

There and back

What people tell us about their experiences of travelling to
and from NHS services

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Forewords

Imelda Redmond, CBE, Healthwatch England

The NHS is regularly ranked as one of the best healthcare systems in the world. We have access to state-of-the-art facilities, a huge range of experts and some of the best clinical outcomes for patients.

Yet for many people the overall experience of achieving the best long-term outcomes of treatment can be seriously affected by other real-world factors.

Perhaps one of the most common and basic issues people face is physically travelling to and from appointments. This may be because they lack mobility or capacity, they live in rural areas, or they don't have access to a private car. Whether it's just one of these things or a combination of factors, transport issues affect a huge number of people.

Earlier this year Healthwatch England carried out a nationwide conversation on the NHS Long Term Plan, engaging with over 30,000 people across the country. We found that travel was a key issue, with nine out of 10 people telling us that convenient ways of getting to and from health services is important to them. Indeed, people put transport above other things, such as choice over where to be treated and improving digital access to services.

In two thirds of the country, communities told us they wanted more focus in local plans on improving the links between transport and health and care services.

In partnership with Age UK and Kidney Care UK, Healthwatch England has been working with the NHS to take action. NHS England have announced they will carry out a national review. We look forward to working with them on this to ensure that people's views and experiences inform their plans, from improving commissioning and provision of non-emergency patient transport services to exploring how the NHS can become more connected in practical and affordable ways with the wider world.

Receiving medical treatment is often one of the most physically and emotionally challenging experiences, both for people receiving treatment and those caring for and supporting them. By addressing this issue, the NHS can show that it is listening and acting on feedback to provide a truly person-centred service for the future.

Caroline Abrahams, Charity Director, Age UK

When you are living with a long-term condition it can feel like your life is spent going to and from hospital appointments for treatment. This is stressful enough for anyone, but imagine being in a situation where, on top of this, you have to take a long, painful and stressful bus journey every time you attend. Or, you may even have to cancel your appointments and risk your health because you have no way to physically get there.

This is the reality every day for many older people across the country. We know from the older people we speak to that the patient transport system isn't working. We have heard from older people in poor health and with mobility difficulties who are forced to spend half a day on buses, with multiple changes, to get to the hospital. Or from carers who say that their

husband or wife has dementia, but they are unable to accompany them to their appointment because of lack of space on patient transport. This causes stress and anxiety for older people and ends up making them more unwell.

This isn't a new issue - in fact we have been campaigning for a full review of the system since 2017 - but it doesn't have to be this way. There are pockets of good practice already happening across the country that we can learn from and build on. That's why we are so glad to be working with Healthwatch England and Kidney Care UK to support the government to end painful journeys for every patient once and for all.

Fiona Loud, Policy Director, Kidney Care UK

Transport for kidney patients represents about 50% of all non-emergency patient transport by volume.

If you have kidney failure, getting to and from hospital is not the first thing on your mind. However, six journeys a week, every week, has a major impact on how you experience care.

The national survey of *Kidney Patient Reported Experience Measures*¹ shows that transport has the greatest variance of all experiences measured.

The provision of transport to allow people to attend a dialysis unit for treatment is essential, and kidney healthcare professionals support this. Dialysis is a medical treatment that removes both poisons and fluid from the patient. The effects include exhaustion, nausea, giddiness, variations in mental state, and rapid fluctuations in blood pressure. Patients often feel at their worst immediately after treatment. Many are frail. One in three have clinical depression.

However, patients report major differences in the provision of transport to dialysis units. A comprehensive survey of dialysis units in the UK commissioned for our recent report, *'Finding a Way Together'*² confirmed these differences; only 60% of services use key performance indicators. There are differences between units in how transport is organised; there are different policies for the reimbursement of patients for the few who make their own way to hospital. Patients, healthcare staff, and healthcare providers are concerned that there is evidence accumulating that these differences may become worse due to increasing financial pressures on commissioners. There have been attempts to remove kidney patient transport altogether, which could have resulted in patient deaths.

Recently Kidney Care UK set up a working group with a broad range of representatives, from patients to commissioners, to develop guidelines to support standards for the provision of transport for patients requiring haemodialysis. The approach used for this was inclusive and recognises that this is a complex area: colleagues in all sectors are focused on providing a quality service in a challenging financial environment. We'd like to see these guidelines adopted as part of the wider review of NHS transport services.

¹ <https://www.kidneycareuk.org/news-and-campaigns/news/results-2017-prem-survey-released/>

² <https://www.kidneycareuk.org/news-and-campaigns/news/comprehensive-kidney-patient-transport-guidance-launched/>

Introduction

In January 2019, NHS England published the [NHS Long Term Plan](https://www.england.nhs.uk/long-term-plan/)³, a vision for changing how the NHS operates and what it delivers for the public.

Building on the policy direction set out in the [Five Year Forward View](https://www.england.nhs.uk/five-year-forward-view/),⁴ this new plan outlined a vision for a more integrated health and care system that will make better use of technology and seek to deliver more care in the community.

Healthwatch helped to develop this new plan by sharing what we heard from more than 85,000 people's experiences of care, which identified significant public support for moving care closer to home.

