options for treatment and support for long term conditions and

use of Technology in communications.

Access to services - Language barriers were raised as an issue in accessing GP services with the length of appointments being a problem if people struggle to understand English well and cannot access a GP who speaks their language. Communication with receptionists was deemed to be harder for the group than with GPs and Language Line was not often used. The group also felt that adjusting to receptionists asking details about conditions was problematic: -

“I just don't feel comfortable telling them what is wrong with me in front of other members of my community”

Alternative Therapy - The group felt that social prescribing could be good, but it would take both a shift in cultural views and a change in services for women from South Asian backgrounds to access this kind of support. They felt that it would need to be tailored to the needs of their community with GPs having knowledge of South Asian groups who could offer support.

Mental health - The group felt that mental health is still taboo within their community and whilst depression is now more accepted, complex issues such as schizophrenia are just not recognised. Improved partnership working between health services and mosques or voluntary organisations would help to make progress in this area.

Dementia care - Communication between services was described as poor and that there were not enough support for families or carers. The community wants more support to help keep family members at home for as long as possible “that's so important in our culture”.

Implementing cancer health and care services

Summary

We heard from 26 people in total, more than 80% of those being patients with a first hand experience of accessing cancer support services. More than 60% of these people told us about their experiences within the last three years of being diagnosed with cancer. We also found that more than 30% of these people had other additional conditions.

Generally the feedback we gathered around assessment, diagnosis and treatment was predominantly positive, however, it did highlight some areas of improvement. Similarly, were experiences of ongoing care and support. The feedback highlighted a need for better communication and readily available information for patients, when it matters.

When people first seek help and during diagnosis and treatment they would rather see any appropriate professional who is available immediately. However, for long term support they would rather see a familiar professional even if they had to wait a while.

Assessment, diagnosis and treatment

- 50% of people told us when they tried to access help the support did meet their needs

“The oncology unit was outstanding. There was ‘joined up’ thinking with other departments when co-ordinating both my wife’s cancer as well as mine. We were put up in a hotel and had treatment on the same days and at the same time”

- 25% of people told us when they tried to access help the support did not meet their needs

“There was no information whatever available at the oncology department or at my GP surgery related to my kind of cancer. I was given three badly photocopied sheets - two were not about my cancer and the third was links to Macmillan”

- More than 79% of people described their overall experience of getting help very positive, positive or average
- When reflecting on waiting times for an initial assessment, diagnosis , receiving treatment or seeing a specialist most people felt it was ok, fast or very fast
- After being diagnosed were people offered access to further health and care support?

Yes - More than 40% - people commented how the staff were friendly and helpful and external support such as MacMillan and palliative care services was put in place very quickly.

No - More than 57% - people reported that there was too long of a wait for district nurses to visit when they were in pain. In addition there was little input from Mac Millan nurses, no information given and long waiting times in clinics.

The provision of ongoing care and support

- The majority of people reported that it was ok or easy to find access to ongoing support, however some were unsatisfied with the support they received

“The nursing team did not understand my cancer diagnosis and were confused by my treatment plan. They didn't read my notes and were unprofessional when I was an inpatient”

“The care was OK but I had difficulty with accessing a cancer nurse when I had decisions to make over treatments”

- When considering timely and consistent communication there were conflicting responses

People told us how some phone assessments were planned for a specific time but the oncology unit didn't communicate well regarding when they would be calling. Patients felt that their conditions went un diagnosed due to lack of understanding from their GP. We were told that one patient learnt more information by 'googling' their condition.

Prevention and/or early intervention

- What level of support could the NHS provide to help people stay healthy?

More than 90% of people would want a lot or some support - people suggested a range of medications, holistic treatments, psychological and talking therapies. Others spoke about gaining support close to home by specialist nurses and help with diet and exercise.

“I appreciate there are a team of specialists working together to give me the most effective treatment. However, It can get quite complicated and the nurse specialist had to intervene when I seemed to drop off everybody's radar for about eight weeks. I phoned her up and asked what was happening”

In Focus: Dementia Care Service in Lancashire

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

Genesis 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 words, 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, and the next day Mum thought the burglars were at the Magistrates court. I went to the GPs with Mum as she was confused 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 a keysafe, Mum’s medication was put in to blister packs and she had a Lifeline 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 Social work support and a carer’s assessment from Ncompass a care package of domiciliary care was put in place and other adaptations made at home, to support Mum’s independence.

Through Ncompass there was a referral to the British Legion Admiral Nurses, as my Mum had been in the services. “My 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 help line to be promoted right across health and social care services so that carers and families know there is support available.

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 Charnley 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 phonecall. 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 ongoing support.

Could it be improved and how?

A referral there and then to Ncompass 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, ncompass, Dementia uk, social services. A named person to follow up with a pre arranged phonecall.

