

Introduction

Each month, thousands of people share their views with us about health and social care services.

This report aims to provide NHS and social care leaders with a summary of:

- Key issues the public have told us about primary, secondary, mental health and social care support.
- The top questions people are seeking advice about.

This report covers the period from October to December 2019 and provides a snapshot of people's care based on the experiences of 8,690 people.

In focus

We take a closer look at what people are telling us about NHS funded wheelchair and home equipment services, as well as the issues trans people experience when it comes to health and care.

What issues cut across health and care?

Read about the impact that staff attitudes are having on people's experiences.

What's happening in my sector?

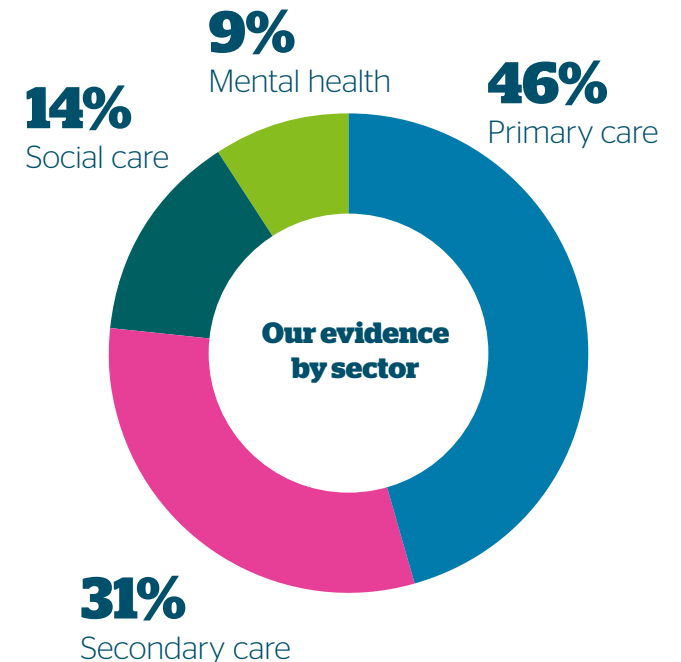
Look at our primary care, secondary care, mental health and social care snapshots to see the ongoing concerns people would like services to address.

What other research might interest me?

Check out other research from Healthwatch that might help you better meet the needs of service users.

The evidence that informs this report
8,690 people's views

drawn from 149 Healthwatch reports across England about local NHS and social care services, as well as individual feedback from the public.¹



¹ This briefing is informed by feedback from 8,690 individuals. The views are drawn from either reports published by or feedback provided to local Healthwatch between October and December 2019.

In focus

We look at two areas of care and what services can learn from the stories people have told us.

Access to wheelchairs and home adaptations services

Over 700,000 people are registered to get NHS funded wheelchair services.² This support, along with equipment and home adaptations provided by councils, plays an important role in improving the quality of life for disabled people. A review of people's experiences points to several areas that services can focus on to make sure they are meeting people's needs.



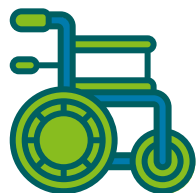
Information

Disabled people who need equipment don't always know what help is available and how to access this support.



Long waiting times

People have told us that they can wait a long time to have their needs assessed and that they have also experienced delays with getting equipment serviced, adjusted or repaired. When services don't provide equipment in a short timeframe, people can be left with a poor quality of life.



Getting the right equipment

People don't always get the right wheelchair, despite having an assessment which is supposed to identify how their needs should be met. This has an impact on their health. People have also told us that it can be hard to get problems resolved quickly.



Responding to changing needs

People can struggle when their circumstances change but their needs are not reassessed – for example when young people outgrow their existing wheelchair. People have told us about being left with no option but to use an unsuitable wheelchair, resulting in pain, poor posture and injury.

The impact of providing the wrong equipment

In September 2018 my relative's chair was referred to Wheelchair services for attention as the design of the chair was causing his head to be injured. Since then his chair has been assessed and it was recommended that his chair updated. It is now January and he still hasn't been provided with the improvements to his chair. Over Christmas, he injured one of his ears due to problems with the chair and had to have an operation and spend four days in [the] hospital. The delay to repairing the chair is now seriously impacting on his quality of life. Because of his physical disability, these injuries can become very serious and stop him from attending college, affect his quality of life, as well as causing him a lot of pain.'

² National Wheelchair Collection Results July - September 2019, NHS England.