One significant advantage of this approach is that it should reduce both the number of times and the distance people have to travel to access healthcare. NHS England has set a clear target to reduce the number of out-patient appointments by 30 million over the next five years. This shift is significant given the logistical and financial challenges people often face getting to appointments.



Personal story: Making the most of tech

“It would be helpful to be able to Skype or FaceTime appointments which are really not necessary to be in the room with my epilepsy nurse. Sometimes these are just reviews and travelling all the way to the Poly Clinic is a pain and it would be more suitable to FaceTime.

[Response to the LTP engagement in the South East](#)

However, even if the NHS Long Term Plan (LTP) achieves everything it aims to, physical access to services and treatment will continue to be a necessary part of delivering healthcare. Despite this, there is limited policy focus on transport in the plan.

Between March and May 2019, Healthwatch across the country carried out a national conversation to support implementation of the LTP. Communities from the majority of the 44 Sustainability and Transformation Plans (STP) /Integrated Care Systems (ICS) areas highlighted a need for more focus on transport. The issue features prominently in 28 of the 44 local level reports produced by the Healthwatch network.

This briefing brings together what we know about people's experiences of getting to and from appointments at hospitals, GP surgeries and other NHS services. It looks at the different

³ <https://www.england.nhs.uk/long-term-plan/>

⁴ <https://www.england.nhs.uk/five-year-forward-view/>

methods of transport and highlights an important question about data, as well as sharing some examples of promising practice. This summary of our evidence should help leaders in the NHS understand the barriers people face and explore possible solutions.

Our evidence base:

- 773 people’s experiences of travelling to appointments shared with Healthwatch England via our network over the last two and a half years.
- Analysis of 15 local Healthwatch reports on transport and the NHS, which included views and experiences from a further 2,114 people. Methodologies of these reports included:
 - Surveys and one-to-one interviews with patients and families
 - Site visits to hospital discharge lounges and ride-a-longs with transport services
 - Desktop analysis of local travelling times and public transport options
- 44 Integrated Care Systems (ICS)/Sustainability and Transformation Partnerships (STP) level reports developed by local Healthwatch to support implementation of the NHS Long Term Plan. These reports drew on survey responses from over 30,000 people and 500 focus groups between March and May 2019. (The comments from people shared in this briefing are taken from this work and have been broken down across the seven NHS England and NHS Improvement regions).
- Data from 61 of 191 Clinical Commissioning Groups (CCGs) in England on the use of non-emergency patient transport services (gathered via a Freedom of Information request).
- Age UK report “*Painful Journeys*”,⁵ which includes
 - Focus group discussions with older people’s groups in Newcastle and Falmouth
 - Data from a nationally representative survey conducted by TNS for AGE UK with responses from over 1,300 people aged 65 and over in the UK
 - Case studies from Age UK’s information and advice service
- Kidney Care UK report “*Finding a Way Together*”,⁶ which includes:
 - The annual kidney patient experience survey (13,000 responses)
 - Survey responses from 46 renal units
 - Regular patient feedback through their team of 11 advocacy officers
 - Consultation with the kidney community and meeting with commissioning groups

⁵

https://www.ageuk.org.uk/contentassets/7354623c9df1491a84cc34ef46105647/painful_journeys_campaignreport.pdf

⁶ <https://www.kidneycareuk.org/news-and-campaigns/news/comprehensive-kidney-patient-transport-guidance-launched/>

⁷

How people are travelling to appointments

When the NHS thinks about transport it tends to focus on services within its direct control, such as non-emergency patient transport. These services are a lifeline, as they help those with severe medical conditions access care. At the same time, they are reserved for people who have no other way of getting to their appointments or need specialist assistance during their journey.

Looking at how these services can be improved is therefore vital, ensuring those who need help with travelling to appointments can get the support they need.

The NHS can also think more widely about how it improves the experience of travelling to appointments for everyone. The majority of people make their own way to appointments, either by driving or on public transport. However, these journeys are not always straightforward and it is important for the NHS to think about the stress travelling can put on people.

To help the NHS understand how people travel to appointments, we carried out a nationwide survey of current NHS users with a variety of health conditions. The survey received 5,221 responses from a self-selecting sample.

Condition	Access to a car (includes lifts from family, friends, carers)	Taxi	Bus and Train	Other
Cancer (670)	82%	3%	9%	5%
Dementia (294)	79%	4%	8%	4%
Heart and lung diseases (484)	83%	7%	15%	3%
Long term conditions e.g. diabetes, arthritis (1834)	74%	4%	15%	5%
Autism (313)	71%	4%	17%	5%
Learning disabilities (210)	61%	4%	28%	7%
Mental health conditions (1416)	57%	4%	27%	10%

It is worth noting that the NHS does offer a [Healthcare Travel Costs Scheme](#)⁸, which helps

⁸ <https://www.qvh.nhs.uk/wp-content/uploads/2015/09/Help-with-travel-costs-all-areas.pdf>

cover certain expenses, such as bus fare or petrol and parking. This is for people who receive certain benefits or are on a low income.

