What people want from the MCXICEN LYCAIS

of the NHS

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When changes are happening to services - big or small - our network of 152 Healthwatch go out into communities to find out what people from all walks of life think. We then share these findings with those in charge to help inform decisions.

When the NHS Long Term Plan was published in January 2019, we were asked by NHS England and NHS Improvement to engage people across the country about how the priorities set out in the plan should be implemented in their area.

Between March and June 2019, we asked people to share their views about how the NHS can better support their overall health, and how it can improve care for specific conditions as well.

Collectively, more than 40,000 people across the country shared their experiences and ideas with us online and at local events. Healthwatch then published 44 regional reports, one per NHS Sustainability and Transformation Partnership / Integrated Care System area to help local leaders understand what their communities want to see improved.

As well as providing a national summary of our activities and the evidence we gathered, this document brings together insight developed through our wider work to explore what this means for policymakers and health professionals.

Highlights:



More than **40,000 people**shared their views
with Healthwatch.



Our network held over **500 focus groups** reaching different communities across England.



Healthwatch
attended almost

1,000 community
events, including
festivals, carers cafes,
shopping centres and
NHS services to speak
to the public about their
experiences.

Background to our involvement

In the summer of 2018, the Prime Minister announced a major injection of new money for the NHS. In return, Theresa May asked the NHS to develop a ten year plan for how this money would be spent to improve the health of the nation.

To inform the plan, NHS England and NHS Improvement wanted to find out from patients and the public what they thought the NHS should prioritise over the next decade.

Because the Healthwatch network engages with hundreds of thousands of people across the country every year about their experiences and views of health and social care services, NHS England and NHS Improvement approached us to see if we could help draw out any insight that would help them.

Areas our evidence covered

Between August and September 2018, we analysed feedback from 85,000 people on a number of key areas NHS England and NHS Improvement were exploring, including:



45,000 views on primary care.



34,000 views on mental health.



6,400 views on A&E.



5,500 carer's views.



700 views of homeless people.



Experiences of the 18-week referral to treatment target (RTT).



Experiences of delayed transfers of care and emergency readmissions.

How people's views shaped the national plan

When the NHS Long Term Plan was published in January 2019 it was positive to see the views people shared with Healthwatch had informed NHS England and NHS Improvement's thinking.

This is testament to the increasing importance being placed on responding to the views of patients and the public when setting policy.

Areas of the plan where we see people's views reflected include:

- Committing to increase investment in primary care to improve access - the most common frustration raised with Healthwatch.
- Setting out a growing role for technology to support new ways of accessing services and helping people manage their own conditions.
- Increasing the role of nurses, pharmacists, physiotherapists and other professionals to enable patients to see the right person at the right time.
- Stepping up the focus on mental health, responding to a public demand that has come through strongly in Healthwatch's work in recent years. Notable areas include:
 - Increased focus on maternity and mental health, including support for dads and partners of mums receiving mental health support.

- Ambitious new targets on Children and Adolescent Mental Health Services and positive changes around age of transition.
- Placing a greater emphasis on identifying and supporting carers.
- Developing an 'Integration Index', which will aim to assess how well services are working together. This will be informed by people's experiences.
- Reducing the rate of delayed transfers of care but doing so safely and in a way that works for people.

Scale of engagement on how to implement the NHS Long Term Plan

To support the implementation of the NHS Long Term Plan, Healthwatch were commissioned by NHS England and NHS Improvement to hold a nationwide conversation, reaching out to every community in England.

NHS England and NHS Improvement awarded Healthwatch England a grant to complete this work. We distributed this money to enable every Healthwatch to gather local people's views about NHS Long Term Plan implementation in their area.

We gave 44 Healthwatch a larger sum so that they could work with their local NHS to co-ordinate activities for the Healthwatch in their area and write a report detailing their findings. Between March and May 2019 our network:

- Engaged more than 30,000 people via online surveys.
- Spoke with a further 10,000 people face-to-face by:
 - Holding more than 500 focus groups.
 - Attending almost 1,000 other community events.

Our network worked creatively and quickly to ensure that this investment was maximised and gathered a huge number of experiences with the time and funds available.