Health and care support for trans people

A review of feedback indicates that inequality when accessing services is a significant issue for some trans people.



Staff knowledge of trans issues

People have told us that they encounter issues when using the NHS due to the lack of knowledge or understanding from some healthcare professionals, especially when talking to their General Practitioner.



Improving communication and language

People have raised concerns with us about health staff not using trans people's preferred or correct name, gender or pronouns in written and verbal communication. Some people who have legally changed their name and gender have also told us that they have faced problems getting their NHS records correctly updated.



Referring people to the right services

Despite gender dysphoria no longer being defined as a mental health condition by the World Health Organisation,³ our review of trans people's experiences shows that the correct referral protocol is not always being followed, especially by GPs. People have told us they are being wrongly referred to mental health services, which has affected how quickly they are able to access gender identity services.



The effect of waiting for treatment

Trans people have reported that delays in referrals and long waiting times have forced some to pay for treatment privately. Individuals have told us about experiencing serious effects while waiting for specialist support, including self-harm and suicide. Others have started self-medicating, purchasing hormones online without the expertise or supervision of a medical professional.

Poor administration procedures

Obtaining the result has been fraught with difficulties. Her daughter has recently changed to a female name and from Mr to Miss. This has meant that a new NHS number has had to be assigned. Despite this being organised, the wrong title is often used on blood forms e.g. Mr and then the female name, causing upset to her daughter. In addition, NHS numbers do not seem to match as they should and consequently, the results of the blood test are not to be found. Apparently, the problem is due to the merge of records.'

³ World Health Organisation ICD-11: <https://icd.who.int/browse11/l-m/en/http%3a%2f%2fid.who.int%2fcd%2fentity%2f411470068>

An issue that cuts across care

Find out about the issue that people continue to raise in more than one area of care.

Personal interactions make all the difference

People tell us that how staff interact with them can have a big impact on how they feel.

We continue to hear about this across all sections of health and social care, and the difference it makes when staff are reassuring and empathetic rather than uncaring or dismissive. This is especially important to people who are vulnerable, those who face language barriers or have multiple conditions.

People also tell us the difference it makes to them when professionals have the time to treat them as individuals, understanding and addressing their specific needs, concerns and preferences. They also tell us the distress this can cause when this does not happen.

How does it make people feel?

Words people use to describe how different interactions with staff make them feel.



Positive interactions

“Calmer”
“Safe”
“Supported”
“More in control of my life”
“Feel better about the care I get”



Negative interactions

“Vulnerable”
“Uncared for”
“Negative effect on mental health”
“Distressing”

Steps that could help

- Identify the pressures that can make treating people with empathy and understanding their full range of needs harder for staff.
- Work with staff and service users who raise concerns about the capacity of a service to deliver personalised care to identify potential solutions.
- Promote a culture that consistently acknowledges the importance of empathetic care and track the positive impact this can have on the service users and staff.
- Provide clear information to people about:
 - How people’s individual choices and needs can be incorporated into the support they receive.
 - What people should expect when it comes to the support they are being offered and how long they may have to wait.

Top questions the public are asking

We look at topics where there is a need for better information.

People turn to Healthwatch locally and online when they do not know how to get the information they need about services.

Between October and December 2019, these are the most common questions people came to Healthwatch about.



Questions people are asking local Healthwatch⁴

1. How do I register with a GP?
2. How do I find out if I am eligible for a GP home visit?
3. How do I complain if I'm unhappy? Or challenge the outcome of a complaint?
4. What are standard costs of different dental treatments?
5. What should I expect from mental health services?
6. Where can I find support for specific issues? E.g. autism, carers, bereavement, addiction.

⁴ This briefing is informed by 9,196 items of feedback provided by 8,690 individuals. The views are drawn from either reports published by or feedback provided to local Healthwatch between October and December 2019.



Information people are looking for online⁵

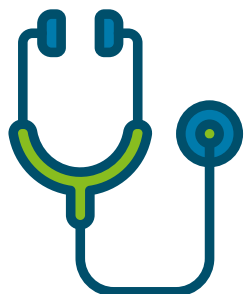
1. Help travelling to NHS services
2. Help making a complaint
3. How to find an NHS dentist
4. Your rights when it comes to registering with a GP
5. Things your pharmacist can help you with
6. Your rights when it comes to care homes

⁵ This analysis is based on website page views of Healthwatch England advice and information content from October to December 2019.