The scheme can help reduce stress and anxiety for people at what can be a very difficult time in their lives. However, this offer is not well-known and does not address the logistical challenges faced by those without access to patient transport. In general, people are expected to pay the costs upfront and claim the money back after, which can be challenging for those on a low income. The issues people face

Driving to appointments

Driving is the most common mode of transport for people living in England, yet driving to an NHS appointment can come with challenges that may increase anxiety and stress for people.

Availability and cost of parking

One of the most frequent issues raised with us, and one that will not come as a surprise to those working in the NHS, is the availability of parking.

Personal story: Problems finding places to park

“My husband drove our daughter to a hospital in Bath for her earlier biopsy appointment but was unable to find anywhere to park at the hospital (as usual), and had to drop her off, go elsewhere and return for her later. We really wanted someone to be with her for this surgery but had no choice but to leave her to it.”

Response to the LTP engagement in the South West

People also find it stressful gauging how long they need to buy a parking ticket for. If appointments are running late they risk fines or missing their appointment to put more money on the meter.

One suggestion put forward to local Healthwatch was that services running behind schedule could display this information online or let patients know via text message, so people know when to leave home. This is similar to the way airports communicate when flights are delayed.

“**Parking is expensive if appointments are running over, let us know by text if things are running late.**”

Response to the LTP engagement in the South East

Blue badge parking

People with disabilities, including those with hidden disabilities, may be entitled to a blue badge to make it easier for them to drive to destinations and park. However, hospital parking, where the blue badge scheme is of particular value, does not always provide the reassurance it should.

While most hospital trusts offer either reduced or free parking for blue badge holders, people often tell Healthwatch that there are problems with the number and location of disabled bays in hospital car parks.

This means it can be difficult to get from the car park to some hospital departments which can cause additional anxiety and physical pain if someone's mobility is limited.

Personal story: Problems with blue badge parking

“One thing I think that should be addressed is certainly parking facilities, this is one of the most stressful areas for people who are chronically ill. First and foremost there are invariably insufficient spaces in the car parks for the amount of outpatients and visitors on a daily basis, I am fortunate enough to have a blue badge but even that doesn't always help, in fact we (my husband and I, who has cancer) went to the hospital and had to ride around 2 multi story car parks and 2 outside car parks and couldn't find a space, eventually we found what we thought was an ok place to park only to come back an hour later to find a parking ticket which cost us £25 - this on hospital grounds is unacceptable! £25 constitutes a large part of our spare income for food. So not only do you have illness stress you also end up with financial stress. Particularly when that week we had to go to hospital appointments between both of us Sun, Tues, Thurs and Sat.”

[Response to the LTP engagement in the Midlands](#)

Using public transport, taxis and community transport

Public transport

People who use public transport to access healthcare have to plan their journeys carefully. The importance of arriving in plenty of time for appointments means they need to allow extra time to get there and consider which route to take.

People told us that they felt frustrated that the NHS did not consider the realities and stress caused when travelling to healthcare appointments on public transport.

The group informed us about the extreme limitations of public transport in their community. “There is just one bus, three days per week”. One lady was referred to Whitehaven in West Cumbria for treatment, a round trip of 110 miles.



Extract from LTP engagement report from the North West

The public transport services available may not work with appointment times allocated by a healthcare provider. For example, we heard of people being given appointment times that are before the first bus would get them there.

People also told us that public transport often doesn't provide a direct link to NHS services and they need to take multiple modes of transport, or change a few times, adding more time and stress to their journey. This is particularly challenging for people with long-term conditions who may be living with chronic pain or reduced mobility.

Personal stories: Support needed for those travelling alone

"To get to hospital, I take three buses, which takes three hours, but over this last year, it has been too stressful to use the buses. My condition gives me awful balance, so I'm always falling over. With my arthritis I can only walk very small distances so it's painful walking between buses."

79 year old patient speaking to Age UK

"My husband has to go to a hospital, which is three bus journeys just to get his blood pressure and weight checked so he can be given a prescription for chemo pills. He has his blood checked at the local hospital and when asked if he could be referred to our local hospital he was refused."

Family member of patient responding to the LTP engagement in the East of England

Taking the bus to appointments or to visit health services has been made more difficult by cuts to local authority funding for bus services in recent years. [*A Freedom of Information request by the Campaign for Better Transport in 2018*](#)⁹ found that public funding for buses that serve commercially challenging routes has halved in the last eight years, leaving many places without public transport.

⁹ https://www.whatdotheyknow.com/user/campaign_for_better_transport

“There are no buses where I live, they have all been withdrawn due to funding issues. A taxi is £13 return for a five minute (two mile) each way journey which is only affordable in emergencies.”

Patient responding to the LTP engagement in the Midlands

When going home after treatment, people who rely on public transport face another difficult journey, which is often not considered by NHS professionals when planning. People tell us that it’s hard and sometimes impossible to plan appropriately because they often do not know if their appointment will finish on time or when they will be discharged.

