# Front and centre

Unlocking the power of people-driven care

Healthwatch England
Annual report 2023-24

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## **Healthwatch England**

Annual report 2023-24

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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 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**

 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 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.<sup>1</sup>

### **Foreword**

Over a decade since Healthwatch was established to champion the public's views on health and care, we stand at a crossroads. The NHS is under more pressure than it has ever been before, making it more and more difficult for it to fulfil the purpose for which it was created.

The Health and Social Care Secretary described the NHS as "broken" within days of taking office, and has also recognised the need for long-term action on social care. The Government has pledged to repair the system, and announced an additional £25.7 billion in investment.

They have also asked the public for their views and ideas to help develop a new ten-year plan to make our NHS fit for the future. This is just as important as additional funding – if the system is broken, the people it serves are key to fixing it.

We have repeatedly shown the power of the public voice. Across the health and social care system, the stories people have shared with us have made a difference. They have highlighted concerns and inequalities, and helped people get the care they need.

Public feedback has led to action on primary and dental care, simplified waiting times targets for cancer care,

and better support for maternal mental health, among other examples.

But the issues the NHS faces are significant and will not change overnight. We must see true reform of dental care, and more done to help people access GP and pharmacy services. The Government aims to return to waiting targets by 2029, but in the meantime, the experience of being on a waiting list must be comfortable, with support and information available. And the NHS must create a true culture of listening, putting the views and experiences of patients front and centre.

This is not only a question of convenience or satisfaction. It's one of safety. It's one of equity. It's vital to fulfilling the NHS's founding goal: to provide free, high-quality care to all. And it's vital if the NHS is going to continue to serve the needs of those using it in the years to come.

We stand ready to support necessary strides forward for the health and social care system. In this report, we show the ways the feedback the public shares with us has made a difference in 2023-24. We show how we're shining a light on some of the most pressing issues people have with their care. We explain where we want health and care services to be by 2030, proposing reforms that put more power in the hands of patients, including:

- Relaunching the NHS Constitution as a new Patient Promise, with the rights and pledges that matter most to patients.
- Investing in the technology and administration staff to transform the ability of patients to get questions answered, access real-time information, and navigate their care.
- Overhauling the confusing and complex complaints system to make it more timely, responsive, effective and empathetic when people raise concerns about care.
- Transforming NHS culture and accountability when it comes to listening to patients by improving training and mandating the use of patient experience as a measure of performance and safety.

Finally, we set out how Healthwatch, too, can become fit for the future, and make the biggest impact for those using health and social care services.

Professor David Croisdale-Appleby,

## Chair of Healthwatch England

### Louise Ansari,

Chief Executive of Healthwatch England

# Our year in review

We supported more than one million people to have their say and get information about their care.

### Top stories from 2023-24

### **Spring**

The primary care recovery plan addressed key issues people have raised with us about GPs and other services.

#### **Summer**

Our research showed how delayed care impacts patients and set out the steps decision-makers must take to address this.

### **Autumn**

A stocktake of 65,000 people's NHS and social care experiences revealed the barriers many face to timely care.

Our insight on hospital discharge highlighted how the Government and NHS staff can make improvements.

### Winter

The NHS approved a plan to improve the six-week postnatal check after our survey found this check-up was failing new parents.

Our new campaign for social care reform started with the first research to gauge unmet need among disabled adults.

The NHS introduced simplified waiting times standards for cancer after we reported people's experiences of trying to get care.

The dental care recovery plan came out after we gave evidence to the parliamentary Health and Social Care Committee.

Our patient vision report outlined where people want the NHS to be in 2030, and set out a path to get there.

### Who we've helped

### **Healthwatch England**

219,761 people used our service to get clear information and advice

13,505 people shared their experiences of care

### The local Healthwatch network

929,544 people used our service to get clear information and advice

390,049 people shared their experiences of care

# Making change possible

We're passionate advocates for putting those who use services at the heart of care, because we know what can happen when their experiences come to light.

Greater understanding of the issues the system and those using it face. A clear path forward. Real change that makes services better for everyone.

We've already seen it. From cancer care to maternal mental health, those who plan services have made real, positive changes by acting on the public's feedback.

In this section, learn about the difference our work made last year, and see why people-driven care is so vital.

# Opening the door to healthcare services: the primary care recovery plan

In May 2023, we welcomed the NHS's new plan to tackle the issues people have with primary care services.<sup>2</sup>

It focused on three big challenges we've told the NHS that patients face, and reflected our recommendations for addressing them. It promised faster access to care, better patient communications, and more effective use of pharmacies.

### 1. Faster, easier, more equitable access

People talk to us about their experiences with GP services more than any other part of the health and social care system, with access often proving a problem.

GP services are the gateway to NHS specialist support. But almost one in five respondents to our research on GP referrals needed four or more GP appointments to get the referral they needed.<sup>3</sup> Mental health referrals were less likely to lead directly to an appointment or waiting list (only 60%) than other conditions like cancer (90%).<sup>4</sup>

Some groups struggled more than others to get the care they needed. Only 66% of respondents aged 18 – 24 and 58% of neurodivergent respondents were likely to get a referral straight away, compared to 71% of respondents overall.

We called for the NHS to expand the role of care navigators, and highlighted consultant-to-consultant referrals as key to decreasing how long people spent waiting for care.

The new plan reflects these recommendations, promising to train more receptionists as care navigators. With upskilled and empowered staff able to

direct patients to the right clinician, people can get the care they need more quickly.