“ 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.”

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 (LCC and Chorley Council)” So a bit in limbo.

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

Tarnia has recently joined a choir it can be beneficial for dementia “I felt relaxed as soon as I got there,” “It's really important to be with people”

I'm a people person.

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 exemplified 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.

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.

Ncompass assessment is really important. As a carer I’ve signed up to Ncompass Peace of mind 4 carers, just in case anything happens to me.

Implementing Heart and Lung Disease health and care services

Summary

We heard from 11 people in total, more than 80% of those being patients with a first hand experience of accessing support services for heart and lung disease. More than 70% of these people told us their conditions started more than three years ago. We also found that more than 50% of these people had other additional conditions.

Generally the feedback we gathered around assessment, diagnosis and treatment was predominantly positive, however, did highlight some areas of improvement. Similarly, were experiences of ongoing care and support. The feedback highlighted concerns around waiting times to see a specialist as well as the delays in communication between specialists and GP's.

When people first seek help they would rather see any appropriate professional who is available immediately. During diagnosis and treatment they would rather see a familiar professional even if they had to wait a while. For long term support, 55% of people are happy to see anyone appropriate, whilst 44% would rather see someone familiar.

Assessment, diagnosis and treatment

- 90% of people shared that the initial support they received met or somewhat met their needs

“I had my first of six heart attacks 42 years ago and a stroke 6 years ago. Support has improved over time. I have benefited from the hospital recommending me to a gym for people with a heart condition. With people who attend having similar problems we talk about our problems and learn from each other”

- More than 80% of people described their overall experience of getting help very positive, positive or average
- We asked people what they thought of the length of time waiting on an initial assessment or diagnosis and over 40% reported it was ok.
- When reflecting on the waiting time between the initial assessment and diagnosis and receiving treatment responses were conflicting

More than 50% of people commented that the waiting times were slow or very slow. 40% of people commented that waiting times were fast or very fast. *Waiting times to*

see a specialist was similar with almost 40% of people reporting it was fast and 50% of people reporting it was slow or very slow.

The provision of ongoing care and support

- More than 40% of people found it easy to find ongoing support after they were diagnosed or assessed but whether the support met expectations was conflicting.

People expressed their disappointment at not being taken seriously until their conditions were fully diagnosed. Others spoke about there being no local support and having to contact a national society to get information.

- When considering timely and consistent communication there were conflicting responses

People commented how it can take a long time for letters from the consultant to reach the GP and at times support was absent

Prevention and/or early intervention

- What level of support could the NHS provide to help people stay healthy?

100% of people would want a lot or some support

Support suggestions were:

Support groups with health professionals in attendance

Quicker appointments

Provide specialist health care practitioners

Regular assessments and reviews

Ongoing treatment with a consistent professional medical practitioner

Regular check-ups to see if any change of condition

Implementing Mental health and care services

Summary

We heard from 36 people in total, more than 70% of those being people with a first hand experience of accessing support services for their ill mental health. 55% of these people told us their conditions started more than three years ago. We also found that more than 60% of these people had other additional conditions.

Unfortunately, in general the feedback we received was negative. People told us about their disappointment with waiting times, ongoing support and lack of communication. In addition people shared how the support they eventually received had not at all been helpful or met their expectations.

When people first seek help there was a difference of opinion in preference to seeing any appropriate professional who is available immediately or someone who is familiar. However, during diagnosis and treatment and for long term support they would rather see a familiar professional even if they had to wait a while.

Assessment, diagnosis and treatment

- More than 50% of people reported that when they initially tried to access help the support did not meet their needs

“I have been waiting to see someone and I’m classed as urgent. Both my support worker and councillor have written to the mental health nurse and neither have had a reply. I was promised an update at the end of the week, however they never keep to promises. I have now lost all faith in the mental health services in Blackpool and it had taken me years to build up the courage to ask for help”

- When people reflected on the time they waited to see a specialist the vast majority felt it was slow or very slow - most commented that they waited over a year.

The provision of ongoing care and support

- More than 50% of people found it difficult or very difficult to find ongoing support and over 60% of people did not feel the support met their expectations

“I wasn't offered any counselling initially and had to pay for private treatment”

“I've been told that my mental health issue is best treated with talking therapy and although I'm under the care of the mental health team, I have not been offered any therapy”

“I was offered Cognitive Behaviour Therapy, 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”

- When considering timely and consistent communication more than 60% of people were unhappy

People expressed the lack of communication about waiting times and diagnosis was disappointing. In addition they expressed that appointments were cancelled at very short notice with no explanation.

Prevention and/or early intervention

- What level of support could the NHS provide to help people stay healthy?