Personal story: A journey far from home

“You can be admitted or taken in an ambulance, to a hospital far away, and then discharged when there’s no public transport running. You’re expected to get back home from wherever the ambulance has taken you – not everyone can afford taxis”

Response to the LTP engagement in the North East and Yorkshire

Discounts on bus travel, for those who are state pension age or who have certain disabilities, is often only available at non-peak times, which doesn’t always work with the appointment times offered by healthcare providers. Those who need to travel at specific times due to other commitments, or those on a limited budget, can be disproportionately affected by this.

“My bus pass can only be used after 9am so I cannot attend earlier appointments.”

Patient responding to the LTP engagement in the East of England

In 2018, Age UK’s *Painful Journeys*¹⁰ report found that of people aged 65+ who had been to a hospital appointment in the previous year (either their own appointment or in support of a loved one):

- 26% said there is no form of public transport that will get them to their hospital appointments on time.
- 26% would not be able to get to their hospital appointments if family and friends weren’t able to drive them there.

¹⁰

https://www.ageuk.org.uk/contentassets/7354623c9df1491a84cc34ef46105647/painful_journeys_campaignreport.pdf

- 28% say it takes them most of the day to get to and from hospital.

Taxis

Travel by taxi can be a quicker and more direct way of getting to healthcare appointments and may be necessary if someone is not well enough to use public transport, or if they live too far from a convenient public transport route.

Taxis may also provide a more appropriate method of transport home from appointments for people who have been given an anaesthetic or have been sedated during treatment received that day.

Although taxis may be more convenient, the cost can make them an unsustainable way of getting to and from healthcare, particularly for those who have regular appointments and/or are on a low income.

Personal stories: Travelling by taxi

"NHS was great, all tests done, and treatment provided but having to travel large distances to get to the Royal Berks and the lack of parking, meant long bus journeys both ways, which when you're having chemo is not a great experience. Taxis cost £70. Unsustainable."

Response to the Healthwatch LTP engagement in the South East

"I have arthritis in my knees and have to wear special leg braces. Amazingly, I don't qualify for hospital transport. I've been forced to rely on my savings and am spending £1,000 a year on transport to the hospital."

Comment received by Age UK from a 79-year-old hospital patient

Taxi drivers are also not consistently able to help people with the additional physical or mobility needs they may have as a patient travelling to or from an appointment.

Sometimes this may be because drivers don't have the skills to help people in and out of the car safely, or we have heard drivers are pushed for time to get to their next job.

Special taxis are available in some areas, for wheelchair users for example, but these are often more expensive.

Personal stories: People with accessibility needs travelling by taxi

“Patient who is elderly and in a wheelchair was dropped off at the entrance to hospital by a taxi (no transport available) and left there. She had to ask someone passing to take her to the ward.”

Comment received by Kidney Care UK from a patient about another patient

“I got in the taxi, was half way home and crashed (fainted). Taxi driver had no idea what to do and carried on driving with me on the floor of the taxi. Drivers need basic training, all he had to do would have been to lie me flat.”

Comment received by Kidney Care UK from a patient

Volunteer and community transport

Volunteer and community transport services, such as those provided by the [Royal Voluntary Service](#), can be a useful and low cost resource to help bridge the gap where there’s a lack of public transport services. People tell us that demand for this service can be high, and it may not be appropriate for appointments that are late in the day or running late, as these services usually run during normal business hours only.

Age UK found in their research that there is low awareness of community transport, with patients not being routinely informed about the services available in their area and missing out as a result.

The volunteer driver scheme is much appreciated for hospital visits but is generally oversubscribed

Response to the LTP engagement in the North West



In 2017, health and social care stakeholders across North Yorkshire identified a growing issue with patients missing their appointments. At the same time, residents were raising concerns with Healthwatch about poor access to health services .

[Healthwatch North Yorkshire](#)¹¹ carried out an investigation and found that transport links were the key factor causing the problems. They found that the NHS services on offer were not conveniently located and for many people who rely on public transport, the times that they ran gave them a very limited window of suitable appointments.

However, because local NHS services had no way of recording people’s issues with transport, they were not able to offer appointments that would work for them. The Healthwatch has since worked with local services to extend the opening hours of some services to fit in better with transport timetables.

¹¹ https://healthwatchnorthyorkshire.co.uk/wp-content/uploads/2018/06/rural_access_2017_0.pdf

NHS commissioned patient transport services

For people who meet certain criteria, the NHS offers a Non-Emergency Transport Service (NEPTS). These services pick up and drop off patients for scheduled appointments and treatment, primarily in hospitals. Only in some cases is a relative or carer able to accompany a patient in this form of transport.

The Department of Health and Social Care sets out the [national eligibility criteria](#)¹² for this service to ensure everyone across the country has equal access. However, the criteria are vague, making it difficult to apply meaningful standards.

The way the criteria are applied locally has created some inequalities. For example, in some areas certain conditions, such as cancer, automatically qualify yet other serious and often debilitating conditions, such as dementia, do not. Every time a patient needs transport for a new appointment or a course of treatment they must be reassessed, even if they have a long-term condition that will not improve, making it a long and arduous process.

Funding pressures on the NHS mean that non-clinical services have come under significant pressure, with Clinical Commissioning Groups (CCGs) using their own interpretation of the criteria to tighten eligibility. As a result, there is significant variation in how the criteria are applied across the country. This can leave patients and families unclear about whether they are likely to be able to access help.

