

# The public's perspective

The state of health  
and social care

November 2023







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# Introduction



**Louise Ansari,**  
Chief Executive

## The aim of this report

**How do we judge the current state of the health and care system? Is it through the headlines describing record waiting times? The NHS data on the hours people spend waiting in A&E?**

Performance numbers and the media highlight the issues the NHS faces. But while this information is essential, it only tells part of the story. We believe that to truly understand the state of health and care, we must listen to the people using it.

We've drawn on feedback from over 65,000 people who told us their experiences of health and social care services from October 2022 to September 2023, as well as external data. This report stands back from the headlines, and looks at care from the public's perspective.

## The issues we explore

**We've focused on ten key areas.**

These include parts of health and care that people talk about most: GPs, dentists, hospitals, and social care. We've covered experiences of getting help for cancer and mental ill health. Finally, we've looked at broader changes – developments in technology and the cost of living crisis, and the impact these have on those using services.

In each chapter, we've shared a snapshot of the positives and negatives, particularly highlighting the experiences of those facing substantial inequalities. And we've outlined the steps health and social care decision-makers must take to create a better experience for everyone.

## What we've found

**While we hear stories about excellent NHS support, accessing this support in the first place remains the biggest challenge people face.**

Stories about barriers and delays to timely care in every part of the system paint a bleak picture. Many can't see a GP quickly, the gateway to the rest of the NHS. It's getting harder to find NHS dental care, forcing people to go private. Rising demand means delays to potentially life-saving treatment, with long waits for mental health support and cancer care.

Many of those waiting for planned medical procedures aren't getting the support they need while they wait. Lack of support also impacts those using social care services, as they and their carers try to navigate a complex system.

These pressures across health and care services affect some more than others. In deprived areas, people already face challenges accessing care, and have poorer health outcomes. But more and more, we're seeing a two-tier system emerge, where healthcare is accessible only to those who can afford it.

Rising financial pressures keep people from seeking needed care because they can't afford associated costs, such as travel and prescription medication. One in five people on means-tested benefits said they'd avoided booking an NHS appointment for this reason, according to our cost of living polling.

And in polling we conducted for this report, we found more financially comfortable people were much more likely to be able to access free or discounted private GP appointments through their work than those who were less financially comfortable<sup>1</sup>.

And concerningly, one in seven people were advised to consider paying for a private health service by NHS professionals.

## What needs to change

We want to see a health and care system that works for everyone. The recommendations we make in this report focus on five key questions.

### Do we understand people's experiences?

NHS and social care teams are taking action to improve services. But waiting list data, annual surveys and other statistics only tell us so much about whether these changes are working. From national plans to daily interactions, services must work with people to understand and improve experiences and confidence.

### Can people access the services they need?

Too often, the biggest issue is accessing care itself. People need more choice and control. We need faster progress with national recovery plans, and a greater focus on ending inconsistent experiences across different areas and demographics.

### Why do some people face inequalities?

Health leaders have recognised growing health inequalities. But there is a long way to go before we fully address why some people face more barriers than others. We must involve communities in designing better services to tackle these disparities.

### What can be done to improve communications?

Poor communication lies at the heart of many stories we hear and affects people's confidence in services. By fast-tracking investment in administration and technology, the NHS and social care can reduce preventable errors, keep people informed about their care, and improve access to quality services.

### How can we create a better listening culture in health and social care?

People still experience staff or services that don't listen to their concerns. This can lead to tragic consequences. The health and social care system must create a better listening culture that sees feedback and public involvement across all levels of decision-making as key to preventing harm and improving care and safety.

Our full recommendations article contains more details on our calls for NHS and social care decision-makers to improve services, based on feedback from the people who use them.



respondents to our poll reported that an NHS professional has advised them to consider paying for a private health service<sup>2</sup>.



# 01

## Getting a GP appointment

GPs are the gateway to the NHS. But many people can't access the care they need, especially in the most deprived areas.

“

**“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 morning.”**

– Story shared with Healthwatch England

**In 2022, there were an estimated 319,800,000 NHS GP appointments<sup>3</sup>. Over the last year, we've heard how positive visiting the GP can be – especially when it comes to quality of care.**

We've heard from patients who felt listened to, whose practices worked to meet their needs. Other research backs up this feedback. Although satisfaction has fallen in recent years, the latest GP Patient Survey found that 71%<sup>4</sup> of patients reported a good overall experience at their practice.