The plan increases self-referral options, and lets secondary care providers make onward referrals for those already under their care. This saves people going back to their GP to start again if they need further support.

The plan also recognises that services must reflect their patients' diverse needs. It specifically highlights those with mental health issues, dementia, or learning disabilities, autistic people, and people of all age groups. But this more equitable approach will benefit all patients.

### 2. Improved communication

Patient choice and good communication, both within the healthcare system and with the people it serves, are essential for everyone to access timely, appropriate, high-quality care.

But patients have told us they can struggle to get GP appointments, often being stuck on the phone for long periods. They have also said they want to be able to choose how they see a professional, whether online or in person.

"I simply have given up trying to see a doctor or nurse practitioner. By the time I get through on the phone, I get told the same thing each morning, that all the appointments have gone, there's none left and ring tomorrow." — Story shared with Healthwatch England

Those waiting for specialist appointments have also told us about how long it can take to hear from services.

They want to stay up to date on how long they have to wait, and how to manage their health while they do.

The primary care recovery plan takes forward recommendations we've made to address these issues by:

- Enabling patients to choose whether to contact their surgery via telephone, online, or in person.
- Promising to make services more accessible by improving booking and phone systems, addressing the "8 AM rush", and saving patients time waiting on the phone.
- Empowering patients to manage their own health by improving the NHS App. The NHS aims to help more people access their health records, order repeat prescriptions, manage appointments, receive messages from their practice, and see average waiting times for care.

Signs of progress:

Eight in ten practices were upgrading their systems by the end of 2023, up from five in ten the previous year.<sup>5</sup>

Repeat prescription orders through the App rose by 45% over 2023.6

More than four in five GP practices in England now give patients access to their health records through the NHS App.

### 3. More care through pharmacies

People have told us they value the accessibility of community pharmacies.<sup>7</sup> Now, thanks to the Pharmacy First scheme, people can go straight to their pharmacy for prescription treatment for conditions like earaches.

We've made recommendations based on research with the public to help make the scheme a success. These include further communication to make people aware of the scheme, greater support for pharmacy teams, and involvement of those using pharmacies in the scheme's evolution.

Pharmacy bodies welcomed the research, and we will continue to highlight people's experiences of using pharmacies for faster access to care.

### The next steps

As the NHS implements its ambitious plans, we will continue highlighting people's experiences of primary care, helping NHS decision-makers hear what's working and where more needs to happen.

With an increase in the number of community pharmacies closing and considerable workforce pressures, we will also monitor the impact this is having on patients.

### On the ground

As more NHS services become available online, the risk of digital exclusion becomes greater.

Thanks to the work of local Healthwatch, more people in North Somerset, South Gloucestershire, and Bristol can now access online health services.<sup>8</sup>

Over 1,000 people directly benefited from a digital guide and in-person training on how to use key services such as the NHS App to book appointments, order prescriptions, and view medical records. Local Healthwatch also trained GP practice and care home staff on how to help patients get online.

The training resources, which were also translated into Chinese, were made available through local community groups, libraries, and healthcare staff in the community.

### Why it matters: Leonora's story

Leonora, 50, needs regular appointments with her GP. But since changing surgeries in 2018, she struggles to get an appointment in person.

"In the last six years I've only seen a GP in person once,"
Leonora told us. "And after a few minutes in the
consulting room, they actually opened the door to usher
me out."

Leonora has decided to delay an operation because she couldn't discuss her concerns with a GP. And sometimes it can be a struggle even to get in touch with one.

"You need to book via a webform, that opens at 7:30 in the morning," she says. "But because of the shift pattern I work, I don't normally get up until later in the day... And even then, the appointments all get booked up very quickly."

This means Leonora is stuck in a pattern of attempting to book an appointment online, before getting an urgent referral for an emergency appointment from NHS111. This

process is restricting her ability to get the care she needs.

### **Dental** care

After we gave evidence to the parliamentary Health and Social Care Committee about the problems people experience, MPs recognised the need for fundamental reform.<sup>9</sup> The dental care recovery plan, published in February 2024,<sup>10</sup> is a step towards seeing this happen.

### Helping those who've been left behind

We hear constantly how people have struggled to get NHS dental care, particularly since the pandemic.

"I fear that I will continue to live in torturous pain, unable to eat or go out or obtain work for the remainder of my life." — Story shared with Healthwatch England

Lack of NHS dental care services has forced many to consider private care. For some, this just isn't feasible – our cost-of-living research in January 2024 found 21% of people avoided going to the dentist because they couldn't afford the cost.<sup>11</sup>

The previous Government's dental care plan promised to make NHS dentistry more widely available through:

- Mobile dental care services, helping those living rurally to get the care they need.
- "Golden hello" payments to incentivise dentists to work in "dental deserts".
- Bonus payments when dentists see patients who haven't had an appointment in two years or longer.
- Giving Integrated Care Boards the tools they need to commission the right NHS services.
- Looking at ways to further reform the contract NHS England have with dentists.