Healthwatch, Age UK and Kidney Care UK hear from an increasing number of people with high-level health needs being turned down for patient transport. In some cases, this means people have to cancel their appointments, or appointments are missed because people are forced to use less reliable methods, such as public transport or asking for lifts from friends and family.



More support accessing hospital transport is needed. I was shocked to hear that I wouldn't be attending my appointment because they couldn't cope with numbers.



Response from a patient to the LTP engagement in London

Appeals

People who are denied patient transport can appeal and, because the eligibility criteria are so vague, previous decisions are frequently overturned. This is a waste of people's time and NHS resources, which could be better spent on providing more places on patient transport. It also places unnecessary stress on people who are already coping with health conditions.

¹²

https://webarchive.nationalarchives.gov.uk/20130124040549/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_078372.pdf

In 2018, *Healthwatch Northumberland*¹³ heard from a large number of people who were experiencing problems with booking patient transport. They found that around 4,000 patients a year were being declared ineligible, only to have the decision overturned on appeal. Overall they found that 70% of refusals in Northumberland were granted second time around.

While many people appeal decisions successfully, not everyone realises they are able to appeal or have the capacity to do so. When people seek help to appeal it also places additional burden on limited advocacy services.

Poor experiences

Even for those who satisfy local thresholds, the services do not always work well. People are often told to be ready for pick-up up to two hours before the collection time and then have to wait for hours after their appointment before being driven home again. Drivers have to collect people from different locations, leaving patients waiting for long periods often without food, water or access to a toilet. This can be extremely distressing for patients.

“My personal feelings are that the provider is treating us as items to be delivered rather than people with feelings and lives, and commitments outside of dialysis.”

Comment received by Kidney Care UK



Personal story: Delays in patient transport

"The transport does not come to pick up patients in a timely fashion, this sometimes results in patients waiting many hours for their appointment time. Often patients miss their appointment because it is booked for early in the morning and the transport doesn't arrive in time.

Response to the LTP engagement in the East of England

¹³ <https://healthwatchnorthumberland.co.uk/wp-content/uploads/2018/02/Patient-Transport-Service-Insight.pdf>

Personal story: Services working to their own timetables

Our local service is using a four-hour window, i.e. If your appointment time is 1300 then you can be picked up at any time up to four hours beforehand. My specific run actually takes an average of 45 minutes. The service, however, I assume in an effort to contain costs, wants to fit in collection of five patients all who have differing appointment times. This results in a 45 minute journey actually taking about an hour and a half along with the uncertainty of when one is actually going to be collected. I have had a driver turn up at 1020hrs for my appointment time of 1330hrs. A major factor in why I now drive myself at my own expense.

Patient experience shared with Kidney Care UK

Those worst affected

Healthwatch has identified three specific groups who face even greater challenges.

People living in rural areas

Getting to healthcare appointments is a greater problem for those living in rural communities.

Not only are journeys longer for people in these areas, but they are also often more inconvenient because people have to take indirect routes.

This is most stark when we look at public transport, with people from largely urban areas almost twice as likely (23% of patients) to use a bus or train compared to those from more rural areas (12%).

Interestingly, our qualitative analysis suggests that people are not so concerned about the issues of travelling long distances when it is for a specialist intervention, such as surgery. However, it becomes much more of an issue when they need follow-up care or more regular treatment. People tell us that what they want is more rehab and community services delivered closer to home.

A friend is currently having to make 110-mile round trip daily for six weeks

Response to the LTP engagement in the North East and Yorkshire

One suggestion put forward was for health and care services to do more to coordinate appointments for people in the same location and on the same day.

We heard from one man who is quadriplegic and lives in rural Bedfordshire.¹⁴In the last 12 months he has had 23 separate hospital appointments, many of which he feels could have been grouped together, if tests and scans were offered on the same day.

Personal story: Why co-ordinating appointments matters

"It would be nice to have one appointment rather than several, so if I needed a scan, blood tests and a consultation, I could have them all in the same day rather than going backwards and forwards."

Response to the LTP engagement in the South East

People who need to be accompanied on their journey

For many people, such as those with long term conditions, older people, and people using a wheelchair or living with dementia, travelling alone can be very distressing.

Yet because places on patient transport are limited, services tend to prioritise patients over relatives and carers. Many people must then face the difficult choice between a long and uncomfortable journey on public transport for which someone is able to accompany them, or travelling alone on the hospital's patient transport service.

This is also an issue for people who may be physically able to get to appointments on their own, but who find the journey home difficult as a result of the treatment they receive. For example, someone who has had radiotherapy or chemotherapy may need extra support to get home in comfort.

Personal stories: Support needed for those travelling alone

"My husband is housebound and disabled. In order to get him to hospital I have to pay for a special taxi because if he goes by hospital transport, I'm not allowed to go with him."

Response to the LTP engagement in the Midlands

With the NHS looking to deliver more complex procedures as day cases, it is becoming increasingly important that the health service thinks more about people's support networks.

