

# Speaking up for better care

Our annual report 2024-25

# **Speaking up for better care**

Healthwatch England

Our annual report 2024–25

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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-a-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

- **Equity:** We're compassionate and inclusive. We build strong connections and empower the communities we serve.
- **Collaboration:** We build internal and external relationships. We communicate clearly and work with partners to amplify our influence.
- **Impact:** We're ambitious about creating change for people and communities. We're accountable to those we serve and hold others to account.
- **Independence:** Our agenda is driven by the public. We're a purposeful, critical friend to decision-makers.
- **Truth:** We work with integrity and honesty, and we speak truth to power.

## Our purpose

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

When the Government announced that functions of Healthwatch would be transferred to national and local government, as well as the NHS, it was clearly disappointing news. Not only for our staff and volunteers, but for everyone associated with Healthwatch, who have proudly supported communities across England in speaking up about their experiences of health and social care.

However, we welcomed the Government's acknowledgement of the difference we have made and their aspiration to build on our work. With the NHS and social care services under huge pressure, it is more essential than ever that the experiences of the public, especially those already facing inequalities, are heard, understood, and acted upon.

### **Listening matters**

Healthwatch was established as an independent champion for health and social care users because policymakers understood it pays to listen. Patients know when care isn't working. Their feedback helps services spot risks, improve safety, and make more informed decisions.

And listening leads to better outcomes. Care becomes more tailored, effective, and trusted when services act on what people say.

In stark contrast, ignoring patient and service user voices has deeply damaging consequences – especially in communities that already face health inequalities. A history of repeated scandals in the NHS, like the failures in care at the Mid-Staffordshire NHS Foundation Trust, has shown that when concerns are dismissed, harm often follows.

## **A legacy you can build on**

Today, listening is more important than ever. The NHS and social care services are under pressure, but people still need care that is safe and works.

The Government's 10-year plan aims to fix care, but it won't succeed without continuing to understand the issues that communities face. Decision-makers in the NHS and local and national government must listen to service users and track progress to know if the steps they're taking are working.

We've shown the way and created a legacy to build upon. We've shown that gathering feedback from every section of the community is essential – but to do this, you need to build trust.

We've shown how independent, impartial local evidence can illuminate inequalities and get care services to pay attention. We've shown how, with the right infrastructure, you can turn community feedback into actionable steps that improve care at a local and national level.

## **The lessons we've learned along the way**

The full details of the system that will replace Healthwatch nationally and locally are yet to be unveiled. However, the Government has said that it aims to make it easier for people to share their views directly with the system to improve health and social care, and make it clear where accountability sits at all levels of the system.

Our strength has been our reach into every community, our independence and our statutory role. If the Government is to realise their ambitions, we strongly advise that any new system be based on six tried and tested principles.

- Be locally driven: National policymakers will get the full picture only by ensuring the consistent collection of

people's experiences on the ground and having the infrastructure in place for this insight to reach them via the NHS and local councils.

- Reach out to communities: Many people don't trust formal feedback routes and won't talk to organisations unless they see them as independent and impartial. To hear diverse views and identify inequalities, NHS and social care decision-makers must work hard to reach out to communities and demonstrate that they are listening. Our experience has involved ensuring Healthwatch staff have the right skills to engage every community, working with local groups and harnessing volunteers that local people trust.
- Value qualitative evidence: Quantitative data only tells part of the story. Collecting and analysing people's experiences is essential to understanding the impact of good or poor care, the existing blind spots, and the solutions.
- Make patient experience central to decision-making: Hardwire links between the NHS, councils and the Department of Health and Social Care's Patient Experience function and ensure that patient experience staff have a strong presence at every policymaking level.
- Be transparent and show you are listening: The system, from the national Government down, must be honest and transparent about people's concerns, open to getting views on "difficult" issues, and demonstrate that sharing feedback leads to change. It's also important that the public understands how NHS and social care services can be held to account when they don't listen.
- Build a system of accountability: Ensure those responsible for commissioning or providing health and care are held accountable for their responses to the voices of patients and service users.

Without these principles, there is a real risk that the voice of patients and service users will become marginalised within the system, problems will be missed or ignored, and uninformed decisions will be made.

We'll continue to carry out our role until new legislation is enacted. But we also stand ready to help those who will take over our work ensure that the public has an even stronger voice in tomorrow's health and care system.

**Professor David Croisdale-Appleby, Chair**

## Our year in review

Between Healthwatch England and the local Healthwatch network, over a million people shared their experiences or sought advice and support last year.

### Our top stories

- We helped secure changes by Royal Mail to ensure NHS letters are delivered in time to give people essential information about their tests, treatments and appointments.
- The elective care reform promised new minimum standards of patient experience for people on waiting lists, in line with recommendations we made.
- Our research led to NHS England adopting our recommendations to make cervical screening more comfortable and convenient.
- The patient voice is clear in recommendations from the independent ADHD taskforce following our research with people waiting for a diagnosis.
- The NHS is publishing waiting times demographic data after we advised this was a key step towards tackling variations in how long different communities wait.
- Our evidence led to new NHS guidance that patients starting cancer treatment should get priority access to an NHS dentist.
- A major piece of research revealed that millions of eligible adults may be missing out on social care.

## Who we've helped

### Healthwatch England

People used our service to get advice and information about their health and care **266,695** times

People shared their experiences to help improve services **21,452** times

### Local Healthwatch network

People used their local Healthwatch to get advice and information about their health and care **925,224** times.

People shared their experiences to help improve services **389,284** times.

## What are people telling us about?

People tell us about every area of care, from commonly used services to highly specialised support. From 57,567 experiences of GP care to 230 experiences of pain management clinics.

## Who are we hearing from?

We hear from every section of the community.

- **52%** women
- **40%** aged 50 years or older
- **36%** disabled
- **17%** from a Black, Asian, African or Mixed Ethnic Background

## Healthwatch engagement through the years

Healthwatch England and local Healthwatch support people across England online and face-to-face to have their say or access advice the advice they need.