Ongoing issues by service area

Primary care

General practice



Problem:

Long waiting times to get an appointment

Digital exclusion

Deregistration with no prior notice

How services can improve:

- Offer more dates in advance for online appointments.
- Understand the barriers patients face to book an appointment, such as time left on hold on the phone, and the problems this can cause like individuals having to visit a service in person to book an appointment.
- When services are merging, take steps in planning to make sure it doesn't affect people's care or the time they wait to access support.
- Make sure on and offline booking systems allow patients to access the same amount of available appointments to prevent excluding those who have no access to the internet or may have limited digital skills.
- Make sure the implications of deregistering a patient are understood, especially for those who are on repeat prescriptions for long term conditions.
- Communicate well in advance if someone is going to be deregistered, explain the reasons why, and provide support with finding alternative surgeries.

4,203 people's

experiences informed this section.



I have no access to the internet and because of that cannot access the GP appointment system. I was going on holiday and wanted to see the GP before [I went away] ...but had to wait one month for my appointment. One of my friends who has internet told me...there were two earlier appointments available [online] but could not book one for me as only patients can... It is discrimination.

⁶ This analysis is based on individual feedback provided to Healthwatch.

Problem:

How services can improve:

Dentists

Access to appointments



- Recognise the considerable amount of time people are having to wait to see an NHS dentist due to problems finding practices accepting new patients and, in some areas, a shortage of appointments. Take time to address this and understand that this is especially challenging for:

- Pregnant women
- Housebound people
- Homeless people
- People living in rural communities with poor transport systems

Costs of care

- Be transparent about costs prior to treatment.
- Promote sources of help with finances, such as the NHS Low Income Scheme, to help people avoid delaying treatment.

Pharmacies

Unavailable medications



- Continue monitoring the availability of medications and support people to find alternatives when shortages occur.
- Carry out regular reviews to understand what medicine is in demand in communities, to assess customer needs and ensure a consistent supply. This should prevent people stopping or changing their medication, which can worsen symptoms or give rise to new ones.

I have been prescribed HRT as I was really suffering with menstrual issues. It was a life saver... I have had to change [medication] twice due to the product I am prescribed being in short supply... each time my life was turned upside down getting used to the new treatment.



Secondary care

Urgent and emergency care



Problem:

Inappropriate and expensive car parking systems

Waiting times for treatment

How services can improve:

- Review the affordability of car parking costs.
- Take steps to address the problems people encounter when they must leave A&E to top up their parking fees.
- Provide information about subsidised costs for people on low incomes.
- Help people understand what they should expect when services are busy by:
 - Assessing people quickly and explaining to them what will happen next
 - Communicating realistic waiting timescales and, if they have to wait for a long time, explain why
 - Providing updates if anything changes
- Look at reviewing the facilities available whilst people wait.

Hospitals

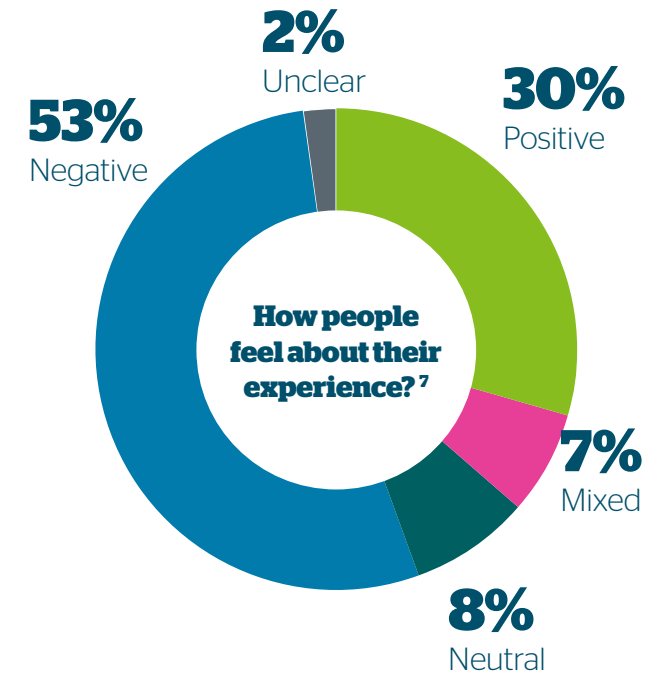


Appointment cancellations

- Provide clarity around why appointments are cancelled.
- Follow up with information and new appointments.
- Find ways to minimise cancellations, especially repeat cancellations.