By working with family, friends and carers to enable more people to have a travel companion with them, the NHS can help prevent unsafe journeys home and avoidable readmissions. Some people do not have a support network, so their transport needs need to be incorporated into NHS and social care discharge planning.

¹⁴ <https://www.healthwatch.co.uk/news/2019-04-16/how-does-living-rural-area-affect-access-healthcare>



Personal story: Lack of support

"I have nobody who can take me to hospital. I usually drive myself. When I have an exacerbation, I am too ill to drive and there is no transport for me. These arrangements should be part of a package of care. The feeling of being 'dropped in a hole' causes a lot of anxiety."

Response to the LTP engagement in the Midlands

This is particularly important as shorter hospital stays are increasingly being referred to as a key success indicator the NHS. Whilst spending less time in hospital is often good for patients too, shorter stays cannot come at the expense of people getting home safely.

People who are digitally excluded

We have been hearing that digital technology will enable more appointments to happen remotely, either via phone or video conferencing services, such as Skype or FaceTime. For some people this will mean they can avoid having to make a journey at all, which we know many people would appreciate.

My daughter recently took 1.5 hours each way by public transport to get to hospital in Bath to get her biopsy results which took two mins and were clear/negative.

Response to the LTP engagement in the South West

However, it is important to remember that although many people would be happy to access healthcare professionals online, there are people who cannot do so for a variety of reasons, such as cost, poor access to broadband internet, lack of computer confidence or skills, or a preference for face-to-face interactions.

I don't have a new phone that can do everything, and I don't have a computer. How does this work for me?

Response to the LTP engagement in London

The NHS cannot afford to overlook these people in its enthusiasm to roll out new technological solutions and achieve the headline targets set out in the Long Term Plan.

There are many places in Bucks where you can't get a good signal/adequate broadband, so people could miss vital information.



Response to the LTP engagement in the South East

Services need to record better data on people's needs and preferences, and work together to make receiving care as stress free as possible. Care should be provided in a variety of ways, including face-to-face, for those who require it.

Gaps in NHS data

One of the biggest challenges with transport is that NHS services don't think broadly enough or capture enough information to support the commissioning or delivery of support for travel to and from appointments.

With services that are outside of its direct control, like public transport, the NHS is not routinely looking at publicly available data to understand the options available to patients. There is a real opportunity for the NHS to work with local authorities, local transport providers and those responsible for regional transport planning to create a more integrated service.

When it comes to services within their own control, the NHS is often not routinely collecting its own data to support decision making. For example, CCGs are *responsible*¹⁵ for purchasing Non-Emergency Patient Transport Services (NEPTS), however, our research shows that most CCGs are not collecting data.

What we asked

In May 2019, we wrote to all 191 CCGs under the Freedom of Information Act (FOI) and asked them:

1. How many people accessed the NEPTS service in their area for each of the financial years from 2015/16 to 2018/19?
2. How many people requested access to NEPTS but were refused the service for each financial year over the same period?
3. Have there been any changes in the guidance issued to those conducting eligibility assessments during this period, and if so, what were they?
4. How many people were reassessed for eligibility for access to non-urgent patient transport services for the same period? What was the outcome?

¹⁵ <https://www.england.nhs.uk/wp-content/uploads/2014/05/who-pays.pdf>

What we found

In total, 107 of the 191 CCGs in England responded (56%). Roughly half of these were unable to provide any of the information we asked for, mostly stating that they do not collect it. However, 61 CCGs did provide either all or some of the information we requested.

Even though only a limited number of CCGs were able to respond, the data they provided did suggest some concerning trends, which we believe require the NHS to investigate further.

- Between 2015/16 and 2018/19 the number of journeys completed by NEPTS across the 61 CCG areas fell by 42%.
- For the 18 CCGs that recorded the number of times people were denied access to the NEPTS we found that refusal rates rose by 182%.
- In real terms that means the number of times people were turned away increased from 13,025 in 2015/16 to 36,719 times in 2018/19.
- None of the CCGs who responded recorded any data relating to appeals or the outcome.

Without routine data collection, CCGs cannot make informed decisions about what services they need to provide in the future. This lack of data also means the commissioning of services cannot be scrutinised effectively to make sure that the needs of local people are being met.

How non-emergency patient transport services are funded:

In April 2018*, Age UK contacted a randomly selected sample of 50 CCGs to ask about funding of NEPTS and their commissioning structures. In total they received 42 responses.

As with our own FOI request, the quality of the data CCGs provided made it difficult for Age UK to draw concrete conclusions, particularly in identifying trends over time. However, from what was provided, they found that:

- Spending on NEPTS in 2016/17 ranged from between £1 million and £3 million, with a rough mean spend per CCG of £1.6 million. (Based on data from 31 comparable CCG contracts).
- Across a large county like Derbyshire (where all CCGs provided data) this means that the spend on NEPTS was £10.9 million.
- Across a city like Leeds (where all CCGs provided data) the spend was £4.5 million.
- Overall the research suggested that spending on NEPTS accounted for roughly 0.5% of CCG budgets in 2016/17.

