

The value of listening

Healthwatch England
Annual Report 2022–23

A photograph of a woman with a blue headband and a denim shirt, smiling. The image is framed by a pink graphic element on the left and a green circular graphic at the bottom. The Healthwatch logo is in the bottom right corner.

healthwatch

The value of listening

Healthwatch England Annual Report 2022–23

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About us

Healthwatch is your health and social care champion.

If you use health services or need care, we want to hear about your experiences. We have the power to make sure NHS and social care leaders listen to your feedback and improve standards of care. We can also help you to find reliable and trustworthy information and advice.

Wherever you live in England, you'll also have a local Healthwatch nearby. Last year, we helped over one and half million people like you to have your say and get the support you need.

Our strategy



Our vision

To bring closer the day when everyone gets the care they need.



Our mission

To make sure that people's experiences help make health and care better.



Our aims

1. To support more people who face the worst outcomes to speak up about their health and social care, and to access the advice they need.
2. To support care decision-makers to act on public feedback and involve communities in decisions that affect them.
3. To be a more effective organisation and build a stronger Healthwatch movement.



Our values

- **Listening** to people and making sure their voices are heard.
- **Including** everyone in the conversation – especially those who don't always have their voice heard.
- **Analysing** different people's experiences to learn how to improve care.
- **Acting** on feedback and driving change.
- **Partnering** with care providers, Government, and the voluntary sector – serving as the public's independent advocate



Our committee

The Healthwatch England Committee is a statutory committee of the Care Quality Commission (CQC). Our main functions are to:

- Provide leadership, guidance, support to local Healthwatch.
- Escalate concerns about health and social care services to CQC.
- Advise Government, NHS England and local authorities about the quality of services.
- Set our strategy, provide scrutiny and oversight, and approve the policies we need to work effectively.

As public servants, we are committed to being open, accountable, selfless, objective, honest and displaying leadership as set out in the seven Nolan Principles of Public Life.

Foreword

Professor David Croisdale-Appleby OBE, Chair

Over the last decade, Healthwatch has empowered millions of people to share their personal experiences of care.

In sharing those experiences, members of the public have demonstrated the power they have to show what is and isn't working about our health and social care system. They have been pivotal not only in identifying the issues, but in highlighting how to make real and lasting change.

2022-23 was our 10th year, and it is clearer than ever that it's essential to listen to these voices to bring about better care for the nation. Only through listening to the public will we shape an NHS and social care system that works for everyone, for the next decade and beyond.

I am privileged to take on the role of Chair of Healthwatch England, not only as it enters its second decade of essential advocacy for better care, but at a critical time for health and social care services.

There are major challenges ahead. Our recent review of 65,000 people's stories over a 12-month period highlighted the barriers and delays to timely care that patients face in every part of the system. It also shone a light on the disproportionate impact that access issues are having on those already facing deprivation, vulnerability, and poorer health.

But by listening to those using health and social care services, commissioners and providers can more accurately identify and act upon the barriers to high-quality care. They can build safer and more effective services around people's needs, and in doing so also increase productivity and efficiency.

Overcoming the problems services face will take time, but there are three key areas on which decisionmakers for the health and social care system must focus.



“There are major challenges ahead. Our recent review of 65,000 people’s stories over a 12-month period highlighted the barriers and delays to timely care that patients face in every part of the system. It also shone a light on the disproportionate impact that access issues are having on those already facing deprivation, vulnerability, and poorer health.”

Making the NHS easier to access and navigate

People told us they felt administration and communication can be slow, inefficient and sometimes lacking in empathy. The NHS must demonstrate an ‘excellent customer service’ ethos, prioritising quicker access, clarity and simplicity at each touchpoint to ensure that people can book the appointments they need and get answers to the questions they ask. Patients should also be able to access real-time information about their care, and have an informed and constructive dialogue with those responsible for their care.

Tackling health inequalities

Health inequalities in England are stark and growing. Those living in the most deprived areas can expect to live in good health for a far shorter time compared to those in the least deprived areas.

We want the NHS to provide excellent care for everyone. Differences in both life expectancy and life expectancy living in good health between the most and least well off should be falling by 2030. Integrated Care Systems should work with local authorities to ensure communities get the advice and support they need in order to prevent ill health, and people with extra communication needs get full support every time they interact with the NHS.

Building a patient-centred culture

Whilst the majority of patients told us they felt respected by healthcare professionals, we see that the quality of care people experience varies very considerably. The NHS still has a culture focused on the priorities of the delivery system, rather than the needs and wishes of patients.

We must see a fundamental shift in the culture of the NHS so that there is a greater focus on listening to patients and acting on their experiences to improve the care they receive – today and in the future.

If these three areas are left unaddressed, embedding a two-tier system is a real risk. A system where those with the means to do so increasingly turn to private healthcare, and those without the means are forced to wait. An NHS that no longer upholds the founding principles of universality, equitable and free care.

Those leading services can prevent this happening by working hand in hand with those they serve. By listening to patients, they can build a different kind of future for our health and care system. One where services recover from the pressures that have buffeted the system, and can offer everyone safe, high-quality, tailored care.

Healthwatch, both locally and nationally, will do all we can to help make this happen.



“If these three areas are left unaddressed, embedding a two-tier system is a real risk. A system where those with the means to do so increasingly turn to private healthcare, and those without the means are forced to wait. An NHS that no longer upholds the founding principles of universality, equitable and free care.”

Our year in review

We supported more than one and a half million people with information, and to have their say on care.

Our top stories from 2022-23

Spring

We drew attention to the “hidden waiting list” created by delays to GP referrals.



We took steps to get people the support they need while waiting for planned care.

Summer

We highlighted the increasing issues people have getting mental health support, contributing to the release of the primary care recovery plan.



We made recommendations that would make it easier for people to monitor their blood pressure at home.

We called on the NHS to review and update the Accessible Information Standard to make sure everyone gets the care they need.



The NHS announced changes to their contract with dentists, after our data showed widening inequalities.

Autumn

Our “Because we all care” campaign encouraged more people to share their experiences, helping us improve care further.



NHS England published a plan to improve Long Covid care after people shared their stories with us.

Winter

The NHS ran a campaign around the NHS App and how it can help patients after we highlighted the need to increase confidence in the NHS.



We highlighted the impact of the soaring cost of living on healthcare.

Nationally



230,000

people used our service for clear information and advice

11,615

people shared their experiences of care

Locally



1,000,000

people used our service for clear information and advice

373,000

people shared their experiences of care

1

Highlighting safety and quality concerns



Waiting times have soared, inequalities are widening, and people's health is affected as a result. With patients facing problems with access in every area, this is more than just an issue of timely care – it's an issue of patient safety.

In this section, we highlight the stories behind the numbers waiting, and the changes we called for.

- We showed that the NHS must prioritise those who most need elective care, and the importance of supporting people struggling with daily life whilst they wait.
- We called for fundamental reform in dental care to avoid severe consequences for many untreated patients, especially those already facing inequalities.
- We showed how issues in mental health care have become worse since the pandemic.

The wait for elective care

In April 2022, the total elective waiting list grew to a record 6.53 million appointments, with over five million people waiting for planned care².

NHS England's Elective Care Recovery Plan³, which our evidence helped inform, promised an expansion in capacity for tests, checks and treatments. It also promised better support and communication with patients waiting for care. But seeing the results would take time.

Over the year, the backlog continued to grow, and by February 2023 the total list grew to 7.22 million appointments, with over six million people waiting⁴. Patients also continued to share experiences of operations cancelled with little warning, waiting for planned support without updates, and symptoms worsening over time.