2,854 people's

experiences informed this section.



I waited 12 hours in A&E. No one asked if I needed any help to the toilet, or if I was OK or needed a drink. No one offered me food and I had been sat there by myself for 12 hours. There was not even a tea or coffee machine in the waiting room...

⁷ This analysis is based on individual feedback provided to Healthwatch.

Mental health services

Problem:

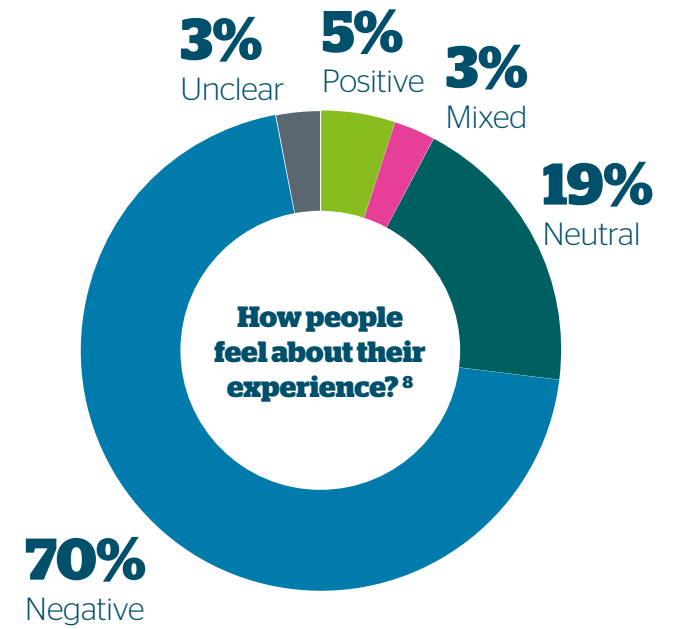
Long waiting times for mental health support

How services can improve:

- Provide estimated waiting times; to prevent people feeling concerned about how long they will have to wait.
 - Communicate whilst people are on the waiting list; to prevent people worrying they have been removed from the waiting list in error.
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- Ensure handwritten prescriptions are written clearly and correctly to prevent people being refused the medication they need by pharmacists and having to travel between services to get prescriptions corrected.

Prescription mistakes

840 people's
experiences informed this section.



The impact of prescription mistakes

A mother went to pick up her daughter's prescription, which she needed to collect before going on holiday. The pharmacy said it was written incorrectly and refused to give her it. The mother drove back to the doctor where they wrote it again. On arriving back at the pharmacy, the prescription was still wrong.

e The pharmacist could see how upset and frustrated I was... I just broke down in the pharmacy.'

⁸ This analysis is based on individual feedback provided to Healthwatch.

Social care

Problem:

People can't access the information they need

Difficulties communicating with staff

How services can improve:

- Invest in making information clearer to the public, especially:
 - What care people are entitled to
 - Who to contact for advice
 - How to access care
- Be transparent about changes to care to prevent people feeling like staff are withholding information.
- Be responsive and easy to contact when people have questions about their care.

The impact of poor information and advice

A woman with terminal cancer told us about her struggle to get a self-reclining chair, to help reduce swelling in her feet. She contacted social services, who said she could have a care needs assessment. As they had provided a chair for her previously, they said she would only be provided with a stool. However, as the woman and her husband both have sight problems, a stool would be unsuitable and cause a trip hazard.

They gave me some numbers to ring... [and] briefly asked about my benefits but didn't really give me any advice. It seems like you always have to find things out for yourself and it is really complicated.'

1,299 people's

experiences informed this section.



⁹ This analysis is based on individual feedback provided to Healthwatch.

You might also be interested in....

New reports from Healthwatch

- **What do people want from the next ten years of the NHS?** This report sets out what over 40,000 people across England told us when we asked them how they would like the NHS Long Term Plan implemented where they live.
- **Young people's mental health and well-being.** Find out what young people who had experienced mental health problems said when we asked them about the triggers for poor mental health and how the services of the future could provide better mental health support.
- **What matters to people using A&E?** Our latest research illustrates the chain of factors which impact on people's experience in A&E. The purpose of our research is not to argue for or against replacing the current four-hour target, but to inform the ongoing debate surrounding NHS England's Clinical Review of Standards.
- **Shifting the mindset: A closer look at NHS complaints.** We look at how well NHS Hospitals are demonstrating to patients that they are learning from mistakes.