### The next steps

Dental care continues to be a major issue for the people who get in touch to share their stories. We will continue to highlight the access and affordability issues people tell us about with NHS England, as well as the with the Government, who laid out their own Dentistry Rescue Plan in their 2024 election manifesto.<sup>12</sup>

### On the ground

In Derbyshire, local Healthwatch used people's feedback to make it easier for them to find an NHS dentist after 82% of feedback on dental care highlighted this issue.<sup>13</sup>

Healthwatch Derbyshire found many dental practices didn't include up-to-date information on the NHS Find a Dentist website. <sup>14</sup> Staff contacted the dental practices whose listings were out of date to make them aware of contractual obligations to share the number of available NHS spaces.

As a result, Derbyshire was recognised as the best county in the country for updated NHS Find a Dentist profiles, with 89% of dental practices regularly updating their NHS patient spaces.

Healthwatch Derbyshire continues to work with the local NHS to implement solutions that will improve access to appointments and increase awareness of good oral health.

### Why it matters: lan's story

Ian was medically discharged from military service after experiencing a head injury during a training exercise. The injury left him suffering from epileptic seizures that led him to grind into his teeth, causing have caused significant damage to lan's teeth and jawbones.

"I tried to get NHS [dental] care when I left the army," Ian told us. "But because it was during Covid, I couldn't get an appointment and there are no dentists offering NHS care in the area."

Unable to access NHS care, Ian has learnt to manage his dental problems. When he's in pain, he uses overthe-counter medication. But for more complicated issues, like his missing front tooth, there's nothing more he can do.

"I've lost two molars that have gone down to the pulp, so this is quite sensitive," Ian explained. "But it's got to the point where my nerves are used to it."

Ian says he would pay for private care if he could afford it. But the seizures caused by his epilepsy mean he's unable to work.

"I'd love to just be able to smile without a big hole in my mouth," he says.

### **Cancer care**

Cancer can be one of the most frightening and stressful things a person can go through. Feedback people have shared with us has shown that many face long waits during their care journey.

Changes to cancer care waiting times targets and commitments about staffing resource will help people feel more supported as they go through diagnosis and treatment.

### A smoother, clearer journey for patients

People told us about long waits at various stages of their treatment journey.<sup>15</sup>

"Routine mammogram to surgery, fantastic, six weeks.

But then it took five weeks for histology results, then another six weeks until [I was] seen by [an] oncologist! ...

The staff are amazing, but waiting times are too long." — Story shared with Healthwatch England

In our research on GP referrals, we found 45% of respondents who'd sought cancer treatment hadn't been referred after their first appointment.

We called for people with cancer to receive timely, compassionate, high-quality care.

New, simplified waiting times standards make it clearer to patients what kind of timeline to expect, and are more straightforward for services. NHS England have streamlined the ten previous standards into just three. People should:16

- Have cancer ruled out or get a diagnosis within 28 days of being urgently referred.
- Begin treatment within 62 days of an urgent referral.

 Begin treatment within 31 days of a patient deciding to have their cancer treated.

And the Long-Term Workforce Plan<sup>17</sup> includes steps NHS England will take to build its workforce to support the ambitions for cancer care laid out in the NHS Long-Term Plan.<sup>18</sup>

These include a pledge that planned expansion of medical training places will support planned growth for cancer care. The Workforce Plan also commits to ensuring everyone with cancer has access to a clinical nurse specialist or other support worker.

### The next steps

Our research suggests much more could be done to ensure diagnosis and treatment happens as early and is as smooth as possible.

We've called for NHS England to measure the diagnosis and treatment targets from the moment the GP makes a referral, rather than when the hospital accepts it.

And in the longer term, we've called for targets that measure people's real-time experience of care, as well as total numbers and annual experience reporting.

We've made further recommendations around personalised aftercare support, and on accessible

information about treatment for everyone, including those with sensory impairments, disabilities, or language barriers.

### On the ground

Cancer screening is more accessible at a service in Surrey thanks to Healthwatch Surrey's work with local resident Chantelle and her support worker.<sup>19</sup>

Chantelle, who has a learning disability and uses a wheelchair, shared with her local Healthwatch that her GP practice didn't meet her accessibility needs. This meant she didn't have access to the cancer screening she was entitled to.

With support from Healthwatch Surrey, Chantelle was able to fight for change at her practice. They've since made changes that mean Chantelle and others with accessibility needs can get the support they need. They've also improved the way they monitor accessibility needs for patients and carers.

### Maternal mental health

In December 2023, the NHS approved a plan to improve the six-week postnatal check,<sup>20</sup> after our survey of over

2,500 people demonstrated that this check-up was failing new parents.<sup>21</sup>

This is the next step in our ongoing work on mental health support for new mothers and birthing parents. The Government first introduced the six-to-eight-week check in 2020, after we shared people's experiences with their mental health during their journey to parenthood.<sup>22</sup>

### Making the six-week check work for new parents

Six-week checks-ups, provided by GP practices, are to check the mental health and wellbeing of new mothers and birthing parents.

But we found more than one in ten new parents hadn't had this check-up. Of those who had, a third said the GP didn't mention mental health during the appointment.

Thank to their feedback, NHS England promised improved guidance for GPs on carrying out the six-week checks, and better access to specialist community perinatal mental health services.

They also set out plans for responsibilities for Integrated Care Boards to implement equity and equality plans for maternity and better monitor maternity care.

This will ensure a consistent approach where every new parent gets the best care possible.

### The next steps

Ongoing work around maternal mental health shows new policies and initiatives must work in practice as well as in principle. It's essential that new parents are involved in their continued evolution.

So we'll keep sharing what new parents tell us with NHS leaders and other decision-makers, to build a picture of how well the new guidance is working.