More than 80% of people would like a lot or some support

Support suggestions were:

Support through alternative solutions when on a waiting list

Regular appointments to track my progress and help keep me on track

For teams within mental health and physical health services to work together and share information on an individual's overall well being

“Provide timely, helpful and supportive information, without judgement blame or unhelpful attitudes especially around mental health issues which may impact physical health”

“Provide better access to mental health services, and also advertise services better, as I have suffered from depression for 20 years, but didn't know I could self refer to minds matter”

Implementing Long Term Conditions and care services

Summary

We heard from 69 people in total, more than 94% of those being people with a first hand experience of accessing support services for a long term condition (for example, diabetes or arthritis). More than 79% of these people told us their conditions started more than three years ago. We also found that more than 45% of these people had other additional conditions.

Generally the feedback we gathered around assessment, diagnosis and treatment was predominantly positive and waiting times were reported to be ok. The feedback highlighted a need for better communication, especially in relation to professionals sharing notes timely.

When people first seek help and during diagnosis people would rather see an appropriate professional who is available immediately. However, for treatment or long term support they would rather see a familiar professional even if they had to wait a while.

We also completed a focus group in Blackpool where we spoke to 10 people with long term conditions. They provided us with feedback around getting help and support, highlighting areas of improvement. The feedback was also extremely insightful in regards to what support would assist people to have more control over their own care.

Assessment, diagnosis and treatment

- More than 50% of people reported that when they initially tried to access help the support did meet their needs

“Support was very varied depending on who I saw. It was very apparent that professionals didn't share notes so it was a continuous feeling of having to repeat my story over and over. Lots of clinicians also knew very little about the condition and failed to look at me holistically instead trying to fob me off with short interim fixes or 'it will pass' references meaning I spent more and more time trying to access health care support and the impact this had on myself, family, work and social life was huge”

- When reflecting on waiting times for an initial assessment, diagnosis, receiving treatment or seeing a specialist most people felt it was ok.

“Despite some initial confusion at my GP practice when I initially came requesting a diagnosis, the response was then very rapid (1

hour later they rang me back to get me in). I was then seen by a diabetic nurse the next day and set up on an insulin regime”

“My Symptoms started when I was about 10 years old and I finally received a diagnosis at the age of 31. Since then I have been passed around from professional to professional and eventually I sought support online and found out about a specialist place in a different locality over 200 miles away. The service they provided has been fantastic but within my Borough professionals did not appear to be aware of them or what they offered and don't offer anything similar”

- When considering timely and consistent communication there were conflicting responses

People told how they got all the support they required, there was good communication and their experience could not have been improved.

However, others told how they had difficulties chasing test results and there was a huge delay in separate professionals getting access to individual care notes.

Prevention and/or early intervention

- What level of support could the NHS provide to help people stay healthy?

More than 66% of people would like some support

Support suggestions were:

- *Regular contact with a specialist nurse or other expert in my condition*
- *Prescriptions for specialist gluten-free flour*
- *Referrals to Slimming World to help weight loss*
- *More staff, money and resources*
- *No parking charges at any hospitals or clinics or walk in centres*
- *Useful ongoing support*
- *Ongoing physiotherapy treatment*
- *Education about my condition.*
- *Knowledge of a long term condition changes*
- *Help to access fitness/be healthy and have an active lifestyle*

“My own condition and life circumstances change and it is very helpful to be in a group of people who have similar experiences. The professionals, with the best will in the world, do not always understand the realities of living with a long term condition. Often it is small things that make managing difficult and a suggestion from

someone else who has struggled can change the way you do something and makes life easier, or can change your outlook on life”

Focus Group Feedback



We visited Warren Manor Day Centre in Blackpool and spoke with 10 people, aged between 20-80 years old presenting with the following single or multiple conditions:

- Muscular Skeletal
- Arthritis
- Learning Disabilities

Summary of findings:

Experience of getting help and support

“It’s a postcode lottery getting a GP appointment”

“Ten minute GP appointments are a nightmare when you have multiple health conditions”

“The GP and consultant do not refer to my notes therefore I have been prescribed unsuitable medication”

“I waited over three months to see consultant and feel this is unacceptable”

The health and care support you received after initially seeking help

- There were varying experiences in the length of time that people had to wait to receive an initial assessment and depending on the consultant, waiting times between initial assessments and treatment varied. After assessment a number of people said they had to fight for all of the things they needed for ongoing support “Continuity of care does not exist”. We heard that there is an over reliance on technology and a need to have a more positive, person centred approach. In general people felt they did not receive consistent and timely communication from services.