Importantly the work reached out to a variety of hard to reach groups. Examples of engagement activity included:

- Healthwatch Shropshire held 16 focus groups with people with dementia and their carers.
- Healthwatch in South Yorkshire and Bassetlaw engaged with asylum seekers, prisoners, veterans and the deaf community.
- Healthwatch Somerset's campervan made 18 stops across the county in hospitals, shopping centres and supermarkets.

We also heard from:

- 3,632 respondents to our online polling who said they have a disability.
- 6,668 respondents who said they have a long-term condition, and 2,351 who had more than one long-term condition.

All 44 Healthwatch reports can be found on the <u>Healthwatch</u> Reports Library.



Access to services

The number one issue people raised with Healthwatch was about accessing primary care services. This is in line with the feedback we receive usually. People did talk about access to NHS services in general, but primary care was the main area in which people wanted to see improvements.

The NHS Long Term Plan acknowledges the challenges people face at the moment and sets out ambitious targets to improve access to primary care services. This means increasing the primary care workforce to include not just more GPs, but more nurses, pharmacists and other health professionals.

The plan also sets out how some services in hospitals could be increasingly provided through primary care settings closer to people's homes.

I was recently diagnosed as pre-diabetic, so they want me to go on this eight-week course, but I work Monday to Friday, and I could only get these courses during working hours. That's not practical. It would be helpful if it were on an evening or weekend.'

Personal story, Birmingham and Solihull

What people want

Easier access to GPs

- People said they want it to be easier to see 'their' GP. However, when we dug deeper it was clear this doesn't necessarily mean that people want to see the same GP each time, but for it to be easier to see a GP at their regular surgery.
- The type of issue people experience also affects how they want to be seen. For new issues, people are more interested in getting a quick response from a trained professional. For ongoing issues, people want continuity. People said they want more power to choose who they'll see so they can decide based on their needs.
- People are frustrated about the process for booking non-urgent appointments. In many cases they say they cannot book in advance and have to ring up in the morning at 8am which can be difficult.
- Some people want greater flexibility around the length of appointments so that they can discuss all their health problems in one slot.

Appointments at more flexible times

Working people told us that, although they can request time off from employers for medical appointments, this is not always practical – especially if they have a long-term condition. They also find it hard to get to health-related support groups and courses that are generally held during working hours.

The support they need, when they need it

- People want GP surgeries to give them access to different health professionals who can help them with particular issues. For example, they'd like to be able to book directly to see a practice nurse or a pharmacist to talk about a minor ailment, or a mental health nurse to discuss a mental health concern. People suggested this might help reduce the burden on GPs and waiting times.
- People talked about how they feel there are unhelpful and arbitrary limits placed on the number of treatment sessions they're allowed to access.
 E.g. physiotherapy, smoking cessation support or talking therapies. In other cases, people need less support than they're prescribed. It's vital that people have a say so they get the right support to meet their needs.

Support closer to home

In some areas services
 traditionally provided by GPs,
 e.g. chiropody, phlebotomy and
 ear wax removal, have moved
 into hospitals, meaning that
 people must travel further to
 access them. This seems to be in
 direct conflict with the policy set
 out in the NHS Long Term Plan
 to move these services closer to
 where people live.

Improving people's experiences of digital services

The NHS Long Term Plan commits to making better use of digital tools and technology to improve people's experiences of healthcare support. Some elements of this are already available and we know from our broader engagement that there is significant public support for greater use of technology across the NHS. It is crucial that the health service builds on this support and helps people benefit from digital developments.

GP surgeries have offered online access to appointment bookings, repeat prescriptions and medical records for some time, and in the last 12 months, 95% of surgeries have started supporting all these functions via the NHS app. In some areas, patients have also been able to access video appointments with their GP.

However, for a range of reasons that have been well documented, many members of the public haven't felt the benefit of being able to access services digitally.

We heard that the NHS needs to avoid making assumptions about who will use different forms of technology. People consistently raised the need to ensure technological solutions are designed to address real world problems and are properly usertested before being rolled out.

What people want

Systems that make accessing the NHS easier

- People feel frustrated by slow developments to NHS online systems. They'd like it to be easier to access their notes, make all types of appointments, and see their test results online.
- We heard that virtual appointments could be particularly helpful for people living in rural areas who have to make long journeys to hospitals for check-ups, and for working people who find it difficult to get time off for medical appointments.
- People would like to be able to check real-time A&E waiting times online, and to have access to apps that provide support whilst they're on waiting lists.
- Individuals for whom English isn't their first language said they'd benefit from digital access to translated materials and interpretation, too.