	<b>Experiences shared</b>	<b>Advice and information</b>
2016/17	341,000	176,000
2017/18	406,567	707,816
2018/19	336,000	413,000
2019/20	350,000	960,000
2020/21	732,700	2,164,000
2021/22	417,000	1,814,000
2022/23	384,615	1,230,000
2023/24	403,554	1,149,305
2024/25	410,736	1,191,919

During the COVID-19 pandemic, we saw a surge in people seeking our advice and wanting to share their care experiences.

## **1: The public voice at the heart of our impact**

The public voice has always been at the heart of what we do, and last year was no different. We demonstrated once again how the stories of those using services can make a real difference, from reforming key areas of care to providing evidence for important health legislation.

In this section, we share some of the important changes to health and social care services that came about because people shared their experiences with us.

## Improving experiences of waiting for care

The new elective care reform plan aims to shorten how long people must wait for tests or treatment, and introduce minimum patient experience standards, in line with recommendations we made based on public feedback.<sup>1</sup>

### What we found

In 2023, our research looked at how people experienced delays in care.<sup>2</sup> We found:

- Almost one in five people only learned their appointment wouldn't go ahead on the day it was due to take place.
- Nearly **40%** of people who'd had their care delayed had experienced multiple postponements or cancellations.
- This number was even higher for groups already facing health inequalities. About half of disabled people, neurodivergent people, people on lower incomes, people from ethnic minority backgrounds, and LGBTQ+ people had experienced multiple cancellations.

People told us that delayed care often resulted in negative effects like poorer mental health, worsening symptoms, and disrupted sleep.

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“The mental health is worse than the pain. Waiting years to see someone and getting bounced from department to department and starting from the bottom of a list, do doctors not actually know how to communicate?”

— Story shared with Healthwatch England

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## What we did

In our research and our Patient Vision for 2030 report,<sup>3</sup> we shared key recommendations based on what people have told us about elective care. The Government's new elective care reform plan, published in January 2025, includes several steps that match these recommendations.

We called for:

- The NHS to focus on people's experiences of services, not just how long they wait. The plan announced that minimum standards of what patients should expect to experience in elective care will be introduced.
- Better communication with patients, stressing the importance of accessibility, transparency and collaboration. The plan pledged to increase the amount of appointment information available via the NHS App.
- Improved referral tracking for patients, and expansion of the NHS App to become a one-stop patient portal. The plan announced expanding the NHS App and the Manage Your Referral Website to give patients better information and help them manage appointments.
- Investment in administrative staff to ensure good communication and that people are guided to the care they need. The plan included compulsory training for administrative staff, to help improve communication with patients. It also promised to appoint a patient experience champion at all major hospitals.

## On the ground

Following feedback from older residents in the area, Healthwatch North Somerset researched how patient information can impact people's experiences while on a hip or knee surgery waiting list.<sup>4</sup>

They found that **29%** of respondents to their survey of local people had received no information while waiting. Meanwhile, **64%** of respondents received no communication about their expected surgery waiting time from either their GP or the hospital.

They made recommendations to local NHS leaders based on the research to help support people to wait well. The report had a positive response, with the Bristol, North Somerset and South Gloucestershire One Trauma and Orthopaedics Clinical Network Board asking to work with Healthwatch Somerset to further explore how to respond to patients' needs.

## Why it matters: Patrick's story

Retired NHS worker Patrick, 70, is facing a long and uncertain wait for a referral to specialist care.

Patrick, who lives in Milton Keynes, is living with back and hip pain. The pain has got so bad that it's making it hard for him to do everyday activities like shopping, driving or even putting on his shoes.

"My GP referred me in July, but I'm still waiting to be seen by a specialist," he says. "I just want a scan and to know what the next steps are, but I don't know when I'll even have an appointment."

Patrick says the specialist department never told him or his GP whether the referral had been received. He had to call the department himself to find out. "When I rang, they were nice on the phone, but they couldn't give me any good news. It could be as long as a year before I get an appointment, and that's just to take the first step in a long process."

In the meantime, Patrick's GP is prescribing painkillers to help manage his symptoms. However, the pain persists, and he's stuck with no new information about when he might see a specialist about a long-term solution.

"I feel like I'm stuck in limbo. The pain's impacting how often I can get out and do everyday activities. I certainly don't want to have to wait a year just to get an appointment."

## Encouraging uptake of cervical cancer screening

NHS England adopted five of our recommendations to improve cervical cancer screening after we published new research exploring people's experiences and the barriers they faced.

### What we found

We polled over 2,400 women who were hesitant to attend cervical screening appointments. The main reasons they gave were physical discomfort, embarrassment and not being currently sexually active.

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“The last one I went to, three or four years ago, wasn't traumatic, but I found it really stressful. Not from anyone doing anything to me that I found really uncomfortable, just more so because of my own anxiety around it, and that I generally find them pretty painful. That's what is putting me off doing it just now.”

— Story shared with Healthwatch Central Bedfordshire

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Cultural factors, lack of reasonable adjustments, and booking problems also affected uptake. Some women didn't receive accessible or translated information to understand screening invitations, so couldn't make an informed decision about attending a screening appointment.

### What we did

We shared our findings with NHS and government decision-makers, and suggested ways to encourage more people to get screened. NHS England's new plan to eliminate cervical cancer by 2040 includes several of our recommendations, including:

- The introduction of HPV self-screening, available free on the NHS. Women told us self-screening would improve privacy and convenience, as well as lessening discomfort and the impact of past trauma.
- Clear and consistent information from the NHS about HPV. This should explain how HPV is spread, who can get it, how long it stays in the body, and why screening is still needed if you've had the vaccine. The NHS action plan committed to raising awareness of HPV and screening with a new national campaign to eliminate cervical cancer.
- An NHS-funded review of their current patient materials. Invitation letters must be accessible and appropriate for everyone who would benefit from cervical screening. The NHS action plan committed to reviewing patient materials and working with partners to ensure they are culturally appropriate.
- The option for people to receive screening invites and book appointments through the NHS App, to help avoid busy, main GP surgery lines to book. We also called for appointment letters to be sent by post to people who don't use the App. The NHS action plan committed to offering screening invites through the App but retaining letters to reach people facing digital exclusion.