“It took a long time from the initial assessment to receive a formal diagnosis and then due to the persons Attention Deficit Hyperactive Disorder it took a long time for them to understand the diagnosis and its implications”

“As a person with mental health issues and long term health complaints I needed to access support from a charity organisation to get continued support rather than NHS based support”

“As a person with multiple complex support needs the NHS has not met my expectations”

Time spent travelling to access support and care

The majority of the group reported that they are willing to travel if it meant getting access to treatment sooner or if it was a critical situation. Others would be willing to travel with the support of hospital transport, or were not willing to travel beyond their local hospital at all.

Expectations at each stage of your care

A number of people said that they would be willing to wait to see the same doctor as long as their condition was not serious. Some said they would see an alternative health professional if they took the time to read and digest their notes.

What can the NHS do to support people to have more control over their own care?

- **Effective person centred communication needs to be in place to enable patients to be involved in their care and not to feel helpless and frightened**
- **The system needs to consider different capabilities of the patient and their families in supporting them to stay healthy**
- **The NHS needs to resolve the issue of handling and sharing of medical records and generate trust and faith with patients and their families by demonstrating they have read patient records**
- **There is a need for people with cognitive impairments to have ongoing support to understand their diagnosis and treatment**

Implementing Autism & Learning Disability health and care services

Summary

We heard from 11 people with disabilities who provided some valuable feedback regarding health and care services.

In addition to this, we also completed a focus group in South Cumbria, speaking to 12 adults with learning disabilities. They discussed what the NHS could do to help people keep healthy, what good care looks like and how they would like to interact with the NHS.

Assessment, diagnosis and treatment

People told us how it can take years to obtain a full diagnosis, with there being little or no post diagnosis support offered. Some felt this was due to pre diagnosis concerns not being believed. Most support came from privately funded psychological support and from charity groups

“There needs to be earlier diagnosis and support through transition into clinical medical adult services”

There were concerns around the quality of support offered to people, with people commenting how the Child and Adult Mental Health Service were not useful.

“There needs to be more psychological support to understand how that persons Autism affects them and strategies to ameliorate some of the difficulties”

“They should provide access to Autism knowledgeable psychological support which presently does not exist and is very much needed. I’m against psychiatric input”

The provision of ongoing care and support

“I felt that my case was not taken seriously, despite the severity of it. The team did not treat me with understanding and one specialist would not explain my condition to me, even when asked. I could not access the specialist nurse, which is how I was advised to contact the department. I saw a different member of the team each time, where I had to re-explain what had happened to me and received mixed messages about my care”

“The whole issue of support for adults with Autism needs to be revised for those that do not meet the LD or Elderly criteria, too many of our loved ones are being let down by lack of appropriate and timely support”

Focus Group Feedback



We visited a Self Advocacy Group in Barrow-in-Furness, Cumbria and met 10 adults with learning disabilities. The discussion was focussed around three main areas:

- What could the NHS do to keep you healthy?
- What is good care?
- How would you like to interact with the NHS?

Summary of findings:

Keeping Healthy

The group spoke about their concerns for NHS dentists and many members said they were not able to get an NHS dentist as there were no places available without travelling quite far. They also said they would like more information to be made available in an easy read format about how they can care for their teeth.

Easy read formats were discussed further with many of the members saying that they believed that there was a lot of information available from the NHS on keeping healthy, though this wasn't always easily available in large font or easy read formats. We discussed where the group would like to see this information and they suggested having more information available at GP surgeries or at day centres so that staff members, who know them well can make sure they have access to information that might be relevant to them.

One of the members raised the issue of weight and healthy eating, the group mainly agreed that they had little knowledge of healthy foods and did not use the internet to access information in this area. They discussed the idea of having food workshops for people with learning difficulties so that they can try different healthy foods and recipes in a safe and friendly environment that they could re-create at home.

What makes good care?

- Give us plenty of time
- Let us get to know the environment
- Explain what you are doing

- Talk to us, not to our carer

GP experiences - feedback included: “my doctor listens to me” and “it is a nice place to be and people are friendly”. One person described their experience as being scary, reporting that “they didn’t fully understand what was happening to them” and “they had to wait for a long period of time before their appointment”.

Hospitals - All members of the group felt that they were treated with respect whilst in hospital and that staff showed an interest in them. Some members of the group commented about the experience being positive because they were able to take a family member or, carer with them to the appointment.

Dentists - positive experiences included: “the dentist did not rush me” and “they told me what they were doing”. Negative Feedback included: “feeling rushed” and feeling “scared of the procedure and un-informed about what the appointment would entail”.