Not to be excluded

 People are worried that everybody will be expected to use technology to engage with the NHS and that groups who can't do so or find it difficult will lose out. These groups include people with a learning disability, some older people, those with additional communication needs, those with reduced dexterity, those whose first language isn't English, those on low incomes and rural communities with poor broadband connections. People with mental health conditions felt that their needs might not be picked up through online or telephone appointments. Even those who were confident using digital services wanted the option of a face-to-face consultation.

Technology not to take priority over bigger issues

 Whilst people wanted improvements to the NHS' use of digital technology, it was not as important to them as easier access to appointments or improvements to patient transport.

No assumptions about attitudes

 The surveys revealed some notable differences for people under the age of 25 compared to over 25 when interacting with the NHS. For example, younger people placed greater value on the need for their data to be managed well and kept secure. They were more likely to consider online access to NHS support important, and less concerned about having convenient ways to travel to health and care.





People's experiences of different conditions

The NHS wants to improve care for people affected by a range of specific issues including cancer, mental health, cardiovascular disease, dementia, autism, learning disabilities, stroke, respiratory disease and diabetes.

As part of our research we asked people affected by these issues, and their family and friends, to share their experiences.

What was clear was just how varied people felt the quality of care was depending on which issue they had. For example, those with experiences of cancer or heart disease were overwhelmingly positive about the NHS and the fact that they felt fully supported throughout their care.

Others, especially those with mental health conditions or dementia, said they felt unsupported by the NHS and that professionals didn't give enough consideration to their full range of needs.

Part of the reason for this is likely to lie in the significant emphasis that has been placed on traditional major causes of poor health and early death, such as cancer and heart disease. These have been priorities for the NHS and the wider health and care sector for many decades and significant engagement has happened with patients to ensure services are designed effectively. By contrast there has been less focus on support for issues like dementia and mental health.

There is good practice about how to design holistic services with patients. The Long Term Plan provides an opportunity to apply this learning to a range of conditions, which are perhaps more emerging priorities for the NHS as a whole.

A more holistic approach
would have been much
better for me - I suffer from
diverticulitis (a digestive
condition) and have had
to manage it myself. This
has had an impact on my
mental health.'

Personal story, Sussex and East Surrey

What people want

Good quality support for everybody

- According to the experiences people shared with us, those with heart and lung conditions or cancer have better experiences of support from the NHS and social care than people with other conditions.
- Reasons for this include: timeliness of diagnosis and treatment, access to rehabilitation and support courses, complementary therapies that support general wellbeing, rehab nurses, annual check-ups, good information and good communication from professionals.
- People with other issues (autism, learning disabilities, mental health, dementia, long-term conditions and multiple longterm conditions) felt that similar levels of support were not always in place for them.

Quicker access to diagnoses and support

 People with learning disabilities and autism want a clear diagnosis, quicker referrals and access to support. People are

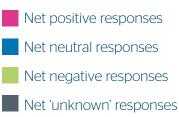
- currently waiting a long time for this, which makes it difficult for them to lead full and productive lives. There also seems to be limited support post-diagnosis.
- People with dementia find that it takes multiple visits to their GP to get a diagnosis. They want faster diagnosis, advice about living well with dementia to help them come to terms with their diagnosis, and for there to be more support available to them and their carers.

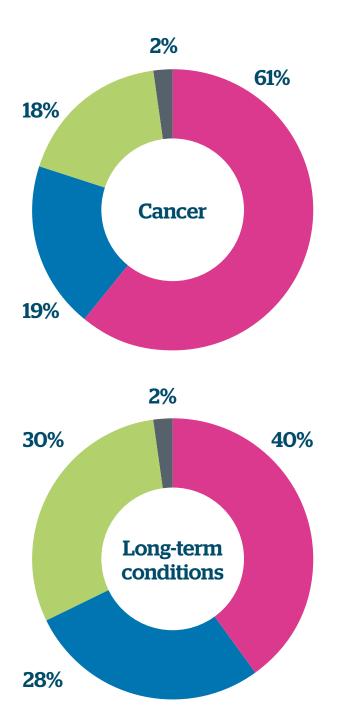
Greater consideration for people's needs