## **On the ground**

Healthwatch Islington helped inform local Turkish and Somali communities about cervical screening and highlighted the considerable barriers to screening that they face.<sup>5</sup>

After North Central London Integrated Care Board asked Healthwatch Islington to build on previous research, Healthwatch Islington, with support from North Central London Cancer Alliance, ran community workshops with over 200 people.

The workshops highlighted reasons for low uptake including not being sexually active, time pressures, the invasive nature of the process, religious reasons, lack of awareness and lack of information. But the vast majority of participants felt able to act on the information they received in the workshops, with some booking their screening appointments right away.

Healthwatch Islington's work found a genuine, widespread lack of awareness about screening, but demonstrated the positive impact it can have when people do get clear and accurate information.

## Helping cancer patients get priority dental care

New guidance from the NHS states that patients starting cancer treatment should get priority access to an NHS dentist, citing evidence we shared about the problems cancer patients face.<sup>6</sup>

### What we found

Cancer treatments, such as chemotherapy, can harm oral health. Patients are more likely to face tooth decay, gum disease, and infections. At their most serious, these can lead to sepsis.

Oncologists advise patients to see a dentist before they start cancer treatment. This helps them treat any existing oral health problems and get advice on protecting their oral health during and after treatment.

But people about to start cancer treatment often struggle to find an NHS dentist. Local Healthwatch across England shared the impacts of this, including delays in treatment or the need to pay thousands for private dental care.

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“I need a dental sign-off in order to continue essential treatment related to a cancer diagnosis. I am unable to find an NHS dentist and cannot afford private treatment therefore I cannot have the medication required to continue my treatment.”

— Story shared with Healthwatch Dorset

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### What we did

We gave our findings to the Chief Dental Officer and the Department of Health and Social Care. In December 2024, NHS England published new guidance stating that patients due to start cancer treatment should get priority access to an NHS dentist.

The guidance tells Integrated Care Boards (ICBs) to ‘review and ensure prioritised access for appropriate oral health assessment, prevention (advice and interventions), and treatment for patients diagnosed with cancer who cannot access a dentist prior to their intended start date for cancer therapy; and to make appropriate provision available if gaps are identified.’

It suggests a variety of ways that ICBs could help ensure this, including:

- Oncology teams referring people to hospital dental clinics.
- Flexible commissioning, like a pilot scheme in the South West, where the ICB paid high street NHS dentists on a sessional rate to give check-ups and ongoing oral health care for cancer patients.
- Allowing cancer patients to see dentists at community dental services

## Shaping standards for healthcare professionals

GPs now have clear guidance to help patients know who is running their appointment and the choices they have.<sup>7</sup> This follows our concerns about public confusion over physician assistants (previously called physician associates).

### What we found

Physician assistants (PAs) are healthcare professionals who work under a senior doctor's supervision. They have limits to the care they can give. For example, they can't prescribe medication. Their role is to complement fully qualified doctors, not replace them.

Yet in a national poll we commissioned on public attitudes to PAs, almost half of respondents strongly or somewhat disagreed that they understood the difference between a PA and a doctor.

Most respondents – **76%** – thought it was important or very important for staff to explain their role to patients. This would be in line with guidance from the National Institute for Health and Care Excellence (NICE). However, only **60%** said that this actually happened at their last appointment.

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“I had a phone call then a face-to-face consultation. I presumed I spoke to and saw a GP but when I looked on the website I found that she was a Physician [Assistant]! While I don't mind this I do think it is misleading not to introduce themselves correctly. I should know who I am seeing and exposing my body to!”

— Story shared with Healthwatch Lancashire

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## What we did

In May 2024, we co-authored a letter with other patient bodies to the General Medical Council about public confusion over associate roles. We also discussed our concerns with NHS England and the Royal College of GPs (RCGP).

In our published evidence, we called for PAs to clearly explain their role to patients. We also asked medical education providers to make clear to healthcare professionals the importance of informing patients about roles and responsibilities.

The RCGP issued guidance citing this evidence. They advised GPs that it should be clear to patients that they can ask to see someone other than a PA. In this event the patient and practice should make a shared decision about who will consult with the patient.

The GMC later announced their decision to update Good Medical Practice – the set of principles, standards and values that professionals it regulates should follow. The new requirement states: ‘You should introduce yourself to patients and explain your role in their care.’

## On the ground

As part of a wider review of local general practice, Healthwatch Richmond upon Thames spoke to local residents about their experiences of additional roles within general practice, such as physician assistants.<sup>8</sup>

More than **60%** of patients who saw a PA in the last six months said their needs were met and they would be happy to see a PA again. However, some people felt confused about who they were seeing, which led them to feel they had to see another professional separately after their appointment.

Healthwatch Richmond upon Thames recommended that local GP services do more to help patients understand who they are

seeing, explain the different roles, and make sure staff introduce themselves. The local Healthwatch also shared its findings with the national Leng review on PA roles and joined a national roundtable to discuss the role of PAs in primary care.

The final Leng report cited Healthwatch's evidence and recommended steps to improve clarity for patients.<sup>9</sup>

## Ensuring patients receive vital information on time

Both NHS organisations and Royal Mail teams are better equipped to deliver letters to patients on time, after public feedback led to us working to tackle delays.<sup>10</sup>

### What we found

Many people still receive information about their care by post, whether by their choice or that of the service providing their care. That can include letters about their health condition, upcoming appointments, or test results.

It's vital that they get this information in a timely fashion. But the public had shared stories with us of delays to letters.

This could mean they missed appointments, and led to confusion, worsening conditions, and risks to patient safety.

Delayed letters could also be costly and disruptive to the NHS, with NHS teams having to deal with the fallout.

On top of this, missed delivery targets and other issues led to Ofcom announcing a consultation on the future of the universal postal service in January 2024. Their proposals included reducing the number of days letters would be delivered, which could further affect people's ability to get timely information from the NHS through the post.