Waiting for treatment had a bigger impact on some groups than others. In a survey we carried out of 1,000 members of the public⁵:

52%

of people from poorer households said long waits had affected their mental health – almost double the 28% from more affluent households.

66%

of disabled respondents waited over four months for treatment, compared to 44% of non-disabled respondents.

63%

of people on lower income from ethnic minority backgrounds reported delayed or cancelled treatment, compared to 38% of white British people from higher income brackets.

41%

of women said that long waits were affecting their ability to socialise, compared to 28% of men.



“It’s critical that work continues to support people while they wait. People need reassuring that the NHS is still there to help them, that they haven’t been forgotten and that the information and support they need are available.

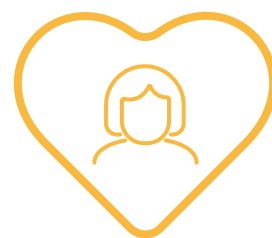
This means better communication so they know how long they will have to wait, better support with pain management and prioritising those in greatest need.”

Louise Ansari, Healthwatch England Chief Executive

To help address these inequalities and the growing waiting list, we called for:

- An increase in the number of non-clinical NHS staff to help cut administration errors and improve support for patients.
- NHS England to work with patient organisations to provide more personalised care for those waiting for treatment.
- Extended statutory sick pay for people not able to work because of NHS delays.
- Integrated Care Boards to cover travel costs where patients are offered quicker treatment at a different hospital.

The subsequent announcement by NHS England that they would ramp up staffing numbers to better support patients with their care was warmly welcomed⁶. This includes increasing the number of care coordinators from 4,000 to 12,000.



Number of care coordinators to increase from

4,000

to

12,000

Across the nation

Devon Integrated Care System (ICS) are addressing the concerns of those waiting for elective care based on findings from focus groups run by local Healthwatch in Devon.

Three sessions commissioned by the ICS focused on groups that face inequalities: people from the Deaf community, LGBTQ+ people, people from ethnic minority communities, and those living in rural areas⁷.



As a result of what people shared, Devon ICS have committed to:

- Work to mitigate challenges when it comes to travel to appointments, recognising that this especially affects those who already face health inequalities.
- Regularly review and improve the information they provide to patients waiting for care.
- Proactively identify and communicate with vulnerable and at-risk groups of waiting patients.
- Use the feedback to influence wider plans for elective care.



Shaun's story

Shaun served as an army logistician for 23 years. His job was physically demanding and took a toll on his body and health, leading to him needing hip replacement surgery in 2014.



In January 2023, Shaun's hip had come loose, and he was referred to an orthopaedic specialist. It was the start of a long and painful wait for further treatment, which had a real impact on Shaun and his family.

"I'm really frustrated with the system. There's lots of back and forth. I'm waiting to be given more information about the next steps. Instead, it's me who has to do all the follow up and chasing."

Talking about what would help, he said, "I just want someone to pick up the phone and say, 'How're you doing, Shaun? This is the next step in the process.'"

Shaun stressed that he's happy with the quality of care offered by the NHS, but long waits for care are a major concern.

"I've got no problem with the staff. I support the NHS, and I'm happy with the care when I receive it. But the communication for me is just not there."

He added, "Not only has this lack of communication caused me unnecessary stress and anxiety, but it has also made it difficult for me to make decisions about my care."



"I've got no problem with the staff. I support the NHS, and I'm happy with the care when I receive it. But the communication for me is just not there."

Reforming dental care

We have repeatedly warned that NHS dental care desperately needs reforming.

In 2022–23, dental care was the second most common issue people came to Healthwatch about, and a majority of the feedback we received was negative.

Our research has highlighted the extent to which this feedback is often linked to issues with access and cost.

In our poll of over 2,000 respondents⁹:

54%

of respondents who'd had an NHS dental appointment in the last two years had had some kind of problem.

46%

of people who'd had a dentist appointment had issues with the costs associated with their dental care.

Clinical guidelines recommend regular dental check-ups. But problems like this meant 38% of the respondents felt they were less likely to visit a dentist going forward.

21% of people who hadn't had an appointment had suffered as a result, with the lack of access to dental care causing anxiety, or making it difficult to eat or speak.

The shortage of NHS appointments hit people on low incomes hardest. There was also a stark North–South divide – 20% of people living in the south of England said they could afford private dental care if necessary, compared with just 7% in the north.

We renewed calls on NHS England and the Department of Health and Social Care to put a reformed dental contract in place. And in July 2022, NHS England announced changes to the contract¹⁰, including:

- Increasing the payments for dentists when treating patients with complex needs, for example, people needing work done on three or more teeth.
- Requiring dental practices to regularly update the national directory on www.nhs.net to clarify if they are taking new NHS patients.
- Moving resources from dental practices that are underperforming.



“Sitting in the dentist’s office, listening to the list of treatments, the cost of £1,100 brought me to tears. These costs were on top of the £50 I had to spend to have the appointment.”

Story shared with Healthwatch England



2021–22

55%
of dental feedback was negative in sentiment.



2022–23

62%
of dental feedback was negative in sentiment⁸.

Although these changes are welcome, we must see more fundamental reforms to put an end to the pain and distress that those who can't see a dentist are experiencing.

And after they invited us to give evidence for their inquiry into NHS dentistry, MPs on the Health and Social Care select committee echoed this view in their final report.

In February 2024, the Government published a dental recovery plan¹¹ backed by an additional £200 million in funding.

While we welcome the plan's aim to deliver more NHS appointments to new patients and improve access in remote areas, we continue to press for long-term reform of the dental contract.

Across the nation

NHS Sussex committed to applying local Healthwatch insight after Healthwatch across Sussex surveyed local people about their experiences of accessing NHS dentistry.

Of 220 respondents, they found¹²:

- 62% weren't confident they'd be able to access NHS dental services over the next 12 months, either for themselves or others.
- 22% of people had paid for treatment privately because they hadn't been able to find or access a dentist to provide NHS treatment.
- 36% of respondents were dissatisfied or very dissatisfied with information on services being accurate and up to date.



“We will ensure this feedback is central to our work as we work with dental providers this year to set out immediate and longer-term areas of improvement.”

NHS Sussex

NHS Sussex said: “We will ensure this feedback is central to our work as we work with dental providers this year to set out immediate and longer-term areas of improvement.”



Abby's story

When Abby moved to Yorkshire from Glasgow, she couldn't find a local NHS dentist. She would travel back to Scotland for routine dental care.



"It had got to the stage that I would do anything. I wasn't eating, drinking or sleeping. For my own mental health, I had to do something."

When she started to experience dental pain, she dialled 111 and made an emergency dental appointment. She was given antibiotics and codeine for the pain, but this didn't resolve her symptoms. Another emergency appointment didn't lead to any further treatment.

"The appointment cost £35, but the emergency dentist couldn't extract the tooth. I had to travel an hour for the appointment too."

Abby wasn't sleeping due to the pain and had missed four days of work.

"I work in patient transport. And if I'm not sleeping it's dangerous to my patients and colleagues," she explained. "So I had to take time off."

Eventually, Abby found a private dentist charging £98 for an emergency appointment. A full root canal was an additional £600.

Abby said, "It had got to the stage that I would do anything. I wasn't eating, drinking or sleeping. For my own mental health, I had to do something."

"I can't really afford it but at least I've got a credit card. A lot of people don't even have that option."

Taking stock of mental health support, pre- and post-pandemic

For many years, mental health has been the service area where we hear the most negative public feedback.