But people can only get high-quality care if they get through the door in the first place. And difficulty accessing GP appointments was one of the most common issues shared last year.

We heard about long waits in phone queues to book appointments. We heard the struggles people had navigating online GP access tools. We heard about individual barriers people faced, and how they found it hard to get appointments that suited them.

And, after struggling to access help in the past, some people shared that they no longer try to book appointments at all.

Research by others showed that in 2023, people's experience of booking an appointment got worse<sup>5</sup>. They found it harder to contact their GP surgery by phone<sup>6</sup>. And when asked for their top priorities for the NHS<sup>7</sup>, making it easier to get GP appointments was second only to increasing the overall number of NHS staff.

The Department of Health and NHS England have acted in response to the challenges patients have raised. The **Delivery plan for recovering access to primary care**<sup>8</sup> aims to end the '8am rush', when patients phone to ask for a GP appointment.

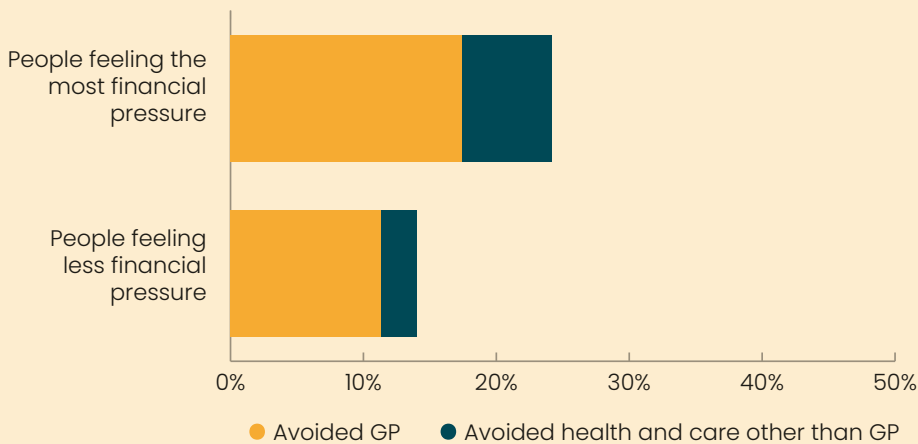
Though we've yet to see these changes reflected in patient feedback, the plan involves rolling out digital tools<sup>9</sup> to make booking appointments more flexible, and telephone systems that cut phone queues. It also funds surgeries to train receptionists as 'care navigators' who can answer queries immediately or signpost patients to appropriate services.

## Across society: Access and deprivation

Too many patients can't get appointments that work for them. According to the latest GPPS data, 2023 saw a slight increase in people offered choices about times and locations. But 41% were offered no choices about their appointment at all<sup>10</sup>.

People experiencing financial pressure and those living in more deprived areas may have the most to gain from increased flexibility and choice around GP appointments.

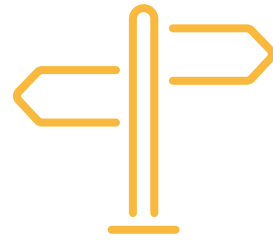
In our cost of living research<sup>11</sup>, those feeling the most financial pressure were more likely<sup>12</sup> to avoid getting healthcare because of associated costs. That included travel, phone and internet costs.



People in more deprived areas face barriers including:

- **Caring responsibilities:** The 2021 census<sup>13</sup> shows areas of higher deprivation have a bigger proportion of people providing unpaid care, and providing care for more hours each week.
- **Pressure on GP services:** According to the Office for National Statistics (ONS) data, GP practices in the most deprived areas have around 300 more patients per fully qualified doctor<sup>14</sup> compared to the least deprived areas.

Unsurprisingly, we found<sup>15</sup> just 22% of people describing themselves as financially uncomfortable were likely to feel confident they could access a daytime GP appointment<sup>16</sup>, compared to 31% of people who were financially comfortable.



# 41%

of people were offered no choices about their appointment at all<sup>10</sup>.