### What we did

Along with National Voices, the Patient Association and NHS Providers, we wrote an open letter to Royal Mail, Ofcom, and key figures in NHS England and the then-government.<sup>11</sup> We shared our concerns about the impact of these proposals on patients and NHS teams.

Throughout the consultation, we worked with these key partners to protect against delayed delivery through:

- A new Royal Mail NHS-specific barcode to help post teams identify NHS letters in their system and make sure they are delivered on time.
- A new briefing for NHS organisations to understand the range of Royal Mail services available for the timely delivery of letters.

We've continued to work with Royal Mail and others to ensure these changes are put in place, and that patients receive communication about their care when they need it.

## Why it matters: Karen's story

Karen, 65, from Solihull, was treated for breast cancer four years ago. Now she attends the breast clinic every December for an annual scan.

However, on her most recent visit, Karen's mammogram results took several weeks to arrive, causing her unnecessary stress and anxiety.

"I should have a scan at the same time every year," Karen explains. "But each year it's happening a little later, and the results are taking longer to come through."

Karen was told it would take three weeks for her results to arrive. But four weeks later, she still didn't have any news.

Karen needed the results – not just for her peace of mind, but for practical reasons too. Without the results, she couldn't renew her travel insurance, and she worried this could disrupt her upcoming travel plans.

Getting increasingly anxious, Karen rang the breast clinic for an update.

"I called on the 20th of January to chase the results," Karen explains. "The results letter actually arrived in the post the next day, but it was dated 7 January. I don't know why it took so long to get to me, if it was due to a delay with the post or some issue at the hospital".

## Influencing the future of ADHD care

The independent ADHD taskforce's recommendations reflect feedback from people with ADHD, gathered during our work around the long diagnosis waits and the support people need.<sup>12</sup>

### What we found

We previously reported on the long waits for ADHD and autism assessments, which several local Healthwatch had researched in detail in their communities. We raised key questions the NHS must ask about ADHD and autism diagnosis, and made recommendations to improve care.

In autumn 2024, NHS England asked us to hold a research event with people who have ADHD. We spoke with 35 participants about what the new ADHD taskforce should focus on. They identified eight main priorities, including:

- Tackling stigma
- Increasing training for health and care professionals
- Improving joined-up care
- Ensuring continuity of care
- Earlier diagnosis
- Providing support while people wait for diagnosis
- Reducing waiting times
- Making it easier to navigate the care pathway

We also polled 2,579 adults in England about their experiences seeking an ADHD diagnosis.<sup>13</sup> Many said a diagnosis can be life-changing: **84%** of diagnosed respondents felt it helped them understand themselves, and **54%** found new ways to manage their ADHD traits.

But long waits were a problem: **70%** of those diagnosed said the wait from referral to assessment was difficult. Nearly half of those waiting (**45%**) had done so for over a year. And almost

two-thirds (**64%**) of those with a diagnosis told us they'd had no or poor information while waiting.

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“The waiting list here is so long that they won't actually disclose the length. It's been three years so far. In the end, I went private as my relationship with 23 my husband was near breaking point. I was exhausted and constantly overwhelmed.”

— **Story shared with Healthwatch England**

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## **What we did**

Our work contributed to recommendations the taskforce made in its reports.

Based on our findings, we set out four key priorities for the Department for Health and Social Care, NHS England, and other stakeholders. These were:

- Collecting data on waiting times to understand demand
- Shifting more ADHD care to community care to reduce waiting times
- Better training for staff in both primary and community care
- Tailored information and support for people on waiting lists

The ADHD taskforce's recommendations reflected all four of these priorities. The Government, NHS and other decision-makers will now consider how best to implement the taskforce's recommendations.

## **On the ground**

When local health services introduced a new pilot pathway for adults seeking a diagnosis for autism and/or ADHD,

Healthwatch York started to hear concerns that it made getting help harder.<sup>14</sup>

After raising the issue with the NHS, Healthwatch York was asked to evaluate the service from the perspective of patients. People said that the new online profiling tool being used as part of the initial assessment process made getting a diagnosis or the right support difficult. Narrow referral criteria excluded some people from even trying to get a diagnosis.

As a result of the findings, the NHS made changes including getting rid of the strict referral criteria. They also addressed issues of digital exclusion by allowing people to speak to someone from the Referral Support Service instead of completing an online assessment. A newly commissioned peer support service will also provide people with support while they wait.

## **Tackling inequalities through waiting list data**

Our push for the publication of demographic data of those on waiting lists for healthcare led to the NHS taking this important step towards identifying and eliminating barriers for the most marginalised groups.<sup>15</sup>

### **What we found**

Our work has consistently found that barriers to care often most significantly affect those who already face inequalities. This includes those on NHS waiting lists. In 2022, we found that women, people from ethnic minority backgrounds, disabled people, and those in deprived areas often waited longer and had worse experiences.

These inequalities are often more severe for people with more than one marginalised identity. For example, people from minority ethnic low-income households were almost twice as likely to have treatment delayed or cancelled than people from wealthier white British households.

It was more than the lack of treatment alone that caused problems. The long wait could have a mental and physical toll. People told us about poor communication from services, lack of support for worsening symptoms and the impact long waits had on their ability to work, do household tasks, and socialise.

### **What we did**

Our research showed the importance of breaking down data to understand the inequalities people experience and to ensure targeted action to address them.

We shared our research with NHS leaders, emphasising the need to equitably manage waiting lists. We called on NHS England to publish waiting list data broken down by demographics, such as age, sex, ethnicity, and deprivation levels.

NHS England published these breakdowns for the first time in July 2025, as part of its Elective Care Reform Plan. We'll monitor how NHS services use this data to tackle the root causes of inequalities and improve patient experiences. We'll also continue pushing for expanded data collection and analysis to cover disabilities and caring roles, too.

### **On the ground**

The NHS asked local Healthwatch in Bristol, North Somerset and South Gloucestershire to explore how they could improve support for people waiting for surgery. Local Healthwatch spoke with patients, especially those in deprived areas, to learn about their experiences.<sup>16</sup>

People said they wanted more regular updates while waiting and clear, evidence-based information to help them manage their conditions during that time.