The stories people tell us often paint a bleak picture. People don't just face long waits for diagnosis and treatment – they also can't access support while they wait. And what support does come is short-lived or inadequate.

In 2019, NHS England prioritised addressing mental health in its Long Term Plan¹³. But the COVID-19 pandemic led to a surge in demand for mental health support. Three years on from publishing the Long Term Plan, many of the views we hear about mental health are still negative.

A review of stories people have shared about adult mental health shows that problems that existed before the pandemic remain¹⁵:

- GP teams can vary in how well equipped they are to deal with mental health issues, and people can struggle to get referred.
- Waiting times for services are long at all stages of the mental health system.
- Crisis services are over-subscribed, and therefore often inaccessible.
- Mental health assessments can feel rushed and often do not lead to the outcome people want.
- Inpatient treatment is an unpleasant experience, while community treatment is patchy.
- Services communicate poorly with both patients and other services.
- Treatment often ends too early, before people feel they are ready, and without adequate follow-up support.
- Those who need to restart treatment because of relapse often have to start the whole process of getting help again.

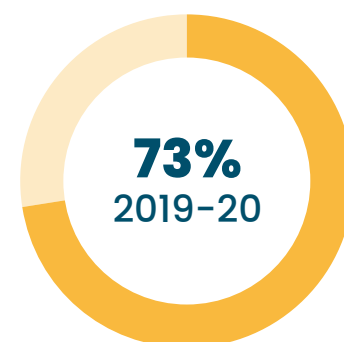
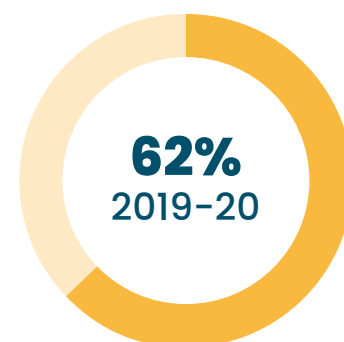
We urged NHS England and the government to deliver on the commitments to mental health services outlined in the Long Term Plan. Our work led to changes that would support maternal mental health¹⁶.



“I have been abandoned by the mental health department in my town. I got discharged with no follow up with very strong meds and I need help. My GP tells me that, unless I’m self-harming or suicidal, they won’t accept a referral. What do I do?”

Story shared with Healthwatch England

Percentage of public feedback about mental health services that was negative¹⁴



It also contributed to the NHS releasing their primary care recovery plan¹⁷, which will make it easier for people to navigate the early stages of seeking treatment for a mental health issue.

You can read more about these changes later in this report.

We're now calling for the Major Conditions Strategy (covering six areas including mental health), which is due to be published in full in 2024, to include a roadmap that:

- Reduces mental health waiting times for assessments, treatment, and crisis support.
- Improves transitions from child to adult mental health services, based on need, not just age.

We are also calling for the Draft Mental Health Bill to be reintroduced onto the legislative programme.

This will ensure patients get more say over their treatment and have improved access to advocates, and that doctors will have a duty to consider patients' wishes before deciding on compulsory treatment.

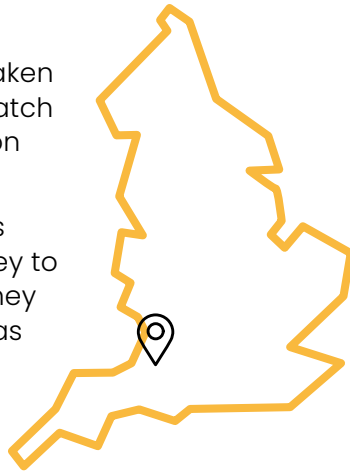
We are committed to working with decisionmakers to tackle critical questions – like how teams and systems could work together, how to improve communication, and how to reduce long waiting times while supporting staff wellbeing.



Across the nation

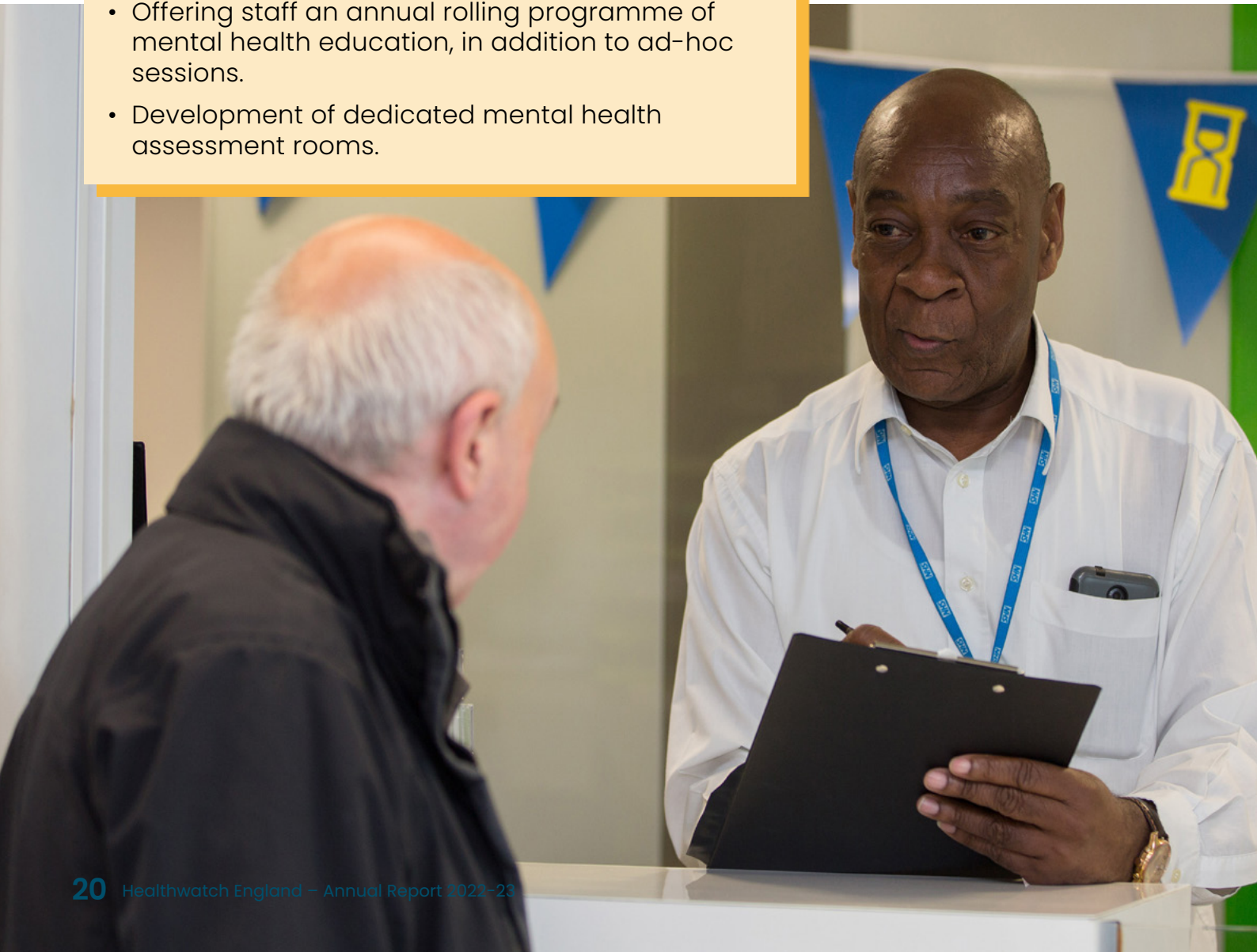
Emergency departments in Gloucestershire have taken steps to improve mental health care after Healthwatch Gloucestershire offered recommendations based on insight from the public.