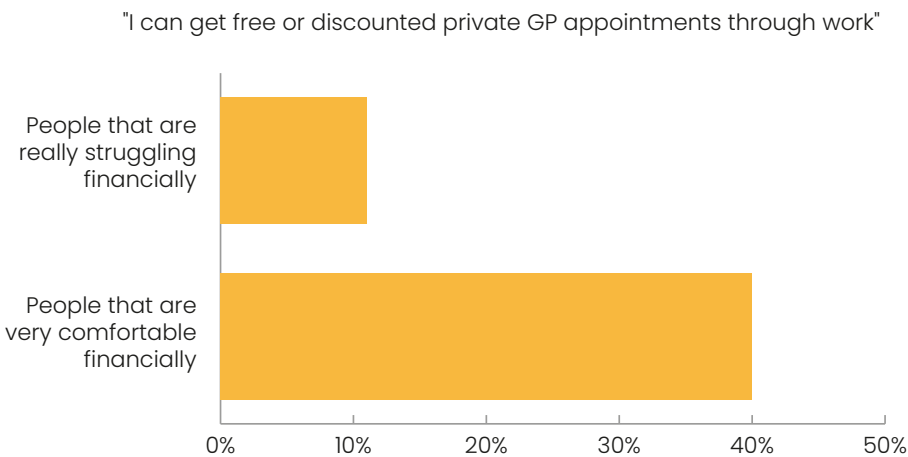


GP practices in the most deprived areas have around

# 300

more patients per fully qualified doctor compared to least deprived areas<sup>14</sup>.

People in better financial positions are more likely to get free or discounted private GP appointments through their work<sup>17</sup>.



Primary care professionals in the most deprived areas are teaming up to address these challenges and help patients affected by deprivation. But the experiences people share with us are yet to reflect these initiatives.



## Our calls for change

People want to have a choice of appointment type, time, and healthcare professional the first time they contact surgeries, with access to care navigators who can answer their queries.

So we must see wholehearted action taken to implement the NHS primary care recovery plan. All patients must benefit from the promised commitments – particularly carers and people living in more deprived areas.

### We want to see:

- 1 All GP surgeries move to digital phone systems by the end of March 2024, so patients spend less time waiting on hold.
- 2 Greater public awareness of, and sign-ups to, the NHS app, through the promised national communications campaign.
- 3 Most patients able to benefit from full NHS app functionalities by the end of March 2024.
- 4 Evidence that Integrated Care Boards plan to tackle health inequalities around GP access, especially in deprived areas.
- 5 All GP practices offering free phone numbers.
- 6 All GP practices sign up for the Register with a GP Surgery Service, which makes registering with a surgery easier for patients, particularly those with no fixed address or ID.



Just

**22%**

**of people describing themselves as financially uncomfortable were likely to feel confident they could access a daytime GP appointment<sup>16</sup>**



### On the ground

Out of 37,957 local participants in a North East London Healthwatch survey<sup>18</sup> on better GP access, 64% wanted to travel under 30 minutes to GP appointments. Evenings were the most popular appointment time.

Being able to see a GP quickly was a higher priority than seeing a specific GP, though older people and disabled people valued consistency more highly.

# 02

## Getting dental treatment

It's getting harder to find affordable, accessible dental treatment, with serious consequences to health and wellbeing.

“

**“I am a nervous patient but they talked me through what they were doing and kept checking I was okay. I no longer have anxiety at going to the dentist.”**

— Story shared with Healthwatch England



**The NHS delivered 32.5 million courses of dental treatment in 2022-23<sup>19</sup>. And this year, people told us about the kind and respectful care they'd received from dentists and dental nurses.**

They shared stories of staff who helped them feel less anxious, and the positive impact of good dental care.

Recent national survey results reflect those experiences – 70% of people<sup>20</sup> rated their experience of NHS dentistry as very good or fairly good.

But this is much lower than the 84%<sup>21</sup> who reported a positive experience in March 2020. Complaints about access exploded during the pandemic, and this remains one of the most common issues people share.

People can't find local NHS dentists. They face long waiting lists, or have to travel long distances. Dentists have closed, gone fully private, or removed people who didn't attend in recent years as regular patients – even when pandemic restrictions meant this was beyond their control.

Those who couldn't get emergency help have faced serious consequences, including septicaemia. People shared stories about being unable to eat, or feeling ashamed of their teeth. Some even resorted to self-treatment.

**“As adults we are able to use pliers to extract our own teeth but I feel that this shouldn't be something that our children should have to endure.”**

— Story shared with Healthwatch Torbay



The GP Patient Survey reflects these issues. 75% of patients were able to get an NHS dental appointment<sup>22</sup> – much lower than pre-COVID levels (94%). People trying to get an appointment at a new practice found it harder, as did young adults and people from ethnic minority backgrounds<sup>23</sup>.