They also said assessments should consider their broader personal needs, such as housing and finances. People wanted more community support to help them cope.

The NHS said these findings have highlighted specific steps they can take to better support patients, such as keeping in touch more often while patients wait for surgery.

## **2: The changes we need to see**

Our purpose is to listen to the public's experiences with health and social care. Only by doing so can we truly understand what's working and what isn't, and be clear on what needs to change so that everyone can get the care they need.

Last year, we carried out research across the breadth of the health and social care system. We looked at pharmacy closures, what people want from cervical screenings, and the unmet social care needs of millions of disabled adults, to name a few.

This section explores last year's research. We also set out essential next steps for the government and NHS, based on the experiences of thousands of people across England.

## The impact of waiting for eye care

The waiting list for specialist eye care stood at nearly 60,000 in December 2024, making it one of the longest in England.

Though the NHS aims for 92% of people to be seen within 18 weeks, around a third of those on the waiting list had already waited 18 weeks or more.

We surveyed 2,568 people with current or recent experience of seeking specialist eyecare.<sup>17</sup> They shared stories of challenges with getting referrals, long waits, and negative impacts on their physical and mental health as a result.

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“My optician is great, the hospital service was poor and the wait for Laser ridiculous. It’s been over six months and I’ve had a reoccurrence of the bleed. I’m unable to drive and consequently unable to work.”

— Story shared with Healthwatch England

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Many people said they could not or did not want to pay for private care to avoid waiting. However, there was strong support for high street optometrists to play a bigger role in helping people manage their eye conditions when safe and appropriate to do so.

### What we found

Of the 471 survey respondents currently waiting:

- **22%** had needed multiple appointments before a healthcare professional would refer them.
- **64%** had waited more than four months.
- **24%** had waited over a year.

For many, this caused significant issues. While waiting:

- **70%** had noticed deterioration in their vision.
- **69%** had experienced negative impacts to their mental health.
- People also noticed impacts to their ability to continue with hobbies (**75%**), work (**54%**), and carry out daily household tasks (**52%**).

Despite these impacts, just **4%** had been given advice or information to help them with day-to-day activities.

## **What needs to change**

Long waits can negatively affect those who need specialist eye care, but there are ways to reduce the number of people waiting and make the wait easier for those who still need to see a specialist. We recommended three steps to Government:

1. The NHS should share waiting list data for eye care by specific condition. This would help track progress for the most serious cases and make sure resources go where they are most needed.
2. The government should use optometrists more, through a scheme similar to Pharmacy First. This would help reduce waiting times and offer more treatment and follow-up care closer to home.
3. Patients should get better support and communication while they wait. This could include more funding for the Eye Care Liaison Officers programme and making advice available in the NHS App.

## Why it matters: Jenny's story

Jenny, 80, from East London, has a history of eye issues from a young age.

“I had a chemical burn to my right eye when I was 15 and was in hospital for a fortnight. They operated to try to reduce the scarring to the eyeball. Fortunately, it didn't affect my sight,” she explains. More recently, Jenny has also had treatment for cataracts.

However, she has become more concerned about her eye health in the last year. “I was getting pain in my eyes, so I took myself to the emergency eye unit at my local hospital,” she says.

An eye specialist at the hospital said that Jenny had blepharitis, and possibly some dry eye, and prescribed some eye drops to relieve her symptoms. However, they didn't share any more information about follow-up care or how to treat her symptoms moving forward.

Since visiting the hospital, Jenny has tried to find out more about the next steps and how to care for her eyes. She spoke to her GP and visited a high-street optician, but they couldn't help her, and now she doesn't know where to turn.

While Jenny waits for her next NHS eye check-up, where she hopes to learn more about treatment options, she's growing more worried about what's happening.

“My right eye is so uncomfortable, and the bottom lid is sagging now so that when sleeping, my top eyelid is not closing properly,” she says. “I feel like I'm in limbo because my symptoms aren't classed as an emergency, but they still need to be treated.”

## How trauma cards could help people get care

Millions of people in England are experiencing or have previously experienced trauma. In 2022, Healthwatch Essex successfully piloted trauma cards – wallet-sized cards people could use to help communicate their needs. We wanted to see if these cards could help more people, so we surveyed a representative group of 3,571 adults in England.<sup>18</sup>

Trauma can make it harder for people to get the care they need. Some may not tell professionals about their trauma, and some may even avoid services because of it.

But there is support for trauma cards, and this simple, low-cost innovation could make a huge difference to millions using NHS services.

### What we found

**Nearly six in ten (59%)** of respondents to our survey said they have experienced trauma at some point in their lives, working out to 34 million people in England.

This included **67%** of women and **51%** of men who took part in the survey.

Of those who'd experienced trauma:

- **39%** feel their trauma has negatively impacted their experiences of health and care services
- **18%** said they had often or fairly often avoided services due to their trauma
- **37%** have never disclosed their trauma to a medical professional, while **35%** of those who had found it uncomfortable to do so.

Not feeling confident or comfortable talking about their experiences was the main barrier. Still, **43%** of people currently experiencing trauma and **30%** of those who had in the past said they would likely use a trauma card.

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“I find it very helpful – because of the anxiety I just shut down and can’t talk. Knowing I’ve got the card means I’m less likely to be triggered. It’s like that comfort blanket. It takes that stress off you.”

— Story shared with Healthwatch Essex

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## What needs to change

It’s clear that trauma can have a significant impact on people’s experience of care. We recommended three steps to the NHS:

1. The NHS should run a national pilot of trauma cards, so anyone in England can order a free card, and get information on how and when to use it.
2. The NHS should invest in a communications campaign to help the public and health staff learn about trauma cards, what they are for, and how to use them.
3. Frontline health and care professionals need better training in trauma-informed care. The number of people who have had negative healthcare experiences in relation to their trauma is highly concerning. Trauma cards are only part of the solution – professionals also need to know how to provide the right care.

## Fixing the complaints procedure

Written complaints to the NHS hit a record high in 2024. With public satisfaction with the NHS at record low levels, it's vital that the NHS effectively handles, responds to and learns from complaints.