### On the ground

Often the people struggling the most are the ones who can't access good-quality care. But in Coventry, asylum seekers and refugees can now get much better maternity care, following a joint project between Healthwatch Coventry and local charity Carriers of Hope.<sup>23</sup>

They sought to understand the experiences of a group of new parents whose voices often aren't heard.

Speaking to participants from 11 different countries, they found people faced issues with communication barriers, costs, and lack of cultural awareness. There were

barriers to breastfeeding, and to identification of mental health issues.

Thanks to the work, support that considers the experiences of this group of new parents is now available. A direct email referral route means those not registered with a GP can still access care. There has been considerable work to improve communication, such as translation tools in maternity units.

### Why it matters: Amanda's story

Amanda, from Hampshire, was never invited to the six-week postnatal check to assess her mental health and wellbeing after her daughter was born. She suffered from anxiety and developed sleep and eating problems. Her healthcare journey was long and tiring, with inconsistent support from health and care services.

Eventually, an asthma consultant at her local hospital recognised that she might have suffered from postnatal depression and helped secure mental health support for her. Amanda started therapy 18 months after her daughter was born.

"When I was pregnant, I received all the instructions I needed," she said. "But once the baby was born, I felt on my own. When you are a single parent, you don't have your own support network and don't get adequate

support, it can be very hard. I felt like I was underwater and couldn't escape.

"If I had had more support at the right time, my mental health would be better."

# No patient left behind

The first guiding principle of the NHS is that its services should be available to all.<sup>24</sup>

But this isn't always the reality. So many people who share their stories with us haven't gotten the right care. Those who most need support are often the least likely to get it, with stark inequalities across geographical areas and social demographics.

In the previous section, we demonstrated where feedback on care has already led to change. But there is still more to be done to ensure the health and social care system meets patients' needs.

So in this section, we share research we've done and recommendations for what needs to happen next – including work to ensure that health and care leaders hear the voices of those who are most likely to miss out on support.

### Taking stock of the state of patient experience

In November 2023, we launched our new report, "The public's perspective: The state of health and social care".<sup>25</sup> The report distilled the experiences of 65,000 people who shared their stories over a year.

It gave policymakers vital insights and recommendations across key areas, from GP services to cancer care. It explored pressing issues like the cost-of-living crisis and accessibility. It also looked at technology's growing role, highlighting where this benefits care and where it risks leaving people behind.

### What we found

Barriers to timely care impact nearly every part of the health and social care system.<sup>26</sup> Combined with issues such as the cost-of-living crisis, this risks widening existing health inequalities.

For example, people in deprived areas wait longer for some care than those in affluent areas. Those struggling financially often avoid healthcare due to additional costs like travel.

For many, difficulty accessing NHS care has led to them turning to private care. In polling we carried out alongside the report, over a quarter of respondents had accessed private healthcare in the last year. Of those who hadn't accessed private healthcare, almost one in five were considering it.

And one in seven respondents reported that an NHS professional had advised them to consider paying for private care in the last year, with under-30s most likely

to receive this advice. Associated costs mean this group is already less likely to access NHS services.

Our report warned of an emerging two-tier system – one where healthcare services are accessible only to those who can afford it.

"It has become very difficult paying for over-the-counter medicines.... Living with chronic pain doesn't help my quality of life." — Story shared with Healthwatch Sheffield

#### What we recommended

We set out solutions for each area of care, rooted in what those using services had told us.<sup>27</sup> We called for faster progress with national recovery plans, and greater focus on ending inconsistent experiences across different areas and demographics.

We made recommendations to improve access for those most struggling to get care.

 Commissioners and providers should take all opportunities to provide early or ongoing support through additional staff roles, including mental health practitioners, peer support workers, and school-based teams.

- The NHS should cover transport and accommodation costs where patients choose to travel for quicker treatment at another setting.
- There should be better signposting to support services, including voluntary organisations and services that support unpaid carers.

We also called for better communication with patients, through:

- Improvements to online referral trackers, to keep people waiting for care updated.
- More proactive NHS communications with patients while they wait for treatment.
- Single points of contact, either in person, over the phone, or via the NHS App, so patients waiting for care can give feedback about issues or changes in their condition.

These are key steps health and social care leaders can take to help ensure patients can make more informed decisions about their care.

"When I chased up my referral the staff member said, 'You'll get it when you get it.' No empathy was shown to the anxiety the wait was causing me." — Story shared with Healthwatch Shropshire

#### The next steps

Our report provides those who plan care services with a comprehensive picture of what's working and what needs to change.

We continue to track whether the issues we have highlighted have been addressed, and whether our recommendations have been implemented. We plan to follow up this work in future with another stocktake of people's health and care experiences.

The Government has announced improvements in patient communications in their elective reform plan. We will work with NHS leaders to ensure that expansion of the NHS App, more training for admin staff, and a greater offer of informed and meaningful choices lead to the changes people need.

#### On the ground

The local Healthwatch network makes a real difference not only in drawing attention to but helping to address the barriers communities face.

Through their #SpeakUp microgrant scheme, Healthwatch Sheffield works with local groups who are trusted partners in their communities. This helps them hear from more people, including those whose voices aren't often heard by services.

Last year Healthwatch Sheffield worked with Sheffield Association for the Voluntary Teaching of English (SAVTE) to explore the experiences of using health services from the perspective of English-language learners.<sup>28</sup>

Thanks to Healthwatch Sheffield's support, SAVTE spoke to 35 people, including refugees and asylum seekers. They shared concerns about language barriers, lack of confidence, and lack of independence when it comes to accessing care.