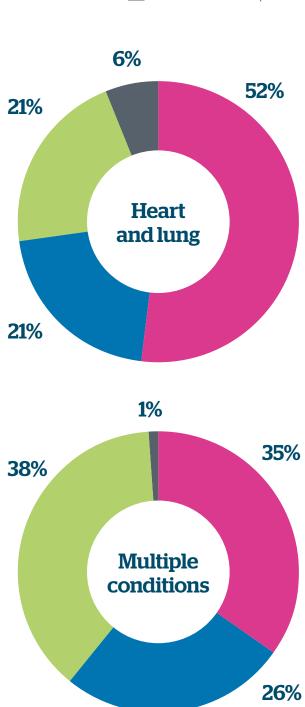
- People with dementia want healthcare professionals to treat them as a person and to talk to them and their carer about their individual needs.
- We heard that people with dementia and their carers enjoy taking part in community and peer support groups and would like more opportunities to do this.
- They also want all staff to be aware that they may have additional needs because of their condition.

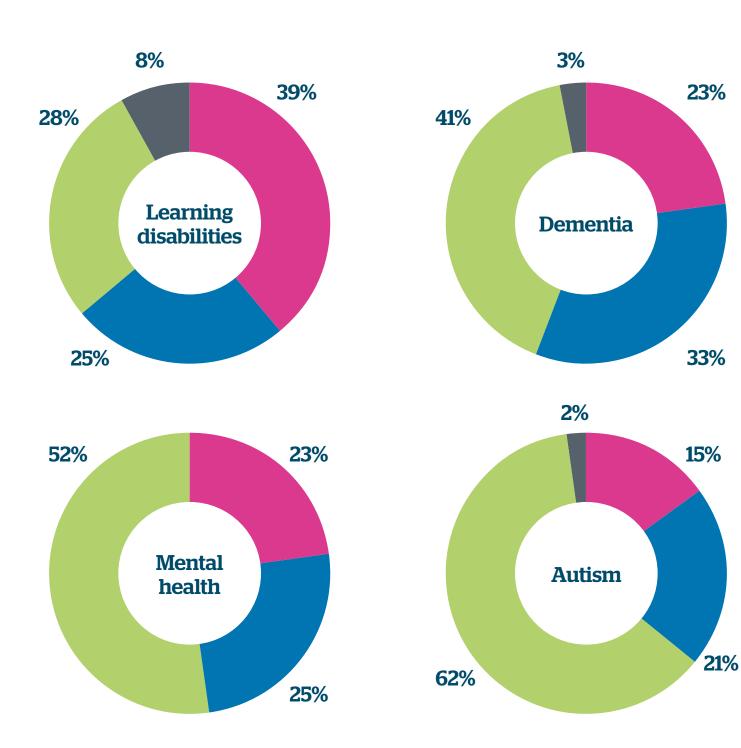
How would people describe their overall experience of getting help?

5,252 people responded to this question in our survey looking at people's experiences of specific issues, which was carried out as part of the overall engagement on the NHS Long Term Plan. Here are the results:











Person-centred care

Understanding and responding to people's individual needs is essential to ensuring everyone receives high-quality and accessible care. As the NHS Long Term Plan itself rightly recognises, 'what matters to someone' is not just 'what's the matter with someone.'

The personal stories we hear demonstrate how a positive experience of the NHS can depend on a range of factors. Some of these might not be obvious, common, or even about a clinical outcome.

Services make improvements by taking the time to communicate clearly and listen to patients about what matters most to them. Creating this sort of partnership between patients and professionals will require new ways of working, shared decision making and a range of choices that help patients manage their own conditions.

The commitments around technology in the NHS Long Term Plan also provide opportunity to ensure care is more personalised. At a very simple level, it should mean that information about reasonable adjustments and personal preferences should be recorded more consistently and shared across services helping the NHS to better anticipate people's needs.

Shared communications between different NHS elements - primary care, acute, hospitals, nursing. Experience of having to repeat information numerous times and notes/test results not being shared between them or appointment conflicts as they don't share information.'