We polled 2,042 adults in England and sent Freedom of Information requests to NHS Trusts, ICBs, and local authorities, to understand people's experience of the complaints process.<sup>19</sup>

Although the NHS Constitution gives patients the right to complain, we found that very few people do. Many avoid complaining because they lack confidence their complaint will be handled properly.

If the government wants a more patient-centred NHS, services need to demonstrate to the public that they welcome complaints and show how they learn from them.

### What we found

- **24%** of those we polled had experienced poor care – yet **56%** had taken no action in response, and just **19%** had made a formal complaint.
- **34%** of those who'd experienced poor care but hadn't complained believed the NHS wouldn't use their concerns to improve services.
- **33%** thought services wouldn't respond effectively.
- **30%** thought the NHS wouldn't see their concern as "serious enough".
- Of those who did complain, **56%** were dissatisfied with the process and outcome.

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"It's very pointless making a complaint as it's brushed off, even in the event of damaging a patient's health, the hospital still brushes it off and takes so long to reply it makes it not worth it unless

a patient is able to afford legal help to tackle the hospital's negligence.”

### — Story shared with Healthwatch Wiltshire

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## What needs to change

We recommended several steps to Government and the NHS:

1. A full review of statutory NHS complaints advocacy services. There should also be clear, mandatory standards to help people navigate the complaints process. NHS bodies should also collect wider demographic data about complainants.
2. There should be required response times for complaints, based on a review of current average response times at all providers and ICBs. NHS organisations should also survey patients after closing their complaint cases to track satisfaction and outcomes, and report on new performance indicators for complaint-handling.
3. Providers should make clearer what they have learned from complaints by publishing more detailed annual complaints reports.

Following our review, the Government announced in its 10 Year Health Plan that it intended to update NHS complaints regulations and set clear standards for both the timeliness and the quality of responses to complainants. It will also explore use of AI tools to analyse NHS complaints data.

## What people want from dentistry

Access to NHS dentistry is consistently something people tell us they're struggling with, and we have repeatedly researched and reported on people's experiences over the last thirteen years.

In late 2024, we looked at people's understanding of how NHS dental care works, polling 1,721 adults in England.<sup>20</sup> Many people believe registering with a dentist works in the same way as registering with a GP, and many would prefer such a system. We are calling for fundamental reform of NHS dentistry so that people can get the care they need.

## What we found

Of the respondents who hadn't been able to access NHS dentistry in the last two years:

- **24%** weren't on an NHS dentist list and couldn't find one with NHS places available.
- **18%** had tried to get a check-up with their regular dentist, but no appointments were available.
- **11%** couldn't get an appointment with their regular dentist for a new dental problem.
- **10%** had ended up paying for private treatment.

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“I have been registered at [my] Dental Care practice for over 50 years...I was notified...that with effect from 1st August the practice was only offering Private Treatment Plans. I have been unable to find a dentist in South Tyneside willing to accept me as an NHS patient.”

— **Story shared with Healthwatch South Tyneside**

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**More than two-thirds (68%)** of all poll respondents believed incorrectly that they have the right to register with an NHS dentist in the same way they do an NHS GP. When asked about what kind of system they'd prefer:

- **55%** want the ability to permanently register with a local NHS dentist as they do with a GP surgery.
- By comparison, **27%** said they want the current system, with flexibility to seek an appointment at any NHS dentist each time, including those outside their area.

## What needs to change

We know the government has already recognised the need for profound change to the way NHS dentistry is delivered. We have recommended several steps to government and the NHS:

1. To fundamentally reform NHS dentistry and give everyone the right to be permanently registered with a dental practice throughout their lifetime.
2. To learn any lessons from initiatives that have aimed to increase dental appointments in the short-term.
3. To improve public awareness of how patient "registration" works and of any obligations to attend to remain on a regular list.

## On the ground

Research by Healthwatch Cornwall has done much to shine a light on the critical state of dental care in the county. They found that **100%** of NHS dental practices in Cornwall were not accepting new adult NHS patients at the time of their research.<sup>21</sup>

Their survey also showed that **61%** of people didn't know how to access NHS dental care. The lack of access was causing vulnerable groups to go into debt or skip treatment altogether.

The report received significant media attention and helped shape a new dental strategy for the county. Thanks to

Healthwatch Cornwall's findings, NHS funding was secured for more than 1,000 extra emergency dental appointments and a new way to prioritise patients who need care most.

## Why it matters: Donni's story

Donni, 65, from Norwich, says the dental surgery she uses stopped seeing NHS patients three years ago. Since then, she's had to pay privately for her care.

"I can't get an NHS dentist since mine left the practice," she explains. "Now it costs me nearly £70 for a five-minute check up!"

Donni says her practice offered her a dental payment plan. But Donni, who lives alone and can only work part-time due to other health issues, says she can't afford another monthly expense.

Donni recently paid privately for a bridge to be fitted. But she was only able to afford this as her father had passed away, leaving her with some inheritance that she could put towards paying for her care.

Without the money from her father, Donni says she wouldn't have been able to afford this procedure. Even then, she opted for a cheaper option as some treatments remained beyond her means.

Donni continues to try and find a dentist taking new NHS patients in Norfolk. However, she says she's been trying for three years and isn't optimistic that any will become available soon. In the meantime, she will keep paying £70 for regular check-ups, for as long as she can.

"I can currently afford to pay privately. But that's not always going to be the case, and I don't know what I'll do then."

## Opportunities and risks for pharmacy care

A key pillar of the 2023 Primary Care Recovery Plan was to expand the role of community pharmacies to reduce pressure on GPs and improve access to primary care services. The Pharmacy First scheme, which is part of this plan, lets people get treatment for several conditions at pharmacies, without seeing a GP.

Around the time of the scheme's implementation, we polled 1,650 adults in England to learn more about their views.<sup>22</sup>

Many people use community pharmacies and value how easy they are to access. However, we also heard that some people had seen their pharmacy close. We submitted Freedom of Information requests to find out how widespread closures were.<sup>23</sup>

### What we found

In our research on attitudes to community pharmacies, we learned:

- **72%** of people had used a pharmacy in the past three months.
- Use of online pharmacies was much lower, with just **18%** having used one.