The work led to the creation of new language-learning resources to support people in the city to understand health services and talk about their symptoms, empowering them to access services more independently.

#### Understanding the impact of delayed care

The lingering impacts of the COVID-19 pandemic, NHS industrial action, and record NHS waiting times mean people have been left waiting for a long time for care. In July 2023, we released new research highlighting the extent of these delays, and the impact they're having.<sup>29</sup>

We analysed the experiences of 1,084 people who had care cancelled or postponed in 2023. The research showed a significant impact on people's lives when their care is delayed – and clear inequalities when it comes to who is most affected.

#### What we found

Delays could happen with little notice – 18% of people only learned their appointment would not go ahead on the day it was due to take place.

Nearly 40% of people who'd had their care delayed experienced multiple postponements or cancellations. But this was higher among groups who already face health inequalities. Among disabled people, neurodivergent people, people on lower income, people from ethnic minority backgrounds, and LGBTQ+ people, around half faced multiple cancellations.

Delayed care could cause ongoing pain, poorer mental health, worsening symptoms, and disrupted sleep. 66% of respondents had dealt with these kinds of negative impact.

Once again, this number was higher among some groups. Delayed care negatively affected 84% of unpaid carers, 83% of neurodivergent people, 80% of people on

low incomes and 79% of people from ethnic minority backgrounds.

Many people faced these delays without the right support in place. Over half – 52% – weren't offered support to manage their condition while they waited for care, and 79% weren't offered support for their mental health.

At the time we carried out our research, nearly a quarter of people – 24% – had no new appointment scheduled. 82% of those respondents said they hadn't been told when they would learn their new appointment date.

"I have been waiting for five years to have my gallbladder removed. My operation got cancelled in March 2020. ... I am still waiting." — Story shared with Healthwatch Coventry

#### What we recommended

Decision-makers need to better understand why delays happen and take steps to tackle them, and support and reassure patients while they wait.

We recommended that the NHS should:

 Collect and publish official data on cancellations to understand what drives delays – whether those reasons are non-clinical, clinical or patient-led.

- Use this data to reduce the high number of lastminute cancellations we highlighted in our research.
- Offer more significant support to those most affected by new delays – especially those with mental health needs or deteriorating symptoms.
- Improve administrative processes and communications to close the gap for those who are left in limbo with no new appointment date.

#### The next steps

As part of the NHS England Elective Care Engagement Forum, we're working closely with the team to improve elective care.

And we're raising the alarm where we see risks of the issue worsening. We wrote an open letter to Royal Mail and Ofcom about plans to delay bulk mail of NHS appointments, and submitted a joint consultation response with National Voices and the Patients Association. We're working with NHS England, Royal Mail and Ofcom to ensure people don't miss vital care because their letters arrive too late.

But waiting times for hospital care are still rising, and the problem requires radical solutions.

The Government's intention to create a new ten-year plan for the NHS presents an opportunity to find better ways to cut waiting times and improve support for patients while they wait.

We're also pleased to see promises from the Government to give those waiting more choice and control, improve the NHS App to give them better information about their care, and train admin staff to provide regular updates to patients. This will help reduce the number of people facing delays, and lead to better communication about when they can expect to be seen.

We'll do all we can to ensure that future plans reflect what matters most to patients.

#### Why it matters: Cindy's story

Three years ago, Cindy, who lives in Leeds, began experiencing shortness of breath. It took until earlier this year to finally get on the waiting list to see a respiratory specialist.

But while this is a step forward, the specialist team told her she'd have a 38-week wait. And with no news since, she's concerned it will take longer still. Cindy used to be very active. She enjoyed walking in the countryside with her partner, and they'd cover 10-12 miles a day without breaking a sweat. But now, even just getting off the sofa to go to the kitchen or do jobs around the house leaves her out of breath.

When her symptoms get very bad, Cindy goes to her local A&E. But because she's already on a waiting list to see a specialist, they always refer her back to her GP.

Cindy described being "stuck month after month after month" on a waiting list. "It's like beating my head against a rock chasing my GP for updates. It's just been so long."

## **Ensuring safe hospital discharge**

With demand for services soaring, discharging patients from hospitals on time is essential for freeing up much-needed beds and clinical capacity. However, discharging people too early or not giving them the proper support or information can risk adding to pressure on services and harming patients' health.

So in autumn 2023, we surveyed 583 people, including 175 carers, who had been discharged in the past 12 months.<sup>30</sup> We aimed to learn more about their

experiences, where there are issues, and how the process could be better.

#### What we found

Government guidance<sup>31</sup> says people should receive information on discharge about what to do if they have further concerns, including their discharge team's contact details. Yet 51% of respondents weren't given contact information when leaving the hospital.

Hospital discharge teams should also ensure people have transport to return home or move to another facility. But 59% of respondents said the hospital discharge team didn't ask if they needed support in getting transport. And people discharged before 9am or after 6pm were significantly less likely to be asked if they needed transport.

Of the people surveyed, 32% didn't feel prepared at discharge, with carers more likely to feel this way than patients, at 44%.