Personal story, Sussex and East Surrey

What people want

Truly personalised care

- People agree strongly with the plan's focus on making care more personalised. They want to be a partner in decisions about their care.
- They want healthcare professionals to see them as a whole person, to ask about all their needs, and to be given information that helps them care for themselves independently. They also want to be able to make informed decisions about their treatment, such as where it takes place, and to be given enough time to make these choices.

Better sharing of patient information

- People are frustrated by the fact that they must repeat themselves to different healthcare professionals. Whilst systems are being developed and rolled out to make sharing people's records between professionals easier, they are not yet in place across the board, causing frustration.
- People want information sharing between services to be simpler, so they can focus on getting the support they need.

Communications that meet individuals' needs

- People would like healthcare professionals to get better at meeting individuals' needs when they're communicating with them. For example, written information should be available in easy read formats for people with learning disabilities, letters should not be sent to people who are blind, and interpreters should be made available for people for whom English isn't their first language.
- People also want it to be easier to get access to an interpreter when needed.
- People want services to consider how they communicate with individuals with learning disabilities. They would like healthcare professionals to check whether they want them to communicate with them directly or with their carers.

Cultural awareness from professionals

 People would like professionals to consider their cultural needs when giving advice, for example, taking their dietary requirements into account.



Prevention and social prescribing

The NHS wants to do more to help people look after themselves and avoid becoming unwell. Not only will this help improve people's health, but it will also ease pressure on services. The NHS Long Term Plan includes a commitment to more investment in social prescribing – giving people access to more non-clinical support in the community.

People have spoken a lot to Healthwatch about the importance of prevention, both for the benefit of their own health and the sustainability of the NHS. They want services to do more to proactively help them stay well, suggesting everything from annual health checks for everyone, to early assessment and intensive early support for those who are at risk of health problems such as diabetes.

What people want

Help to make healthier choices

- People strongly support the NHS' focus on helping people stay well. They want the NHS to help them make healthy lifestyle choices and to know that there is a trustworthy source they can turn to for such advice.
- People also think that central and local government, businesses, employers and schools should play a part in promoting healthy living.
- People with learning disabilities told us they want the NHS to provide appropriate healthy living advice and support services, such as cooking classes.

Support in their communities

- People recognise the value of access to support in the community and the chance to speak to people who have had similar experiences.
- People benefit from peer support as it gives them the chance to socialise with and learn from people who have similar conditions or challenges. Greater use of such groups can also help ease pressure on professionals by giving people access to support outside of a healthcare setting.
- Given that many of the services people are referred to are provided by voluntary sector organisations, which are currently struggling to stay open after funding cuts, we heard that people would like the NHS to help fund these services.

More than medication

 People believe that medication and other medical treatments shouldn't be the only ways to tackle health problems.
 However, people who are used to traditional healthcare approaches may find it difficult to adjust to alternative treatments, so may need appropriate support and communications.



Better access and understanding about how to keep healthy. NHS is very focused on fixing a medical condition and not looking at how to keep healthy whilst living with a condition.'

Personal story, Bedford, Central Bedfordshire, Luton and Milton Keynes

Mental health

Over the last decade the profile of mental health issues and the need for parity of esteem with physical health has grown significantly. Mental health has consistently been one of the top priorities for local Healthwatch in recent years.

The NHS too has placed significant emphasis on improving mental health support, with the NHS Long Term Plan earmarking major new investment in mental health services to support this transformation.

Along with more money, clear and ambitious targets have also been set by the NHS, in particular ensuring better support for children and young people, new parents and at-risk groups such as people experiencing homelessness. There is also a welcome emphasis on ensuring the right crisis services are put in place to support those in urgent need of help.

Those taking part in the NHS Long Term Plan engagement re-emphasised the public support for urgent investment in and improvement of mental health services. They also stressed that the NHS needs to step up efforts to communicate how services are actually changing as this will be key to the public seeing that the NHS is addressing their concerns.

Once I got to see a psychiatrist she was very helpful and kind, but I had to wait almost three months for a first appointment and then another two for the second. I was then discharged back to primary care but my GP, though kind enough, has no specialism in complex mental health conditions I would like to see all GP surgeries having a GP that specialises in mental health ... to be able to support me with my condition.'