People appreciate how easy it is to get to community pharmacies and how quickly they can be seen. Even before Pharmacy First started, many were open to visiting a pharmacy for help with the conditions the scheme covers. People are also open to using pharmacies rather than GPs more generally, particularly for vaccinations and skin care.

But this wasn't the case for everyone. Those who said they didn't want to go to the pharmacy sometimes did so out of personal preference, but some were unaware of the services pharmacies could offer.

Medicine shortages were also affecting people, as were costs:

- **24%** have experienced shortages when trying to get medicine.
- **42%** have experienced problems getting medicine in general.
- **5%** have avoided taking up one or more NHS prescriptions due to the cost.

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“It was some creams which the doctor prescribed for me. It is hard to get it, it disappeared. I went to a few pharmacies, and they did not have it. So, I just left it.”

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— **Story shared with Healthwatch England**

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People also shared the impact that pharmacy closures had on their ability to get care. In our later research, we learned from Freedom of Information requests to ICBs that across the calendar year 2023:

- **436** pharmacies closed permanently in England. This amounts to more than eight pharmacies closing every week.
- There were **13,863** recorded instances of temporary closure. This added up to **46,823** hours lost – equivalent to **5,852** standard pharmacy working days.

There is significant variation in the rate of permanent pharmacy closures across ICBs. Some ICBs saw only **1%** of their pharmacies close permanently, while one saw **11%** of its pharmacies close permanently. Similarly, hours of temporary closure ranged from under an hour to over 17 hours per pharmacy.

There were higher rates of both permanent and temporary closure in rural areas, areas with older populations, and areas that had fewer GPs per head of population. The main reason for temporary pharmacy closures across England is a lack of available staff.

A year after Pharmacy First was introduced, our research found that people liked many aspects of the service. For example, almost nine in ten (**86%**) reported a positive experience of visiting their pharmacy for support with one of conditions covered by the scheme.

However, our insight indicates that public awareness of scheme could be improved. Local Healthwatch reports show variable levels of awareness, from **39%** in Halton to **72%** in Stockton-on-Tees.

## **What needs to change**

Successive governments have outlined how pharmacy can play a bigger role in healthcare. The new NHS 10 Year Plan reiterates this ambition. However, for this to work, Government and the NHS need to take several steps:

1. Further targeted communication is needed to keep raising awareness of the Pharmacy First. People who use the scheme should be involved in its evaluation. Over time the scheme should expand to cover more conditions.
2. Medication shortages must be reviewed and action taken to keep people informed. Steps such as improving awareness of prescription prepayment certificates will also help tackle the cost-of-living issues patients face.
3. To reduce the impact of pharmacy closures, it's vital that people are notified of closures and contingency plans are in place. However, pharmacy teams also need better support, such as improved IT systems, more funding, action on workforce shortages, and support with pharmacy premises.

## Learning the lessons of Community Diagnostic Centres

Established in 2021, Community Diagnostic Centres (CDCs) offer elective diagnostic care in community settings like shopping centres. As demand for this type of care increases, they aim to relieve pressure on hospitals.

We set out to learn about people's experiences of CDC care, to fill a gap in research and help develop this new approach to diagnosis.<sup>24</sup> We asked 18 local Healthwatch to visit a total of 22 CDCs to interview patients, audit site accessibility and record travel information.

People's experiences of CDC care were overwhelmingly positive, but steps are needed to ensure everyone can get care in their community.

### What we found

- **93%** of those we spoke to told us about good experiences at CDCs.
- For most people, CDCs were conveniently located, with **70%** arriving in less than 30 minutes, and **26%** in less than an hour.

However:

- **78%** weren't offered a choice of location for their appointment, while **61%** didn't get a choice of time, something they'd have liked when the appointment they got didn't suit them.
- Local Healthwatch found accessibility issues at several sites, including failure to meet people's communication needs, issues with English language interpretation, and barriers for deaf people, people experiencing hearing loss, and people with mobility difficulties, autism or dementia.

- People told us about issues because of a lack of information about how to get to the site.

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“They could do with having doors in the corridor that open automatically. As I’m using a mobility scooter, I had to rely on people to open the doors for me. I’m guessing it’d be even harder for someone in a wheelchair.”

— **Story shared with Healthwatch Halton**

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## **What needs to change**

The NHS 10 Year Plan aims to move more care out of hospitals and into the community, including through CDCs. This change could help people get care faster, which is a top priority for **31%** of people we spoke to. However, to help ensure this works several steps are needed:

1. There must be up-to-date and detailed information for patients and staff about CDCs, like opening times, services offered and locations. People should have clear guidance on how to get to CDCs and where to find help with parking and travel costs.
2. CDCs also need to be more accessible. This requires independent reviews of each site to ensure people’s communication and access needs are met. This should include listening to people with different accessibility needs.
3. The CDC programme should also be formally reviewed to understand how well it is working.

## Exploring unmet social care need for disabled adults

In 2022-23, local councils paid for social care for 300,000 people. This kind of care can be transformative.

However, our research shows many working-age adults in England could be missing out on social care support they're eligible for. We surveyed 1,505 disabled adults aged 18-64 to better understand this hidden demand for care and other unmet needs.<sup>25</sup>

People told us that social care helps them stay healthy, enjoy their favourite activities, eat and drink well, work or volunteer, and look after themselves and their homes. But accessing this support is often difficult. We believe there must be a fully funded, long-term plan to reform social care so people can get the help they need.

### What we found

When people receive social care support, their experiences are very positive. **78%** of those we spoke to agreed that their care helped them live the lives they wanted to.

But accessing social care can be challenging.

- **28%** of our total sample had never accessed care, despite self-identifying as eligible.
- Up to **1.5 million** disabled adults in England could be eligible for social care or other support, but aren't receiving it.
- And while most people awaiting assessments received information and support, **10%** got no support while waiting.