One of the main reasons suggested by Age UK for the poor data was the confusing and varied commissioning structures in operation across the country. From the sample of CCGs contacted they identified six different models:

1. CCGs directly commissioning NEPTS for their area.
2. Acute Trusts given responsibility for providing NEPT as part of their functions without reporting to the CCG.
3. CCGs commissioning NEPTS directly through Acute Trust providers, who in turn provide it in-house or through a sub-contract.
4. One CCG commissions services for an area (e.g. a county) on behalf of all local CCGs.
5. Acute Trusts are given delegated responsibility for NEPT with the CCG commissioning to cover shortfalls and cross-border arrangements.
6. CCGs commission the local ambulance trust to provide NEPT, often at scale across many CCGs.

Changing between commissioning systems is also not uncommon, making it difficult to draw year-on-year comparisons across the country. It is likely that we will see further changes as commissioning processes become more streamlined, as laid out in the Long Term Plan.

*(Full details of the data collected are available from Age UK on request).

Promising practice

There is good practice out there, which shows some areas are already looking to improve how they provide support with transport.

In some cases, this is shown through services reacting positively to feedback provided by people and making changes. In other areas we have seen people being proactively invited in to contribute to the service design process.

Healthwatch Staffordshire

Earlier this year *Healthwatch Staffordshire*¹⁶ produced a report on what they had been hearing from local people about the local transport service.

Overall there were positive responses from staff and patients which made it clear that if the service didn't exist then people wouldn't be able to get to hospital safely. However, there were also key areas for improvement highlighted by the Healthwatch team, including needs to:

- Keep patients and staff better informed of delays.
- Review the way journeys are organised and routes planned to increase efficiency.

¹⁶ https://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/reports-library/20190701_Staffordshire_Report_on_Non-Emergency_Patient_Transport_provided_by_E-Zec_Medical_Transport_at_Staffordshire_Hospitals.pdf

- Encourage controllers to be more flexible and react to changing circumstances.
- Provide more customer service training for staff.
- Meet with local hospital management to review waiting areas.

The report was welcomed by the local provider, who said it provided them with a “greater understanding of patient, carer and family experiences, which will support Commissioners to continually improve service provision”.

Many of the recommendations made by Healthwatch aligned with what people had told the commissioner and service provider elsewhere, and the commissioning quality team is meeting with the local provider monthly to review progress against the agreed actions.

Healthwatch Barnsley

Following a recent review of patient transport across Barnsley, Doncaster and Rotherham, the three CCGs decided they needed to procure a new joint patient transport service.

The CCGs collectively recognised that people who use the service would have valuable knowledge that could help inform the procurement process, so they approached Healthwatch Barnsley for help.

Healthwatch welcomed the opportunity to share what people in their communities had told them and agreed to share their existing evidence to add to the contributions from the two patient representatives on to the decision-making panel.

This reflects a wider culture across the area, which has seen Barnsley Health and Wellbeing Board take a leading role in shaping the local transport strategy. This means that decisions around the restructuring of local bus services have taken health into consideration.

The transport strategy has also been used to promote increased wellbeing through reducing air pollution and encouraging more walking and cycling.

Kidney Care UK: Help with the cost of travel

“For some patients who must attend hospital regularly, the cost of driving can really add up, especially when adding parking fees on top of mileage.

Kidney Care UK frequently hears from patients who must make up to six journeys a week for dialysis. Most patients are not well enough to drive or do not have a vehicle and rely on patient transport services. For the few who do drive, financial assistance is vital, yet what help is available varies across the country.

Many of these people are able to get some help under the NHS Travel Cost Scheme, but in a handful of areas the NHS has gone further and handed dialysis patients vouchers for free parking. “

NHS England has also made *personal health budgets*¹⁷ available to a small number of patients to support with transport. However, these will only work where personalised care and support planning is available to establish whether such a budget would be what a patient wants and needs.

North East and West Devon CCG has successfully piloted a personal health budget for dialysis transport, to enable to people to manage their own transport arrangements and have more choice and control over how that is delivered. Such innovation is welcome and worth consideration by other CCGs as one of a range of improvement opportunities.

Next steps

At its heart, the Long Term Plan is all about providing better integrated and person-centred care. However, it will be difficult to say it has delivered this unless it directly addresses both clinical and non-clinical issues facing those who use the NHS.

We recognise that many elements of the transport infrastructure are beyond the direct control of the NHS, but this doesn't mean that health leaders can ignore the issue or expect those in other sectors to come up with the solutions on their own.

Solving the problems people experience in travelling between home and healthcare providers is important in achieving truly person-centred services. It would also demonstrate that the NHS is listening and addressing the issues that people say matter to them.

Finding the solutions will require the NHS to work with a range of partners in local government, private transport companies and those responsible for regional transport planning. It will also require an integrated approach at a national, regional and local level.

But, with some truly joined-up thinking and creative use of existing resources, it is possible to improve how transport is provided and there are already some good practice examples, which can be built upon.

Together with Age UK and Kidney Care UK, we will be working with NHS England to support their national review of transport and the NHS. There are some priority areas which we

¹⁷ <https://www.england.nhs.uk/personal-health-budgets/what-are-personal-health-budgets-%20phbs/>

believe the review will be able to resolve more quickly and other more complex areas where the solutions may take longer to develop.