Healthwatch Gloucestershire gathered public views through semi-structured conversations and a survey to make their recommendations for improvement¹⁷. They highlighted that people were being left in busy areas for long periods, and often didn't feel listened to by staff. This meant they were leaving before they had the chance to get the treatment they needed.



Changes made in response included:

- Making sure patients are understood and their voices heard by recruiting two peer support workers who are experts on mental health by experience.
- Updating patient and carer leaflets to include personal safety planning and clear descriptions of processes and onward referral timeframes.
- Offering staff an annual rolling programme of mental health education, in addition to ad-hoc sessions.
- Development of dedicated mental health assessment rooms.



2

Testing if policies are working



Shaping policy that suits patients is a vital step. But to understand if new policies are working, it's essential to keep listening to the people they're meant to help.

In this section we take stock of initiatives introduced several years ago.

- We heard from new mothers who told us they weren't consistently offered the recently introduced NHS wellbeing checks for maternal mental health. Their feedback led to new guidance, and closer monitoring of this policy's implementation.
- We highlighted daily challenges for those with communication needs to get the accessible healthcare information they're entitled to. This led to improved rights – and, crucially, more people able to exercise those rights and get the support they need.

Is maternal mental health working?

In 2019, our research on maternal mental health¹⁹ contributed to the introduction of six-week wellbeing checks for new mothers. In 2022, we came back to the subject of maternal mental health to see if this had led to better access to vital mental health support.

But the experiences of over 2,600 people showed that despite the introduction of wellbeing checks, not everyone is getting the mental health support they're entitled to²⁰. And action may be needed to better protect women's mental health while in hospital.

42%

of people said their hospital care negatively impacted their mental health.

16%

of people hadn't had their wellbeing check.

22%

were satisfied with the amount of time their GP spent talking to them about their mental health.

We also heard about long waits for mental health referrals, and the devastating effect this had on new parents.

Our research led to NHS England updating guidance for GPs on six-week postnatal checks²¹, and contributed to guidance for Integrated Care Boards on monitoring checks.

After we published our research, NHS England released their three-year delivery plan for maternity and neonatal services²¹. The plan addresses several issues our research highlighted, and outlines how the NHS plans to tackle the issues new mothers and birthing parents experience.

Mental health services were also a priority in the NHS Long Term Plan, which committed to transforming specialist perinatal mental health services²³.

Maternal mental illness affects 27% of new and expectant mothers²⁴. Left untreated, it can have a huge and long-lasting impact on a person and their family's mental health. It's essential to keep listening to those affected, and bring about the changes they need to the maternal mental health journey.



"It wasn't someone sitting down and going, you know. 'How are you sleeping? Is there anything we can help with? Any concerns with your own –' It was just kind of read a list off a piece of paper. And then it was like, 'tick, tick, tick. Okay. See you later.'"

Story shared with Healthwatch Wirral

Across the nation

Maternity services in West Birmingham have taken steps to make care better for Black African and Black Caribbean patients after extensive work by Healthwatch Birmingham.



These include:

- Better reflecting the communities they serve by hiring more midwives from the same background.
- Supporting families' access to maternity services through extensive community engagement and training for relevant voluntary sector organisations.
- Providing better continuity of care by hiring a Best Start Midwife who is attached to GP surgeries in areas with high numbers of Black African and Black Caribbean families.



“One thing I have noticed is that when they see a black woman, they just assume you won't understand things so no one explains anything to you.”

Story shared with Healthwatch Birmingham

Healthwatch Birmingham's in-depth interviews with people from these communities had highlighted poor experiences of maternity care, including several that affected their mental health²⁵.

They might have had several different midwives throughout their pregnancy, making it hard to build the trust that would allow them to comfortably discuss mental health concerns. They faced racism and discrimination. And they had poor postnatal support, with only one interviewee offered a six-week check.

Sandwell and West Birmingham Hospitals NHS Trust, who provide West Birmingham's maternity services, shared its action plan to tackle these issues with other maternity services. This will help ensure every new family in Birmingham can get the right care.

Disabled people blocked from care due to poor communications

People need clear, understandable information to help them make decisions about their health and care, and get the most out of services.

But when we reviewed the experiences of 605 people who said they needed support communicating with healthcare staff, we found²⁶:

30%

rarely or never get the help they need.

22%

had been refused information in a format they needed.

28%

had been refused support to help them understand healthcare information.

Not getting healthcare information in the right format has harmful consequences. 38% of people said it affected their mental health and wellbeing. 29% told us it meant they missed out on information about their health. And 27% said it meant they couldn't contact a service they needed.

We have called on the NHS to review and update the Accessible Information Standard, to ensure that:

- Health and care services can be held accountable for fully delivering the standard.
- Every health and care service has an accessibility champion appointed to lead their service's accessible policy and delivery.
- Better technology and systems are available so patients can update services with their communication needs.
- People with communication needs are involved and can regularly give feedback on their experiences to ensure continuous improvement.
- Training on accessible information is made mandatory for all health and care staff.

In February 2023, we sent an open letter to NHS England, together with eight other charities who supported our original campaign²⁷. Our letter expressed our disappointment that the reviewed standard has yet to be published nearly a year after we made our recommendations.

The delays in publishing the new standard have left people who need accessible communications struggling to access the health and care they need.

The NHS have said they are in the process of updating the Accessible Information Standard and they have taken our recommendations on board. We're currently waiting for them to publish the new standard.

“If people cannot get information about their healthcare they understand, this can have a significant impact on their mental health and can lead them to missing doctor’s appointments, or taking the wrong medication, which puts them in danger.”

Louise Ansari, Healthwatch Chief Executive

Across the nation

Deaf patients in Milton Keynes using GP or hospital services are now guaranteed a BSL interpreter if they ask for one, following work by Healthwatch Milton Keynes to ensure services were meeting the Accessible Information Standard.



After hearing from members of the public who'd been refused an interpreter, Healthwatch Milton Keynes shared these stories with GP practice managers and primary care commissioners.

They reminded them of their obligations under the Accessible Information Standard, and called for them to add a clause to GP contracts that would ensure they met those obligations.

Now, GP surgeries and Milton Keynes Hospital have inclusive policies in place. Providing an interpreter is a contractual obligation. And patients who need one can make informed decisions about their treatment.



April's story

Being unable to get appointments in a suitable format presents serious risks to health and wellbeing for people like April.



April is deaf, and has to lipread so she can understand the information her healthcare providers are sharing. This is explained in her records, but despite this, she still struggles to get the face-to-face appointments she needs.

Her surgery "refuses to communicate via email or messaging". This makes it harder for April to get important information about her health and treatment.

"My doctor's refusal to offer a face-to-face appointment meant that I had to make a decision about stopping my diabetes medication without medical advice. In the event, it proved the right thing to do, but if I hadn't done so, I would have been at risk of collapse and possible death if not found and treated in time."



"My doctor's refusal to offer a face-to-face appointment meant that I had to make a decision about stopping my diabetes medication without medical advice."

3

Uncovering hidden problems



Some of the problems people are experiencing with their care are clear. But others are less obvious. Here, the value of listening to what the public has to say is more relevant than ever.

In this section we look at how insight from users of health and care is key to spotting issues.

- Our investigation into GP referrals to specialist care revealed a hidden waiting list of patients seeking support for cancer, mental health, and other conditions not reflected in NHS data.
- Our work highlighting the stories of people with Long Covid led to action and new investment to improve the awareness of GPs when diagnosing and referring patients.
- We worked with NHS pilots to discover that patients like monitoring their health using technology at home, but need better guidance and feedback from services to benefit from this.