Personal story, Hampshire

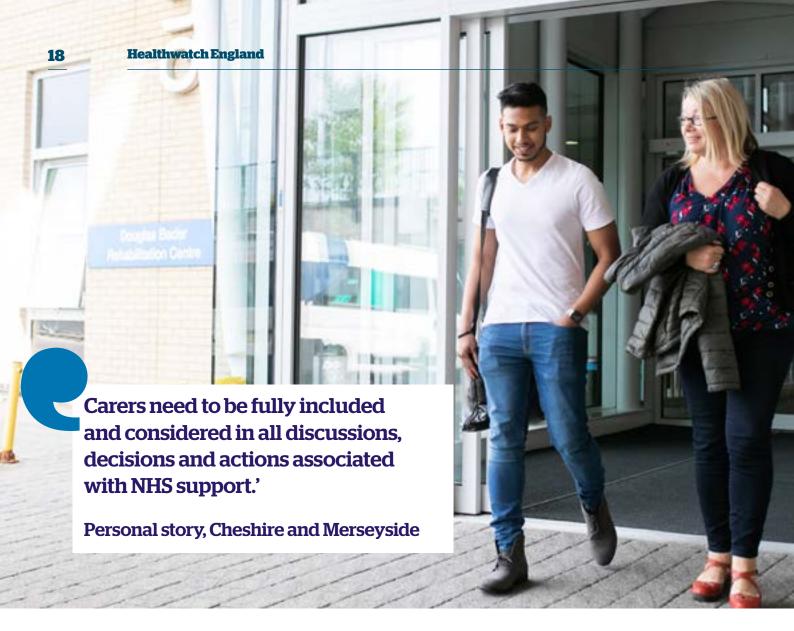
What people want

Quicker access to support

- People feel that waiting times for diagnoses, referrals and treatment are currently too long. They told us they've found GPs in particular to be ill-equipped to diagnose and provide support regarding mental health problems.
- People want quicker access to support and, where they do have to wait, for assistance to be made available in the meantime, potentially via apps or video consultations.

The right treatment at the right time

- People want to be given the right treatment for their condition.
 We heard about individuals who had been offered medication or CBT without consideration for whether they were appropriate treatments. Where people were offered talking therapies, they were time-limited, regardless of their needs, meaning some had to go through multiple cycles of treatment rather than just one round of the appropriate length.
- People want more crisis services to be available 24/7 as well as a choice of treatments appropriate to their needs, including referral to support groups and social prescribing.



Carers

We know from our work with carers that it takes on average two months to apply for and access formal help from their local council. Yet we also know that carers are only likely to seek support once they have already reached a point of crisis. This can put both those being cared for and carers themselves at risk.

The NHS recognises the huge role that carers play and the need to provide more support to help keep them, and those they look after, healthy. To do this the NHS has committed in the NHS Long Term Plan to do more to identify unpaid carers and proactively offer support earlier to help avoid crises from occurring.

What people want

Greater involvement of carers and support

- People felt strongly that the NHS must improve support for carers, who often have support and health needs of their own.
- Carers often feel ignored by healthcare professionals in decisions about their loved ones. They want to be involved in discussions about options for treatment, such as where it will take place.

Specific support for carers looking after people with dementia

 Carers of people with dementia want better access to respite care
 even just an hour a week - to allow them to have a break.

The chance to meet other carers

Carers value the opportunity
to take part in support groups
where they can share information
and experiences with people in a
similar situation. They particularly
welcome sessions run by
voluntary sector groups, which
help them manage practical
issues, emotions and wellbeing.



People's experiences of service integration

At a strategic level, NHS and social care services are becoming increasingly integrated in the way they plan and deliver care and support to communities. Joining up services in this way can help to make them more efficient and ensure that people's full range of needs are taken in to consideration.

This approach is supported by the public, patients and care users, who are often left confused by the current system. One of the best ways to understand whether services are integrating effectively is to speak to people about their experiences.

From the NHS Long Term Plan engagement exercise it was clear that the group who report the worst experiences in terms of integration are those with multiple long-term conditions. The experiences of these groups are also a good measure of how integration is working.