"My father is 80 years old and in poor health. ... He has had several falls and accidents trying to get to the toilet. He struggles with getting in and out of the bath to have a shower. When he was discharged from hospital, they said that someone would come to assess his home for

equipment to help – but this has not happened." — Story shared with Healthwatch Surrey

#### What we recommended

After we published our research, the Government updated guidance on what staff, patients and carers should expect from hospital discharge. This included more detail on support for carers, which we'd previously called for.

But NHS and social care teams need support to follow those procedures even during times of pressure. It's vital to consider hospital discharge in the context of the whole health and social care system. This helps avoid people being readmitted or needing support from other services, creating pressure on the system elsewhere.

Our recommendations included:

- Updates to Government guidance on hospital discharge and community support, including new minimum standards on transport waiting times and post-discharge contact times.
- Consistent implementation of the latest guidance by Integrated Care Boards (ICBs).
- Urgent Government reform of the social care system. This includes ensuring councils and providers have the staff, skills, and resources to

- support people to live independently, including after hospital discharge.
- Capture and reporting of data by NHS Digital that would help the NHS understand where discharge processes aren't working. This would include data on deterioration in people's health after hospital discharge, death after discharge, emergency readmissions, and contact with another health service about the same condition.

#### The next steps

The new Government has committed to shifting more care from hospitals to the community.<sup>32</sup> We will use this opportunity to call for greater capacity to support people recovering from hospital care at home.

We'll continue to monitor whether hospitals are following existing discharge guidance. And while we welcome new data published monthly on delays to hospital discharge, we'll also keep pressing for better data collection and reporting.

By understanding the impact of delays on patients, we can recommend the most effective steps to prevent them.

#### On the ground

Hospitals in Warrington and Halton welcomed a report from local Healthwatch that helped them identify key areas to focus on to improve the discharge process.<sup>33</sup>

Research into local people's experiences of hospital discharge from Healthwatch Warrington and Healthwatch Halton highlighted issues with how patients and their carers were involved in conversations around discharge.

They also heard from people who had been discharged without adequate support or appropriate transport, who were discharged in the middle of the night, or who felt their discharge was rushed.

Their report made comprehensive recommendations, with a major focus on involving patients and their carers at every stage of their care journey. They also highlighted the importance of asking patients and carers about their communication needs, and of providing them with opportunities to feed back on the discharge process.

#### Our call for social care reform

We've consistently worked to improve social care, knowing what a huge difference high-quality care can make to people's lives. Our insights informed the previous Government's ten-year plan for social care, influencing the inclusion of promises like an additional £5 million in funding for local organisations.<sup>34</sup>

In 2023, we announced a larger campaign for social care reform.<sup>35</sup> We highlighted three major challenges facing social care: rising demand,<sup>36</sup> delays to care, and staff shortages.<sup>37</sup>

#### What's happened so far

People have told us about long waits for assessments, reviews, or care, having to rely on their families, and making do without adequate support.<sup>38</sup> Staff shortages lead to problems getting the care they need. People have also found it challenging to find out about the cost of social care, and whether they can get help.

"I have been assessed as being eligible for six hours a week sit-in service, but for months I have only been able to access three hours due to staffing shortages. I understand the pressures services are under but I provide constant care for my husband and I need that

## time to regroup and be myself again." — Story shared with Healthwatch Thurrock

We've called for better resources and support for councils to proactively provide information and advice services to their communities. Working with Directors of Adult Social Services,the Local Government Association and others, we developed a Partners in Care and Health toolkit to help with this.<sup>39</sup>

We've also supported calls for care home residents to have a legal right to care support workers and visitors like friends and family. This right was granted in 2023.

And we've joined calls for major social care reform, promising to keep the challenges the social care system faces and potential solutions at the forefront of policymakers' minds.

#### The next steps

We began our new campaign on social care reform by setting out to understand who's missing out on care, polling 1,504 disabled adults in March 2024. Of those who did have access to care, 78% said it helped them live the lives they want to, helping them learn, work and socialise. Yet we found as many as 1.5 million people may not be getting social care they may be eligible for <sup>40</sup>

This is the first research demonstrating the scale of unmet need among disabled adults. Skills for Care referenced our research in their national workforce strategy,<sup>41</sup> recognising the importance of more staff to tackle the problem.

Our recommendations included greater funding to raise awareness of social care services, to increase the capacity of these services, and to support organisations offering independent advice about care.

But we must see a fully funded long-term reform plan. Establishing a new independent commission into adult social care is an important first step.<sup>42</sup> But we must see greater focus on what can happen in the short term to help those currently struggling to understand, afford or access social care.

Ahead of the independent commission's first report in 2026, we'll continue to inform policymakers about what those using social care are saying, and push for recommendations that help reform a sector that is struggling.

#### Why it matters: Annanya's story

Annanya, 21, lives in Liverpool and is a part-time student and ambulance worker. Health issues including dyslexia, ADHD, suspected autism and diabetes make home maintenance and other chores difficult. Making plans overwhelms her, and makes it difficult for her to get things done in the house.

Annanya reached out to her local social care provider for support, and waited six months for an assessment. But after telling them she couldn't cook or clean, and that she needed help with planning things out, they told her this was a medical issue and they couldn't help her, before closing her file.

"They kept me on a waiting list for six months just to get an assessment, then they called me to say they can't help me," she explained.

As well as struggling at home, Annanya has difficulty at work and with her studies. While her GP is supportive, the lack of social care help makes things like eating well very hard.

Annanya is clear on the difference social care could make for her. "Having this extra support could really help me to manage these challenging aspects of my life."