GP referrals

We know that waiting lists for specialist treatment are growing. But for many the wait begins before they're even referred.

Before people get the specialist help they need from hospital teams, they have to first wait for a GP appointment. They then have to wait for their GP to tell them they will be referred and for the hospital to confirm that referral. The process can be long and often confusing.

We polled over 2,000 adults who'd either been told they'd be referred, or expected or requested a referral but failed to get one²⁸. We found that:

18%

of respondents had four or more GP appointments before getting a referral.

Administrative issues and a lack of communication or patient choice mean nearly

one in three

GP referrals don't lead directly to a hospital appointment or to people joining a waiting list.

11%

waited four or more months after their first GP appointment for their GP to refer them.

People told us that when they didn't get a referral, their symptoms worsened. This could impact their mental and physical health or ability to work, or lead to loss of income.



To support GP practices and hospitals with referral processes, we made recommendations to the government, NHS England and Integrated Care System (ICS):

1. Do more to understand the referral process.

NHS England should work with us to add questions to the annual GP Patient Survey to understand people's experiences of the referral process.

2. Improve communication with patients.

GP and hospital teams need more support to reduce the number of people returning following a referral because of a lack of accessibility, transparency and collaboration.

3. Give people a meaningful choice and flexibility over appointments.

Giving people a real choice of appointment types, times and a healthcare professional can reduce the likelihood of people returning to their GP in a worse condition.

4. Invest in NHS administrative staff.

Improving access to GPs by training and hiring more care navigators – staff who can ensure people's needs are met the first time.

The NHS have since published their primary care recovery plan²⁹, which sets out how they aim to tackle some of the pressures facing GPs and other primary care services. Among the improvements it promises are:

- Easier access to GP practices by expanding the reception team's role to offer better care navigation.
- Updates and improvements to the NHS App. These will make it easier for people to view their records, order repeat prescriptions, and manage routine appointments.
- An ambition to make it easier for everyone to contact their local GP practice in the way they prefer.
- To allow secondary care providers to make onward referrals for those already referred into their care, rather than sending people back to their GP to start the process again.
- To incentivise practices to refine their General Practice Appointments Data, which will allow more accurate tracking of appointments and who is delivering them.



Katie's story

Katie, 24, has struggled to get a GP referral for endometriosis treatment. She started experiencing stomach and pelvic pains five or six years ago. Sometimes the pain was so bad she would have to miss work, and on several occasions, she ended up in A&E.



She was told it was nothing to worry about when she mentioned her pains to her GP. "They'd say, 'some people just get pains' and send me on my way with painkillers."

After "months and months" of GP appointments, Katie pushed her surgery to write a gynaecology referral specifically for endometriosis.

Katie is due to have surgery and hopes this will lead to more treatment for her symptoms. But being unable to get treatment for so long has affected her life. She is a professional actor, but the pain from her untreated condition means she can't perform on stage.

"This dragged on for so long – having those experiences has made me super anxious to ask for help, but also taught me not take no for an answer. It's been really traumatic."

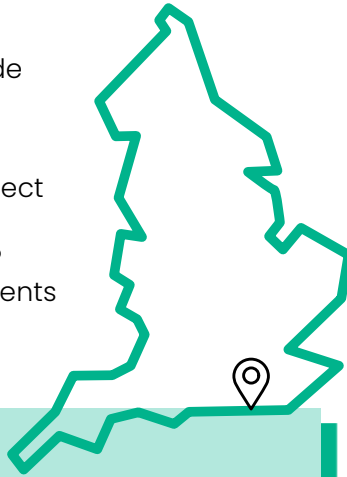


"This dragged on for so long – having those experiences has made me super anxious to ask for help, but also taught me not take no for an answer. It's been really traumatic."

Across the nation

Another factor people mentioned that made it harder to get a GP referral was reduced opening hours.

Negative impacts of reduced hours can affect some groups more than others. Changes to opening hours at the New Larchwood GP surgery in Coldean led to problems for patients relying on public transport and others with accessibility issues.



But thanks to work by Healthwatch Brighton and Hove, the surgery reversed its decision to reduce hours and even increased services by re-introducing dedicated nurse sessions.

Healthwatch Brighton and Hove worked with the Coldean Residents' Association to contact every resident and ensure they had the chance to share their opinions. Healthwatch shared these with the GP practice partner and local NHS leaders to reverse the change.



Using tech to monitor health at home

One in four people in England have high blood pressure³⁰. This is even higher in the most deprived areas of the country. More and more, people are using remote technology to help them monitor their blood pressure from the comfort of their homes.

In 2022, NHS Digital asked us to help them evaluate their blood pressure remote monitoring pilot scheme to understand if it worked well.

People told us there were many benefits to monitoring their blood pressure at home, including peace of mind, feeling in control and convenience³¹.

But we also discovered vital gaps in the process that negatively impacted patients' experiences. People needed more information on how to use their monitors. They didn't submit readings regularly, and when they did, they often didn't hear back from their doctor.

As a result of what people told us, we put a series of recommendations to NHS Digital to help improve the support available and outcomes for people who monitor their blood pressure at home. These included:

- Providing better information about high blood pressure so people understand the importance of monitoring it and what 'normal' readings are.
- Guidance and support to take and submit a reading.
- Providing a better way for people to submit their readings that resulted in feedback from their doctor.



“At no time did anyone ever explain the reasons for me having the monitor, so I do feel a little frustrated about this. In addition, no one has ever told me I should be submitting readings, and nor have they rung me to ask me to do so. On occasion, this has made me wonder what the point is in continuing with this.”

Story shared with Healthwatch England

Your stories help improve support for Long Covid

For some people, COVID-19 can cause symptoms that last weeks or months after the infection. Symptoms that go on longer than 12 weeks are known as 'Long Covid'. Long Covid has a wide range of symptoms, and experiences differ, making it difficult for doctors to diagnose.

Between September 2020 and March 2022, people told us their stories about Long Covid³². While we only heard a small number of experiences, they told a powerful story.

We found that GPs needed more help to identify the symptoms and greater awareness of the support available for their patients. People also said they wanted services to work together better to support their physical, psychological and cognitive issues.

"I really feel like my GP is trying their best, they have been honest with me and explained that the virus is so new, they don't have a specific treatment plan. I've had multiple blood tests, an ECG, I have been having chest X-rays – all displaying signs of 'something', but a something common to those in my position.

Those who had other health conditions highlighted another issue: doctors didn't always consider how their other condition could affect Long Covid. This meant they could struggle to get the help they needed.

Following our research and recommendations based on these stories, NHS England announced a plan in July 2022 to improve support and care for people affected by Long Covid³³. This was backed by an extra £90 million in investment.



"It's been such an incredibly hard time for our healthcare services (I caught COVID working in healthcare, looking after someone much worse off than me). I'm lucky that my GP is supporting me despite their honest admission of not knowing exactly what to 'prescribe' so to speak."

Story shared with Healthwatch Gloucestershire

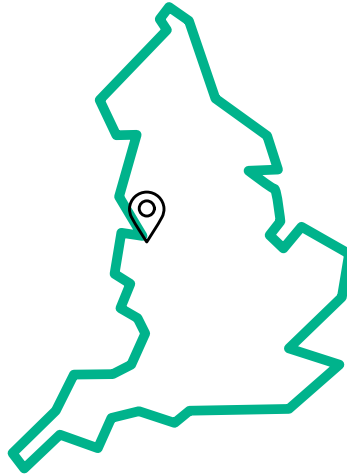


Across the nation

Mersey Care NHS Foundation Trust has taken steps to increase awareness of its Long Covid service and further reassure and empower patients, following “valuable insight” from local Healthwatch.