Interacting with the NHS



The group shared how it is important for them that:

- Medical information is kept safe and secure
- Being told about the results from any tests
- Carers able to make appointments online
- Carers to be able to easily access their doctor

“preferably, test results should come as soon as possible, by letter so that they can read the results or ask someone to read them for them”

The group also shared what is less important to them:

- Accessing their own personal records - no-one expressed an interest to see their own personal records and they were all confident that professionals would use and manage these appropriately
- Speaking to other with the same condition - people preferred to talk to a family member or carer
- Accessing services using a phone or computer - no-one had access to a mobile phone and had very limited knowledge of using computers. They would not feel confident using digital methods to discuss their health

People want to feel respected and listened to, though they mainly trust their health professionals to make decisions about their care and so do not always need to be involved in this decision making process

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

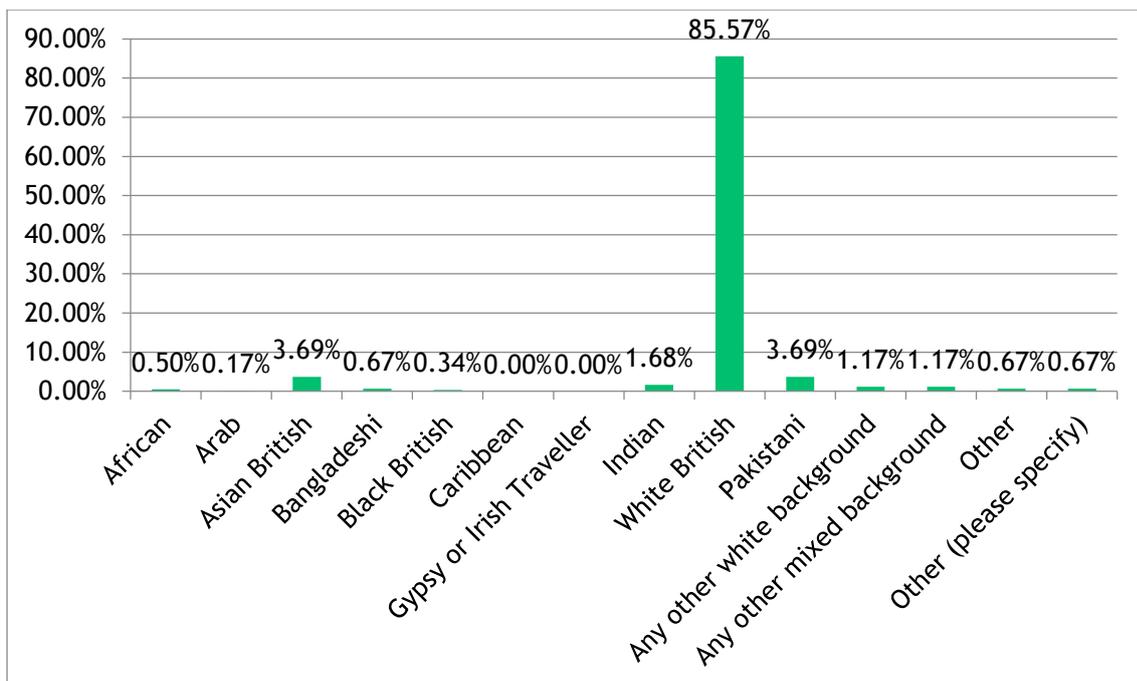
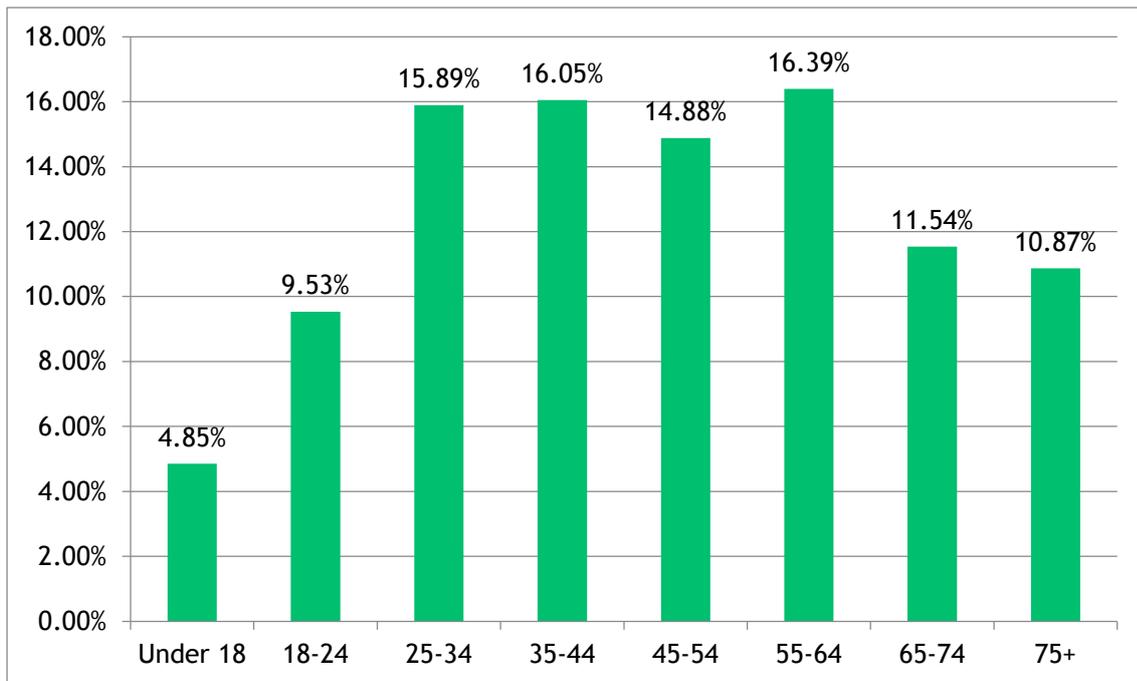
With many thanks to all who have contributed to making this report possible:

- To all of the service users of Lancashire who have engaged with us either online or in person.*
- Barrow-in Furness Self-Advocacy Group*
- Healthwatch Blackburn and Darwen*
- Healthwatch Blackpool*
- Genesis Care*
- Kiran Women's Group*
- Warren Manor Day Centre, Blackpool*

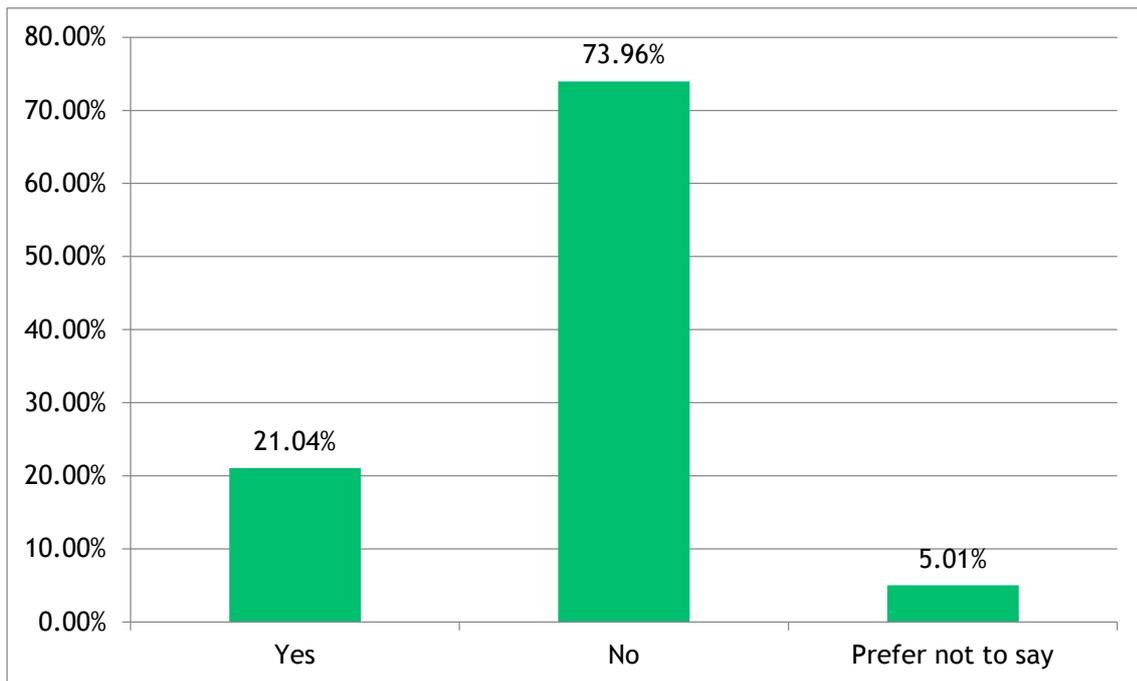
Appendix1 Demographics

Below detail the demographic characteristics of respondents across Lancashire and South Cumbria