## Giving people more power

The NHS is facing more pressure than at any time in its history. But we believe it can still fulfil the promise it's built on: to provide excellent, comprehensive health services to all, free at the point of access.

We want to see a true understanding of what the public needs, shaping health and social care services from the ground up. We already know it makes a difference when we share people's voices.

So in February 2024, we released our vision for the NHS in 2030,<sup>43</sup> and the steps we think will get it to where it needs to be.

Here, we lay out the most important steps, with a focus on three broad areas to drive change and give more power to the people using health and care services.

## Making the NHS easier to access and navigate

In the previous two sections, we highlighted experiences people have shared with us of long waits, confusion about care, and communication that doesn't work for them.

We want to see the NHS adopt an "excellent customer service" ethos. One where people can get answers to their questions, book appointments with the right service, and get real-time information about their care straight away.

#### What that will look like

People should be able to access and communicate with NHS services easily. To make that happen, a plan similar to the NHS Long-Term Workforce plan for clinical staff should set out goals to train more care navigators and other admin staff.

It should be simpler for people to view their records, get screening and health check reminders, send in medtech readings, and get trusted self-help advice. So we're calling for the NHS App to become a digital portal for patients.

Meanwhile phone and in-person support should still be available for those who might not be able to easily use digital systems because of costs, skill level, disability and other factors.

#### What we've called for:

- Streamlined, straightforward ways to connect with NHS services.
- A simple way to view records, get advice and reminders, and send readings, such as through an expanded NHS App.

 Continued phone and in-person communication and administration channels for those who face digital exclusion.

## Tackling health inequalities

Again and again, we find that issues that impact people's ability to get good care affect some groups more than others. Often, the people who most struggle are those who already face worse health outcomes.

When we say the NHS must put its patients at the heart of care, we mean all of its patients. There are gaps in life expectancy and healthy life expectancy between the most well-off and most deprived areas – we want to see those gaps close. We want to see Integrated Care Systems work with councils to give communities the advice and support they need, and full support for those with additional communication needs.

#### What that will look like

A new cross-Government national strategy should set out plans to address social determinants of health and reduce inequalities, supported by local goals. There should be a clear understanding of who's affected by inequalities and why, with the NHS collecting and publishing data on disparities in waiting times, experiences, outcomes and improvements.

The NHS must be accessible for anyone with extra communication needs. There should be regular patient-verified audits to show providers are complying with the refreshed Accessible Information Standard.

And there should be sustained action on cost-of-living pressures, with the Government freezing NHS dental charges after the 2023 record 8.5% increase. It should also improve the Healthcare Travel Cost Scheme so people get financial reimbursement quickly, and extend the Statutory Sick Pay duration for people on long waiting lists.

#### What we've called for:

- A cross-Government national strategy should set out plans to reduce inequalities.
- Regular audits should check providers meet the Accessible Information Standard.
- There should be sustained action on cost-of-living pressures.

## **Building a patient-centred NHS culture**

As we argue in this report, patients should be right at the heart of care. This is a cornerstone of our vision for the NHS. We want to see a fundamental culture shift, starting with the Government launching a major public conversation about the NHS's future.

The system should join up sources of patient feedback, and treat patient experience as an indicator of quality on a par with safety, clinical effectiveness, and efficiency. We want to see trust in individual healthcare professionals grow, and fast escalation of the most serious patient concerns to the right bodies.

#### What that will look like

The Government and the public should agree a new Patient Promise that sets out principles, rights, mutual responsibilities, and culture, replacing the current NHS Constitution.

The Promise should affirm existing key principles, like the NHS remaining free at the point of access. But it should also set new standards and rights when it comes to waiting times, experience, and the handling of complaints.

The NHS should ensure providers are clear on how they 'live the Promise' to patients, and run a national campaign to raise awareness of patient rights.

NHS bodies should provide consistent information to the public about how they can raise concerns, complaints or safety concerns. Services should collect more data on who is reporting poor care, and follow new standards on complaints handling, reporting and learning.

Finally, the patient voice should be stronger at every level. Commissioners should track patient experience as a matter of course, and use it as a key measure of improvements, alongside other indicators like waiting times.

And with protected and increased funding, Healthwatch will be able to increase engagement with the public, champion their views, and shape future delivery of services.

#### What we've called for:

- The Government and public should agree a new Patient Promise.
- People should get quicker and more effective and empathetic responses when they raise concerns or complaints.
- Patient experience should be a key measure of improvements.

## **Moving forward**

Our vision for an NHS that gives patients more power is bold but achievable. The development of an NHS tenyear plan represents a real opportunity to transform services and deliver care that better meets people's needs.

Using the public's experiences, we have made recommendations on what the plan should include. This includes steps to:

- Deliver two-way communication for patients with services and end poor NHS administration.
- Measure care performance by people's overall experiences and outcomes to ensure a safe transition between services and prevent patients from becoming lost in the system.
- Tackle the unequal access to care that leads to lower health outcomes for some communities.
- Reform social care alongside a plan to improve the NHS, as one service cannot work without the other.

Delivering the new NHS plan will require work from all quarters, not least the Healthwatch network.

We know that, with changes to how we work, we can do even more to help NHS and social care services better meet the needs of local communities. In the next section, we outline our challenges and potential solutions to enable us to do more.