Healthwatch Liverpool, Knowsley, Sefton and St. Helens ran a survey and conducted five in-depth interviews after Mersey Care commissioned them to learn more about patient experiences³³.

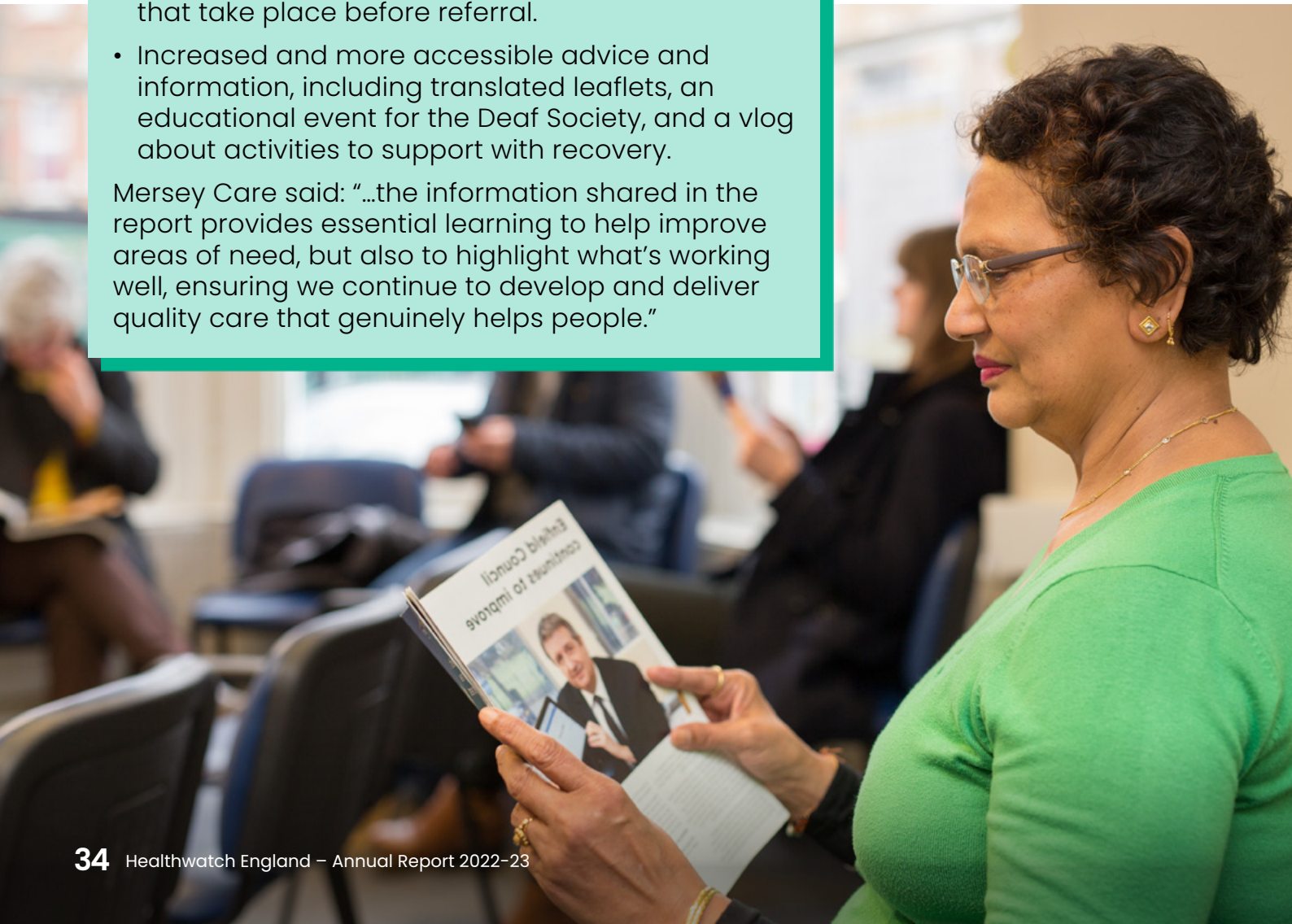
People commented on how well the service understood what they were going through – a relief after others around them, including other healthcare professionals, reacted with disbelief.



Based on what people shared, the four Healthwatch highlighted where the service could make further change. This has led to:

- Improved understanding between the service and those making referrals through visits to GP practices and education about the service and the referral process.
- Clear explanations to patients about the steps that take place before referral.
- Increased and more accessible advice and information, including translated leaflets, an educational event for the Deaf Society, and a vlog about activities to support with recovery.

Mersey Care said: “...the information shared in the report provides essential learning to help improve areas of need, but also to highlight what’s working well, ensuring we continue to develop and deliver quality care that genuinely helps people.”



Ensuring care home residents have the support they need

COVID-19 led to rapid changes across health and social care services, including the suspension of visits to care homes to protect residents, their loved ones and staff.

But while care home visits were allowed from July 2020, in many cases restrictions continued. This led to detrimental impacts on people's health, welfare, and wellbeing. It left residents lonely and isolated, and stopped visitors being able to pick up on issues their loved ones were experiencing that staff may have missed.

We shared our concerns with the Secretary of State for Health and Social in 2020, penning a joint letter with the Association of Directors of Adult Social Services and the Care and Support Alliance.

We were invited to join a working group during the pandemic to develop improved care home visiting guidance, and have since called for the introduction of Gloria's Law, which would give people in all health and care settings the legal right to a care support – a person important to them, like a relative or friend – who can visit to provide emotional support, advocacy, and essential human contact.

We continue to call for this change, and have recently welcomed new legislation which requires the CQC to review visiting policies as part of their inspections.

This is not only a positive step in relation to COVID-19 restrictions – it will help more widely to ensure the loved ones of residents can play their part in care.



4

Spotting emerging trends



In gathering feedback from people who use health and social care services, we get a clear picture of the current state of the system. That includes problems that are just beginning to develop.

By listening to patient concerns now, decisionmakers can put in place the right resources to stop those problems getting worse.

- We helped policymakers understand the impact of the cost of living crisis on people's health so that the Government could do more to support people.
- Following a year of negative headlines, our research highlighted the impact on people's confidence in their ability to access timely NHS care.

Cost of living leads to impact on health

The cost of living crisis has had a major impact on people's ability to pay for necessities like heating. But the results of a survey we ran suggested an impact on health, too, with people avoiding booking or attending NHS appointments or taking up prescriptions and over-the-counter medication because of the costs³⁵.

To help decisionmakers understand the effect of the cost of living crisis on people's health, we conducted a poll with 2,000 adults in December 2022, which tracked people's behaviour as inflation soared.

We found that:

11%

have avoided booking an NHS appointment because they couldn't afford the associated costs, such as accessing the Internet or a phone call.

15%

avoided going to the dentist because of the cost of check-ups or treatment.

39%

said they had to cut back on food and not turn the heating on to keep up with rising costs. They reported that this had harmed their mental (39%) and physical health (35%).

The findings also suggest that spiralling costs disproportionately affect women. 42% of women have not turned their heating on, compared to 33% of men.