What people want

Quicker access to support and more joined-up care

- People with multiple major issues, such as cancer, heart and lung conditions, mental health concerns, dementia and arthritis, face long waits for referrals and appointments to specialist services. They want to get the support they need faster.
- People told us that services don't work together well enough. Individuals often see different professionals for each of their conditions and receive conflicting advice. As a result, some turn to the internet for information, which isn't always reliable.
- People would prefer for their care to be more co-ordinated and would rather wait to see the same person again than take the next available appointment with a different practitioner.





Transport to healthcare

There is limited focus on transport in the NHS Long Term Plan, but it was raised frequently in the feedback people shared with Healthwatch

People are supportive of NHS efforts to reduce the number of inpatient appointments (e.g. through technology and better co-ordination), and as a result, reducing the number of journeys people need to make. However, people will still have to physically access certain appointments and many struggle with these journeys, including those who might be eligible for non-emergency patient transport services.

People accept that health services (and in particular diagnostics) might be delivered further from home, but they want all their recovery, recuperation and ongoing healthcare support to be close to home. When they do have to travel, people want services to consider how they will get to their appointments. This includes, the roads, parking, patient transport services and public transport.

To NHS England and NHS Improvement's credit, they have already responded to the feedback we and our partners, Age UK and Kidney Care UK, have picked up about transport and the fact that it is missing from the NHS Long Term Plan. CEO of NHS England and NHS Improvement, Simon Stevens, committed to carrying out a national review of transport in the NHS in 2020 and we look forward to supporting this. The outcomes of this review will play a vital part in ensuring people feel like the NHS is taking account of people's full range of needs.

What people want

For it to be easier to get to appointments

- Whilst people welcome initiatives focused on things like improving the NHS' use of digital technology, first they want it to be physically easier to get to services.
- When attending specialist interventions, such as surgery, people are less concerned about travelling long distances. However, it presents more of an issue when they must travel for follow-up care or routine appointments. They would like more rehab and community services to be delivered closer to home.
- People with learning disabilities or mental health concerns can find using public transport difficult, so more support needs to be available.

More parking spaces

 The availability of parking is a major source of stress for people travelling to hospital by car.

More considerate nonemergency patient transport services

 Non-emergency patient transport services don't always work well for patients, as they don't take into consideration people's needs for food, water and toilet breaks. People want these services to take their personal needs into account, and to be able to bring their carer with them to appointments.

The bus pass is only valid from 09.30. It would be really good if transport were automatically free for people with an early morning hospital appointment. I use the bus both because it is sometimes difficult to find a parking space and because of the level of parking charges.'

Personal story, Bath, North East Somerset, Wiltshire and Swindon



It was encouraging that from day one NHS England and NHS Improvement included people's views and experiences of the NHS as one of the key sources of evidence for setting national priorities. This was evident in how NHS England and NHS Improvement addressed so many of the issues raised through the 85,000 people's stories Healthwatch originally shared.

As we have moved into the delivery phase it has once again been an incredibly open and collaborative process. By commissioning Healthwatch to undertake what is one of the largest ever public engagement exercises in the history of the health service, NHS England and NHS Improvement really demonstrates its commitment to putting people at the heart of service design.

Healthwatch has shared the additional evidence we gathered with the leaders of each of the Sustainability and Transformation Partnerships/Integrated Care System area across the country. This evidence is now being used to shape the local implementation plans which we expect to be published in February 2020. These should follow the lead of the national plan in addressing people's concerns, and Healthwatch England will be analysing each of the documents to see where people's input has helped to shape local thinking.

This is just the start of the NHS Long Term Plan. Over the next decade it is vital that the NHS continues to work with local people to ensure the impact of any changes is properly tracked and evaluated. Assessing people's experiences of care is the only way that services will know if the changes they implement are having the right impact and delivering the care people said they need.

This feedback exercise highlighted how much appetite there is amongst the public to share their experiences to help make services better. People want to be involved in decisions about how local care will change, so it's vital that the NHS keeps asking people for their views and demonstrates how they're acting on them.

Healthwatch has a vital role to play in this process. Our close connections to people in every area of England and our extensive experience speaking to people about what they want from care makes our network perfectly placed to help the health service keep people at the heart of care. We look forward to working with the NHS more in the coming months and years to help ensure that changes to services are always driven by the people who use them.

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