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“I'm having to pay for [care] from my attendance allowance. However, the cost comes to nearly £170

per month more than my benefits. Social Services say I'm not disabled enough to qualify for any help. I'm having to cut down on my care to buy food. On the days I can't afford the carers, I can't shower or dress."

### — Story shared with Healthwatch England

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## What needs to change

To ensure people get the support they need, several steps are needed:

1. In the short term, the Government should give local authorities funding to raise public awareness and help people access social care services more easily.
2. Local councils also need funding to increase social care capacity and reduce backlogs for care assessments and care packages. Additional funding should also be set aside for organisations providing independent social care advice to the public.
3. In the long term, a fully funded reform plan must address workforce challenges, support unpaid carers, and help people to live well and stay at home for as long as possible.

## On the ground

In Barking and Dagenham, local Healthwatch looked into why the local South Asian community were not accessing social care services.<sup>26</sup>

Working with local faith groups to reach out to the community, they identified several issues, especially low awareness of available support. Some local people also had cultural and religious concerns.

Following the Healthwatch Barking and Dagenham report, the local authority took several steps to improve awareness and access to the service. Actions included making information about social care available in Urdu and Bengali, improving translation services and working with local groups to increase awareness. The recommendations also helped make care more culturally appropriate.

### 3: Looking to the future

Since we began our work in 2013, we have listened to millions of people's stories about their care, including those who feel overlooked or fear speaking out. Because people have shared their experiences with us and with local Healthwatch across England, we've been able to build a clear picture of the problems they face when using health and social care services.

This includes our recent report: "The public's perspective: The state of health and social care".<sup>27</sup> Based on 390,000 pieces of feedback that we received over the span of a year, this report demonstrates some of the most pressing issues that government and NHS leaders must address. We highlighted five major themes:

1. **Access issues remain widespread:** Across GPs, dentistry, mental health, elective care, and social care, people face persistent difficulties getting timely appointments, referrals, treatment, and support. These delays often worsen health outcomes and put pressure on urgent or emergency services.
2. **Inequalities in care persist:** People and communities already facing inequalities, such as those on low incomes, ethnic minorities, disabled people, and those with communication needs, experience disproportionate barriers to care, leading to poorer health outcomes and higher unmet need.
3. **Waiting for care takes a toll on wellbeing:** Long waits for elective care, mental health support, and social care can seriously affect physical health, mental wellbeing, and financial stability. Many people report worsening conditions and a decline in quality of life while they wait.

4. **Digital transformation brings both opportunities and risks:** While digital healthcare innovations (e.g. NHS App, virtual wards) improve convenience for some, digital exclusion and poor system integration risk creating a two-tier system and unequal access to care.
5. **Administrative and communication failures undermine care quality:** Poor administration, inaccessible information, and ineffective complaint handling erode trust and the patient experience. Problems like missing records, lack of updates, and failure to meet accessibility standards persist.

We can only highlight concerns like these because of the work we do to listen to the public at both a local and national level.

Any new system of gathering patient feedback must be based on tried and tested principles. It must rely not just on statistics but on the stories that put a human face to problems like those we've raised.

It must recognise that people's experiences, the care they need, and the barriers they face in accessing it vary across regions and demographics. Outreach must keep happening at a local level, with steps taken to establish trust within communities – especially those who may already face greater inequalities, and whose voices can go unheard.

We will continue to carry out our statutory duties until we are no longer required to, and when this day comes, we'll look back on our work with immense pride. We've shown how feedback can turn into action, working with NHS and social care leaders to make real improvements in care.

The Government must keep its promise of building on that work. The public feedback mechanism may change, but people must still be empowered to share their views. The culture of the

NHS needs to shift to put listening first. And there must be accountability, trust, and true demonstration of learning. Only then can the NHS and the people they serve work together to ensure the health and care system delivers for all.

## Our resources

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

## Our income and expenditure

At the end of the financial year 2024-25 we spent 100% of our budget with a small overspend of just over £1,000.

Income		Expenditure	
Annual grant from Government	£3,343,688	Expenditure on pay	£2,378,891
Additional income	£14,250	Non-pay expenditure	£831,273
		Office and management fees	£148,824
<b>Total income</b>	<b>£3,357,938</b>	<b>Total expenditure</b>	<b>£3,358,988</b>

## Our people

We cannot do what we do without the hard work of our staff and volunteers.

In 2024-25, nationally Healthwatch England employed 35 staff to support our Committee and local Healthwatch and work with the public, policy partners and partners to improve care.

Locally, across 153 local Healthwatch services:

- 842 full and part-time staff deliver the Healthwatch service for local communities.

- 4,268 volunteers kindly give up their time to understand local people's views, provide advice and help improve services.

### **Local Healthwatch funding**

In 2024-25, local Healthwatch reported that they received £25.8m in funding from local authorities to support their statutory activities. This is an increase on the £25.5m reported in 2023-24 but a fall from £33.2m reported in 2013-14.

## 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.

### **Our Committee members:**

Professor David Croisdale-Appleby

Debbie Bartlett

Dr. Joanna Bircher

Belinda Black

Jane Laughton

Sultan Mahmud

## Thank you

We're grateful to everyone who supports our work to improve health and social care, including our dedicated local Healthwatch volunteers and colleagues working hard across the country.

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“When I worked in the NHS, I was always told that patient should be at the centre of everything – but often we failed in that aspiration. By amplifying the patient voice, Healthwatch helps to redress that.

“Volunteers can often more readily make connections to local communities, particularly those which might otherwise be hard to reach. This can give them more confidence in voicing their needs, with a greater expectation they will be listened to.”

## — Graham, volunteer for Healthwatch Southwark

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### **We'd also like to thank:**

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.

And every member of the public who took the time to tell us about their experiences. The stories you share help make health and social care services better for everyone

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- [18 How trauma cards could improve care access to care](#)
- [19 A pain to complain: Why it's time to fix the NHS complaints process.](#)
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<sup>24</sup> [A local diagnosis: Learning the lessons of Community Diagnostic Centres](#)

<sup>25</sup> [Missing millions: Exploring unmet social care need for disabled adults | Healthwatch](#)

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