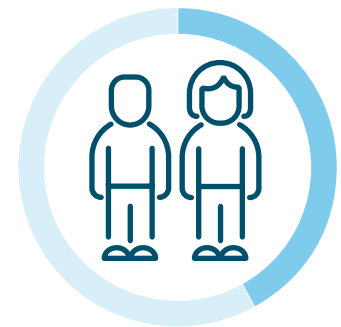
We set out immediate actions the government working with health and care services can take to support people during the cost of living crisis.

- GPs should offer people over-the-counter medications on prescription where they believe social vulnerability will affect patients' ability to pay.
- NHS services should ensure people know if they're entitled to patient transport services or travel reimbursement schemes.
- NHS dentists should follow NICE guidance to offer dental check-ups based on patients' individual risk factors.
- NHS England should work with Ofcom and telecommunications companies to ensure that hospital and GP phone numbers are part of a freephone service, so cost is never a barrier to phoning a health service.



"I can't get a GP appointment. The highest I have ever got in the telephone queue is number 11, and so I gave up in the end as it was costing me a lot of money on my telephone bill and I am a pensioner. All I want is a referral to an audiologist as I am losing my hearing."

Story shared with Healthwatch Wolverhampton



42%
of women have not turned their heating on, compared to 33% of men.



Lynda's story

Living with rheumatoid arthritis means Lynda has to keep her home warm. Otherwise her pain is worse and her mobility even more restricted.



“All of this is very stressful and extremely worrying, so much so it regularly impacts my sleep. I don't feel up to all these challenges and they are contributing to the worsening of my condition.”

“Heating costs are a big concern as my joints stiffen up in the cold. I often switch the heating on or have a bath to ease the pain and stiffness in my joints, so this increases my energy bills. The energy crisis is really bad. I don't remember it ever being as bad as this,” Lynda said.

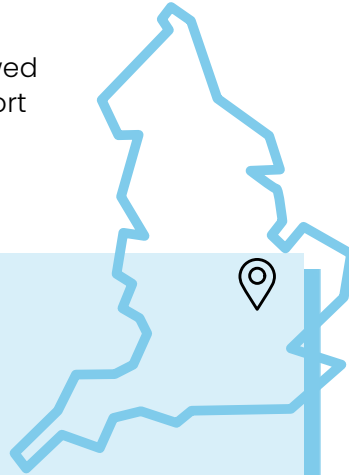
The uncertainty over future energy bill increases is impacting Lynda's mental health too. She's finding it harder to pay for her travel to attend hospital appointments, and experiences anxiety about what the future holds.

On top of energy prices, her social care providers have asked whether she would be willing to consider making financial contributions towards her care. This is an added expense she can't afford.

Lynda said: “All of this is very stressful and extremely worrying, so much so it regularly impacts my sleep. I don't feel up to all these challenges and they are contributing to the worsening of my condition.”

Across the nation

Work by Healthwatch Hertfordshire has allowed Hertfordshire County Council to target support for those affected by the rising cost of living where it's needed most.



Their report³⁶, based on a survey of over 7,000 local people, led to improvements including:

- Immediate support for people accessing mental health services with finance-related issues, following the county's mental health provider partnering with County Council Money Advice Unit.
- Growth and development of the Council's Building Life Chances Programme, which supports communities by addressing issues such as food insecurity, health inequalities, crisis support and employment assistance.
- With 90% of respondents impacted by rising costs, these changes benefit all residents, but especially those disproportionately affected by the crisis.



Public confidence in the NHS needs urgent reassurance

Throughout the year, the headlines reported record waiting times, delays to cancer care and issues with both ambulance and A&E services.

To understand the impact of NHS pressures on public perceptions, we asked 2,507 people to rate their confidence in timely access to 13 NHS services³⁷. These included A&E, ambulances, non-urgent operations and procedures, GPs, pharmacists, mental health services and dentists.

32%

of respondents on average said they were not confident that the 13 NHS services could provide timely care.

43%

of people felt their confidence in accessing timely care was lower than it was at the start of the year.

There's a risk that people may be put off seeking the help they need because they don't believe that services can provide timely care.

So we urged the government to address the lack of confidence that many people, especially older people and those on lower incomes, have in accessing NHS services when they need it. We called for better awareness of the NHS App, and for the NHS to encourage more signups.

The story was published across national media. In response to our work, the NHS ran a comms campaign around the NHS App. They also highlighted other things that would improve confidence in the NHS, such as reminding people they had the option to go to the pharmacy for more minor issues.



Rob's story

Rob, 52, from Derby, has been waiting for an appointment with a consultant for over a year following his surgery to remove part of his bowel. In the meantime, he tried to book an appointment with his GP, but even this didn't prove easy.

As a result, Rob developed anxiety, worrying about his health.

"Over a year after my surgery, I have yet to see a Gastro consultant to understand what this diagnosis means and what ongoing care is required. I have had multiple consultant appointments booked and then cancelled at the last minute by the hospital, often the day before," he said.

"In every case a new appointment was not given – I was just told to wait to receive a letter with a new appointment. Those multiple cancellations made me incredibly anxious."

He added, "I'm not very confident in the NHS. Even getting an appointment at my GP surgery is a nightmare. You are forced to call at 8am but waiting time on the phone is usually around 20 minutes and often you are told that all the slots for the day have gone."



"In every case a new appointment was not given – I was just told to wait to receive a letter with a new appointment. Those multiple cancellations made me incredibly anxious."

5

Making a difference on the ground



Our work brings about real change at both a national and local level. Every year, our network of local Healthwatch reach out to their communities to listen to what people have to say. And the more people whose stories we hear, the more of a difference we can make.

Getting more people to share their experiences

'Because We All Care' was our flagship campaign in 2022-2023.

Working with colleagues at the Care Quality Commission, we ran Because We All Care to make more people aware of why it's important to give feedback about their experiences of using health and social care services.

In October, Because We All Care reached out to people with long-term conditions, specifically looking at the barriers they faced getting specialist support via their GPs.

We surveyed 1,000 people with chronic and long-term conditions about their experiences using health and social care services³⁸.

Our analysis of these responses found that although seven in ten people with a long-term condition would be willing to give feedback to help improve services, more than half had yet to be asked to share their experiences.

Heading into winter, the busiest time of the year for health services, these findings helped us to reinforce to NHS leaders why more people must feel empowered to share their experiences. Listening to people's experiences, good or bad, helps make services more effective.



54%
of people with
long-term conditions
said they are not being
regularly asked by
services to feed back
about their care.



Across the nation

Leeds City Council is transforming home care services across the city thanks to extensive work by Healthwatch Leeds.

When the Council commissioned Healthwatch Leeds to run three annual surveys on home care, the issues local people shared were a key factor in the introduction of the city's Community Health and Wellbeing Service.

To help build a service that would truly address the needs of those using it, Healthwatch Leeds set up a panel of 21 people who have experience of home care services. The panel's feedback fed into the service the whole way through its development³⁹.



As a result, the service will:

- Offer a more flexible model based on personalised care.
- Streamline and localise services, recruiting local people with local knowledge.
- Improve retention and continuity of care through better pay and working conditions for employees.
- Require staff to go through cultural competency training.
- Build a requirement to regularly assess levels of user satisfaction into contracts.
- Incorporate lived experience into its compulsory training programme for staff.

And perhaps most key, the new Community Health and Wellbeing Service has among its service objectives to “ensure the voice of the citizen is central to the design and development of the service”.

This piece of work is testament to the value of listening. It will help create a social care service that puts people at its heart, and that is committed to continuing to do so.

If more services, with Healthwatch's support, make this same commitment, what might we achieve together?”

“Healthwatch Leeds for working with local partners on the rollout of an improved citywide model of home care.”