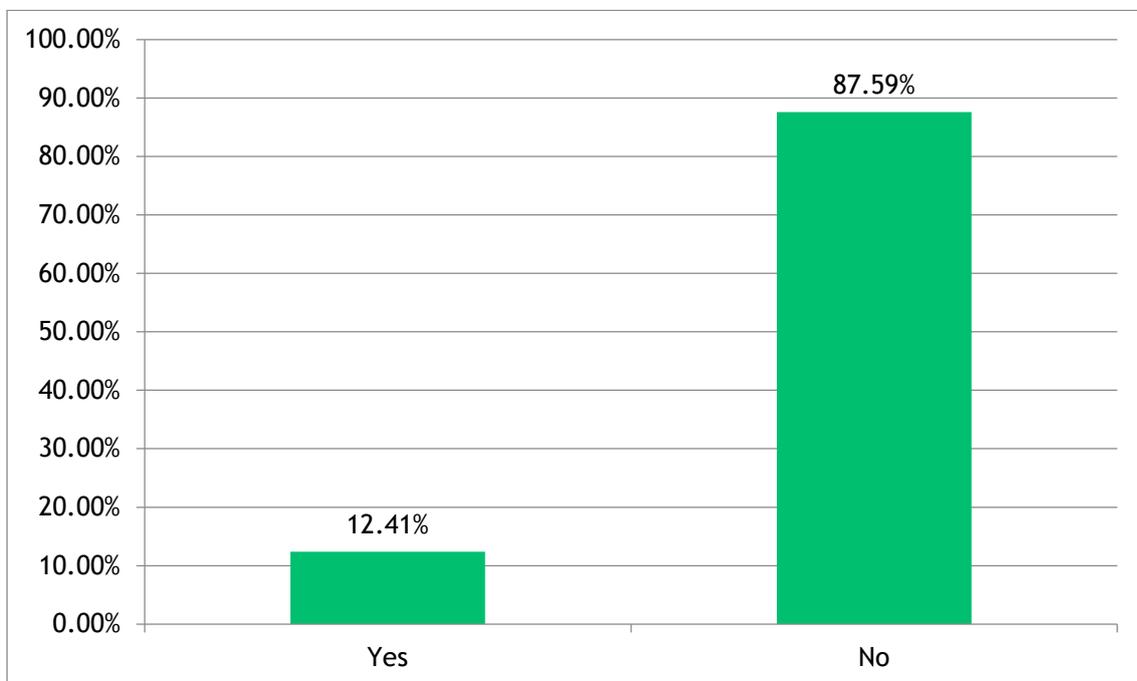
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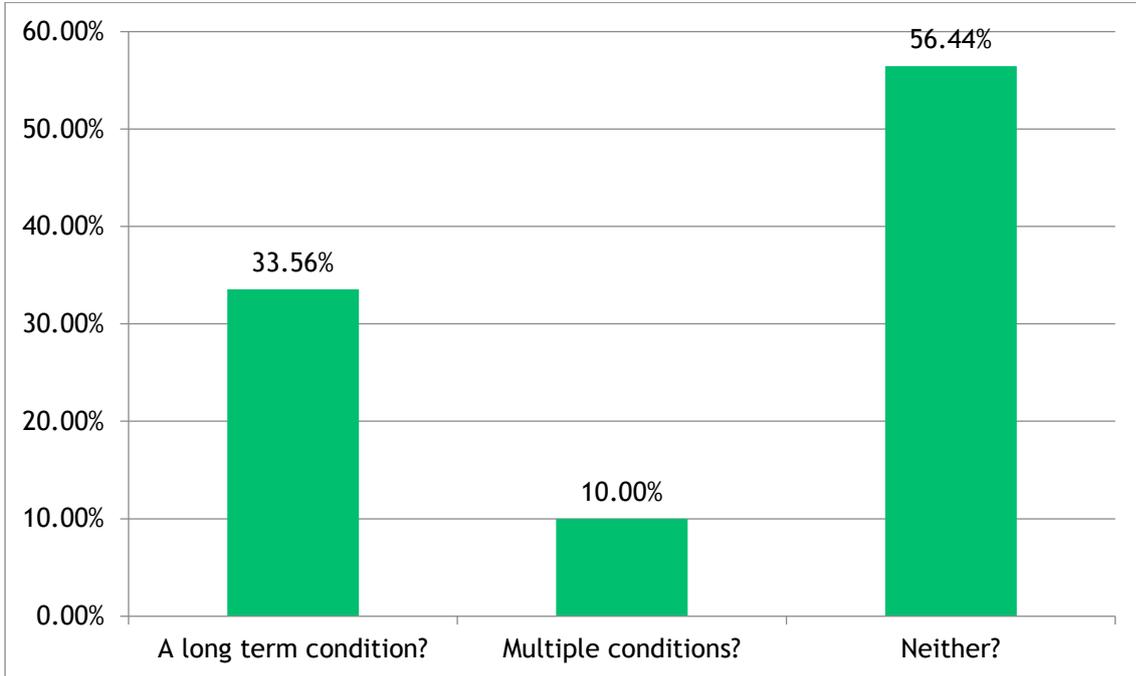
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