# Building a Healthwatch fit for the future

Healthwatch was created with a simple, powerful purpose: to ensure people's feedback shapes their health and care services.

Our role is unique. We cover every health and care service and every community. And as an independent statutory body, we work effectively with the Government, NHS and third sector to ensure they hear patients' voices and act based on their needs.

That's how, over the past decade, we have informed improvements to care, shone a spotlight on people's concerns, and laid out a path forward where change is still needed. Our work is key to creating a health and social care system that truly understands and centres the needs of those using it.

In their 2024 election manifesto, Labour outlined their plans for an NHS fit for the future, including reducing health inequalities and putting more power in the hands of patients. Healthwatch, from our position on the ground in every community, can help make those plans a reality.

But we face major challenges. Rising demand along with a real-terms reduction in our funding makes it

increasingly hard for us to carry out our work, and puts our long-term sustainability at risk.

So if we're to help with the ambitious work ahead, we need a Healthwatch fit for the future too.

#### Where we are

As stories throughout this report show, the network of 153 local Healthwatch is crucial in discovering and addressing the issues local people have with their health and care. Their work can involve advocating for the right care for individuals, all the way up to bringing about region-wide change.

And yet the funding local Healthwatch receives has fallen from £33.2m in 2013-14 to £25.5m in 2023-24. That means in real terms, budgets have plummeted to just 43% of 2013-14 levels.

Funding issues threaten some local Healthwatch more than others. Our current model has local authorities commission Healthwatch services, leading to huge discrepancies in resourcing. This impacts the scale and quality of service each Healthwatch can provide.

The health and social care system has also changed in the decade since Healthwatch's establishment. The introduction of Integrated Care Systems means local Healthwatch now need to operate at a system level, as well as within local communities.

NHS England has recognised the need for more funding to fulfil this expanded role, and some ICSs have provided this to the Healthwatch in their region. But this must be consistent across England.

Finally, we know that more people could benefit from our support. Collectively, the Healthwatch network supports over a million people every year in sharing their experiences of care or accessing the advice they need. Their insight helps bring about real change. But many more voices go unheard. Local Healthwatch do excellent work with the resources they have. But many can't keep up with the needs of their communities without these problems being addressed. For some, funding issues threaten their ability to remain viable at all.

On the other hand, if every Healthwatch has the resources to work to its full potential, there is far more we can do to build the patient-centred health and social care system people need. Reinvestment would ensure each area, including Integrated Care Systems, has an effective public champion.

If every Healthwatch could reach more people, and had the strong leadership essential to holding health and care providers accountable, what difference might we make?

#### Where we could be

It's clear that there must be reform to the way we're funded and commissioned. Not only would this address the challenges we're facing, it would benefit patients and the health and care system alike, at national, regional and local levels.

We believe the most effective path forward would be for new legislation to make Healthwatch England the commissioner of local Healthwatch, with local authorities playing a pivotal role.

This would better protect local Healthwatch funding, and allow the Government to better track their return on investment. Rather than funding being pooled in larger local authority budgets, and subject to cuts, it would flow transparently from one commissioner straight to the local Healthwatch services it's intended for.

With one commissioning body, local Healthwatch would have greater consistency, quality and impact, while saving money on administration. We would be able to pool back office functions, bulk buying services where possible, and standardise systems across the network. This would leave local Healthwatch staff able to focus on doing what they do best: serving their communities.

Where the current local Healthwatch structure doesn't mirror Integrated Care Systems, an updated model would have the ICS system in mind. This would give every ICS an effective partner that can inform their decisions and hold them to account.

And our proposal would enable national infrastructure and real-time data sharing, ensuring we caught every valuable insight local Healthwatch has to offer.

The proposed model would keep the benefit of localism that the existing model has. But it would also unlock new benefits, and allow Healthwatch to do far more.

#### What's next?

We have a new Government for the first time since Healthwatch was established, with an ambition to reform the NHS to give more power to patients. There have been announcements of a new ten-year health plan, elective care reform, and a commission into social care reform.

There is no better time to look at Healthwatch's role, and ensure we are in the best possible position to support

the work ahead. The Government has already taken on board our recommendation to review Healthwatch England and local Healthwatch.

This provides an opportunity to make changes that will enable us to do even more. Whatever the review's outcome, we will continue to do all we can to ensure that the people's views and experiences help drive better health and social care.

#### **Our resources**

## The funding 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 2023–24, we spent 100% of our budget, with a small overspend of £13,741. Our total spend was £3,376,973, comprising £2,236,303 spent on pay, £940,594 on non-pay, and £200,076 on internal recharges.

### Our income and expenditure

Income		Expenditure	
Annual grant from Government	£3,299,760	Expenditure on pay	£2,236,303
Additional income	£63,472	Non-pay expenditure	£940,594
		Office and management fee	£200,076

#### **Our people**

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

#### **Nationally**

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

#### **Locally across 153 services**

578 full-time equivalent staff deliver the Healthwatch service for local communities – an average of 3.8 per local Healthwatch.

3,844 volunteers kindly give up their time to understand local people's views, provide advice and help improve services.

## **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

Belinda Black

Pav Akhtar (Stood down October 2024)

Professor Sul Mahmud

Helen Parker (Stood down December 2024)

Umar Zamman (Stood down September 2024)

Jane Laughton

Debbie Bartlett (Appointed October 2024)

## A big thank you

We're grateful to everyone who continues to support our work to improve health and social care. Thank you to:

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.

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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