Looking ahead

Louise Ansari, Chief Executive

Though many people tell us about the high-quality health and social care they've received, the NHS and social care system faces serious problems.

Waiting times for care are at a record high. The NHS has faced over a year of industrial action. Staff shortages affect every part of the system. Health inequalities are getting worse. And the demand for care – and the rising cost of providing it – shows no sign of slowing.

What will help NHS and social care services overcome these challenges and deliver safe, high-quality, timely care to everyone?

More staff and extra resources are, of course, part of the answer. But so is putting greater emphasis on the wants and needs of patients. Put simply, the NHS needs to listen more to those it serves.

Why? Because listening is the key to unlocking safer and better care. Repeated investigations into NHS scandals have shown that failing to heed patients' concerns can have catastrophic consequences.

But the benefits of listening go wider than just providing an early warning system to services.

Understanding how care works from the patient's perspective also gives NHS managers and clinicians the whole picture. This critical insight helps find new ways to improve care, avoid costly mistakes, and adapt to changing trends and populations.

Helping the NHS to unlock the power of people's views and experiences, especially those facing the most serious health inequalities, lies at the heart of our strategy and future work to deliver it.

Over the next year, we will:

- Keep reaching out to every part of society, especially people in the most deprived areas, so those in power hear their views and experiences.
- Focus on how we can improve the issues that concern the public most, like GP access, waiting times, women's health and social care.
- Use our evidence to set out a vision for what health and care services could look like for patients by 2030 with the right interventions.
- Work with partners to help develop an NHS culture where, at every level, staff strive to listen to and learn from patients to make care safer and better.



“Helping the NHS to unlock the power of people’s views and experiences, especially those facing the most serious health inequalities, lies at the heart of our strategy and future work to deliver it.”

Since Healthwatch launched over ten years ago, demand for our support from professionals and the public has risen. But our funding has done the opposite. Today, local Healthwatch receives just 49% of the budget the Government allocated in 2013.

So to make the greatest difference and support local Healthwatch to do the same locally, we must look at how we can be better resourced.

As this report highlights, the value of listening to people across England is tremendous. But without sustainable funding for local Healthwatch, there is a real risk to the long-term viability of our services. This would mean local people would be unable to access our advice or raise their care concerns.

To help avoid this, we will work with the Government nationally and locally to find a better way to fund work that puts the voice of patients at the heart of care.

Even with limited resources, the Healthwatch network has shown what happens when people speak up about their care, and services listen. Just think how much more we could do if we had the resources to match our staff and volunteers' skills, passion, and dedication.



“Even with limited resources, the Healthwatch network has shown what happens when people speak up about their care, and services listen. Just think how much more we could do if we had the resources to match our staff and volunteers’ skills, passion, and dedication.”



Our resources

The fundings we get nationally and locally

Healthwatch England is funded by the Department of Health and Social Care. We also receive additional funding from NHS England to support specific public engagement projects.

Our strategy commits us to using our resources wisely to help achieve the greatest impact.

At the end of our finance year for 2022-23, we spent 100% of our budget, with a small underspend of £5,747. Our total spend was £3,234,000, comprising £2,100,000 spent on pay, £822,000 on non-pay, and £253,000 on internal recharges.

Our income and expenditure

Income		Expenditure	
Annual grant from Government	£3,208,000	Expenditure on pay	£2,158,275
Additional income	£31,758	Non-pay expenditure	£822,186
		Office and management fee	£253,550
Total income	£3,239,758	Total expenditure	£3,234,011

In focus: The resources of local Healthwatch services

Local Healthwatch across the country are independently funded by councils and supported by staff and volunteers.

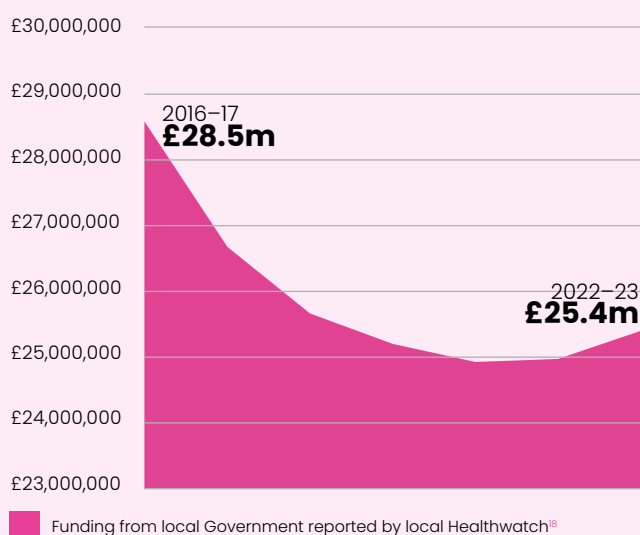
We help them with training, advice and support and are committed to building a sustainable and high-performing network of local Healthwatch services.

153 Healthwatch in England received £25.4 million from local authorities to carry out their statutory activities in 2022-2023. Healthwatch England also supports local Healthwatch and other organisations by funding specific projects to involve people in health and social care.

Funding specific local Healthwatch projects

We provided over £74,000 in funding the involvement of local people in health and care services in 2022-23.

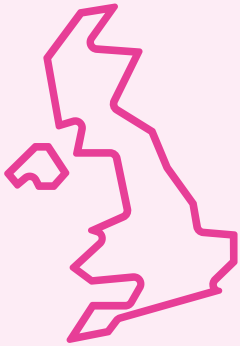
Local Healthwatch funding over time



Our people

We would not be able to do what we do without our staff and volunteers.

Nationally



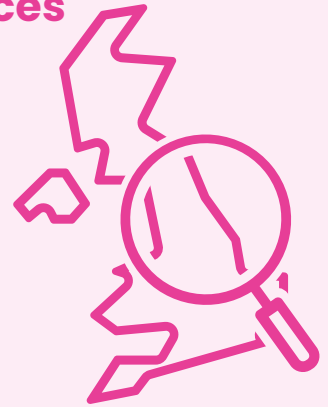
37

staff work with the public, policymakers and partners to improve care.

Locally across 153 services

570

full-time equivalent staff deliver the Healthwatch service for local communities.



3,997

volunteers kindly give up their time to understand local people's views, provide advice and help improve services.

On average each local Healthwatch has

4.08

full-time equivalent staff.

Our Committee

We are governed by a Committee who set our strategy, provide scrutiny and oversight, and approve policies and procedures that are needed for us to work effectively.

They also spend time holding public meetings to hear everyone's views and use this knowledge to inform our decision-making.

Members

Professor David Croisdale-Appleby (Appointed June 2023)

Belinda Black, (Interim Chair until June 2023 – Committee member from June 2023)

Phil Huggon, Vice Chair (Stood down December 2023)

Lee Adams (Stood down December 2023)

Pav Akhtar

Professor Sul Mahmud (Appointed January 2024)

Dr Andrew McCulloch (Stood down December 2023)

Sir John Oldham (Stood down September 2023)

Danielle Oum (Stood down December 2023)

Helen Parker

Umar Zamman

Jane Laughton (Appointed September 2023)

A big thank you

We're grateful to everyone who continues to support our work to improve health and social care. A special mention to:

You – thank you to all the people and loved ones who took the time to share their stories and ideas.

Our dedicated local Healthwatch volunteers and colleagues working hard across the country.

The voluntary organisations that have supported our research to help highlight big issues.

The health and social care professionals who have listened to public feedback and made changes.

Our national partners in the Department of Health and Social Care, Care Quality Commission, NHS England and other statutory organisations who have acted on what the public have said.

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