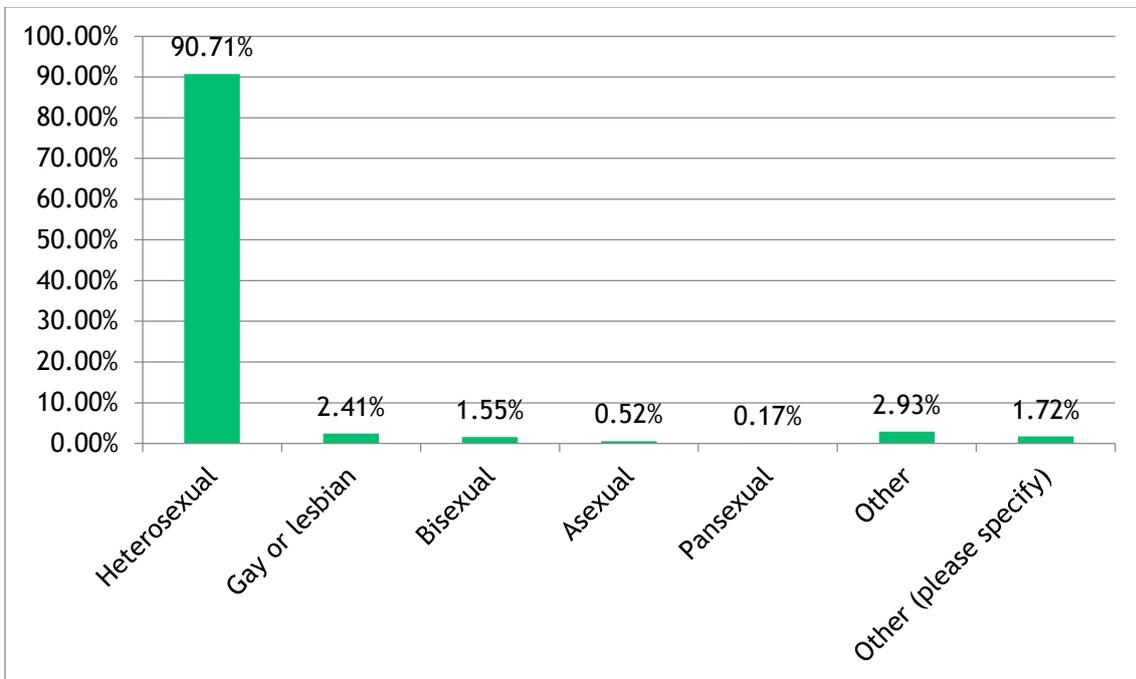
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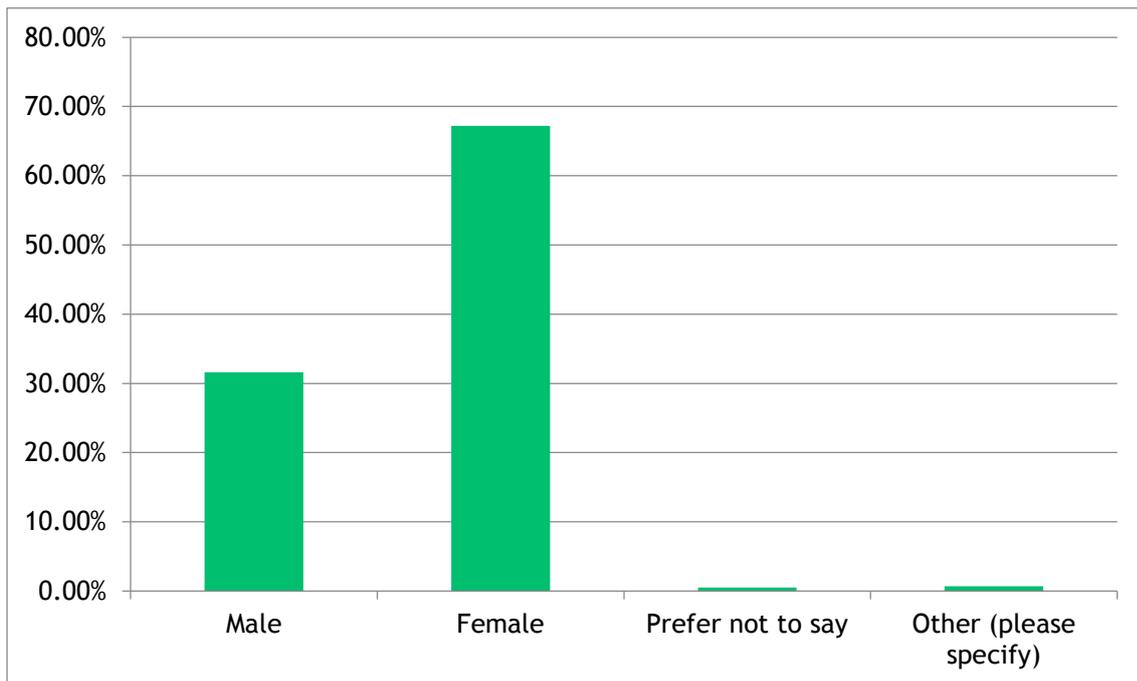
Disability or long term conditions



Sexuality



Gender



Religion