We want this review to set a clear and strategic direction for tackling this issue over the lifetime of the Long Term Plan.

Areas for action within direct NHS control:

- All NHS services to commit to the Long Term Plan’s ambition to ‘save patients 30 million trips to hospital’ over the next five years by offering more digital consultations where appropriate and providing more convenient care in the community, including in people’s own homes.

As part of this, services must make better use of data to ensure that requests for patients to physically attend appointments are co-ordinated. This issue is likely to become more significant as the numbers of people with multiple and complex conditions increases. Aligning appointments would vastly improve the experience for these patients.

- NHS England to establish how improving patient transport could contribute to the overall goal of saving £1 billion a year on outpatient appointments.

For example, NHS England could conduct research on how coordinated appointments reduce the number of trips patients are required to make, or how improvements to patient transport services could help reduce the number of missed appointments. This information will support and enable local areas to invest in patient transport.

- NHS England and NHS Digital to work together on creating a new national data collection on Non-Emergency Patient Transport Services (NEPTS). This should look to capture data for each area of the country on:
 - How many people are accessing patient transport services.
 - Demographic information on users of patient transport services, including their clinical needs.
 - How many journeys are made.
 - The percentage of patients using non-emergency patient transport who successfully made it to their appointment on time.
 - The number of people who had access to patient transport services when returning home who were then subject to an avoidable readmission.
 - Satisfaction rates with the service.
 - Who, and how many people, have been refused access.
 - Outcome of appeals.

These measures are all vital for making good commissioning decisions, helping those designing services understand whether local need is being met and where current gaps are. At a national level, the data can help the Department of Health and Social Care scrutinise how eligibility criteria are being applied and identify if any specific groups are inadvertently being excluded from support.

- NHS England to review how the national eligibility criteria for NEPTS are being applied by CCGs, and to issue new guidance that is sufficiently clear and appropriate to iron out unwarranted variation and ensure patients' needs are being met. This would help to reduce the need for people with genuine need to appeal, which at the moment wastes both people's time and NHS resources.
- NHS England and NHS Improvement to use their regulatory role and influence over NHS standard contracts to introduce clearer obligations on hospitals and GPs to proactively alert patients to available transport options, including how they can get help with the cost of transport if not eligible for NEPTS, and which voluntary and community services are available in their area.
- NHS England should set national standards more broadly about how commissioners and providers should prevent distress, pain and anxiety for patients by making their journey to and from services as easy as possible. This should include stipulating that patients with long-term conditions which will not improve should be exempt from having an eligibility assessment every time they require patient transport.

Areas for action that will require the NHS to explore greater partnership working:

- The NHS needs to make a sector wide commitment to involve transport commissioners and providers as standard in discussions when developing new services or reconfiguring existing services.
- This commitment must cover changes to services at all levels, from major relocation of hospitals to the shifting in delivery of services across the new Primary Care Networks.
- Local NHS services should work with their local authority partners to ensure data on health and the links with transport are fully considered as part of the Joint Strategic Needs Assessment (JSNA).

The JSNAs are reviewed every two or three years and look at both the current and future health and care needs of local populations to inform and guide the planning and commissioning of health, wellbeing and social care services within a local authority area.

Local areas should work together in a similar way when considering the development of their Carbon Reduction Strategies.

- Local NHS leaders to work with those responsible for car parking to improve the way systems work for people.

This should include putting in place policies to waive fines for people who get parking tickets due to NHS delays.

This could also include pre-booked car parking spaces for certain patients or providing better information on the best spaces for people accessing specific areas of the hospital.

- NHS services to explore working in partnership with technology and transport companies to make more intelligent use of patient data.

For example, this could include services matching up records on address, patient preferences regarding transport and data from local public transport timetables and using this to support smart scheduling when offering patients appointment slots.

Technology can also be used to keep patients better informed about on-the-day waiting times, so people can make informed choices about when to arrive. It can also be used to tell patients when their transport will arrive, so they don't have to get ready several hours in advance.

All of the above recommendations should be worked on with people who use services and patient organisations to ensure that the future shape of transport is people-centred.

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- Healthwatch Sunderland
- Healthwatch Surrey
- Healthwatch Sussex
- Healthwatch Tyne and Wear
- Healthwatch Warwickshire
- Healthwatch West Berkshire
- Healthwatch Worcestershire

About us

Healthwatch is the independent champion for people who use health and social care services. We exist to ensure that people are at the heart of care.

We listen to what people like about services, and what could be improved, and we share their views with those with the power to make change happen. We also help people find the information they need about services in their area.

We have the power to ensure that people's voices are heard by the government and those running services. As well as seeking the public's views ourselves, we also encourage services to involve people in decisions that affect them. Our sole purpose is to help make care better for people.

Role of local Healthwatch

There is a local Healthwatch in every area of England. They provide information and advice about publicly-funded health and care services. They also go out and speak to local people about what they think of local care and share what people like and what could be improved with those running services. They share feedback with us at Healthwatch England so that we can spot patterns in people's experiences and ensure that people's voice are heard on a national level.

healthwatch

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