In spring 2023, we shared experiences like these with a parliamentary inquiry into NHS dentistry, which challenged the government to make fundamental changes to improve care<sup>24</sup>.

### Two-tier access

More and more, we’re seeing a two-tier dental system<sup>25</sup>, where those who can’t afford it can’t get the treatment they need.

The most common reason people told us they had used private care in the past 12 months was that they could not find an NHS dentist<sup>26</sup>. 69% of people who accessed private dental care in the last 12 months had no dental insurance<sup>27</sup>. Many are unable to afford private care, but feel they have no other options.

Others are unable to afford even NHS dental care. Yet NHS dental charges increased by 8.5% in April 2023<sup>28</sup>, a much higher increase than for NHS prescriptions.

Our cost of living research<sup>29</sup> showed people struggling financially or who received benefits were more likely to avoid going to the dentist.

And our recent polling data<sup>30</sup> showed just 22% of those struggling financially were confident they could access timely NHS dental services, compared to 38% of those who were financially comfortable.



22%

**of those struggling financially were confident they could access timely NHS dental services compared to 38% of those who were financially comfortable<sup>30</sup>.**



**“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



**NHS dental charges increased by**

8.5%

**in April 2023<sup>28</sup>**

## Across society: Community dental services

Community dental services are a vital safety net, providing specialised NHS dental care for certain children. They also provide specialist treatment when other dentists can't accommodate the needs of disabled people, autistic people, and people with long-term health conditions<sup>31</sup>.

Timely prevention and treatment are essential for these groups. Autistic people<sup>32</sup> and people with learning disabilities<sup>33</sup> may find it harder to maintain good oral health, and between 2021-22<sup>34</sup>, nearly a quarter of children aged five had experienced tooth decay.

People who could get access shared the positive impact of appropriate care.

**"I did see a dentist recently ... They were so accepting. They were aware of all my health conditions and made accommodations, [they] spoke through my carer whilst still always letting me know what was happening next, and reassured me that I was doing well. This helped a lot in making the appointment less stressful for me, and now I'm not as scared to go back!"**

— Story shared with Healthwatch England

But long waiting times are impacting community dental services too<sup>35</sup>.

Wider research<sup>36</sup> found over 12,000 young people under 18 were on waiting lists for community dental services at the start of 2023. Children could face waits of up to 80 weeks for tooth extractions. Across 2022, the difference in the proportion of children with dental decay<sup>37</sup> in the least deprived (13.5%) and most deprived areas (35.1%) grew compared to 2021.

Over the past year, we've heard from people and their carers whose dentist couldn't accommodate their needs, and who've struggled to access community dentistry – leaving them without treatment.

**"My son is seen by the specialist dental service because of his profound and multiple needs. We were late for his appointment in January, having driven through a blizzard to attend ... I was assured that he would receive another appointment. Close on six months later we are still waiting for that appointment."**

— Story shared with Healthwatch England

Over

**12,000**

**people under 18 were on waiting lists for community dental services at the start of 2023<sup>36</sup>.**

**Children could face waits of up to**

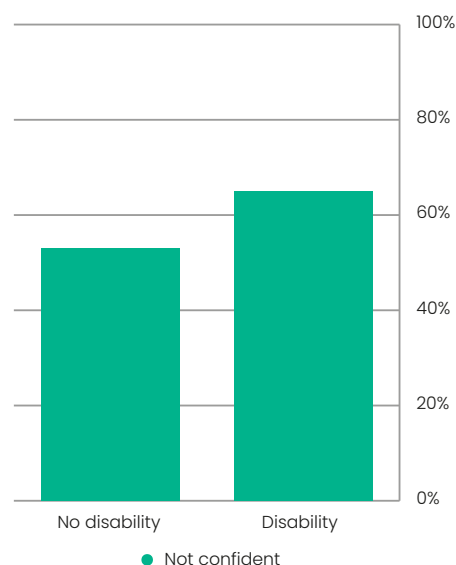
**80 weeks**

**for tooth extractions<sup>37</sup>.**

Our polling<sup>38</sup> found disabled people and those with long-term health conditions were less likely to feel confident they could access timely care from an NHS dental service.

And those with a disability or long-term health condition were more likely to avoid going to the dentist because of the cost of check-ups or treatment<sup>39</sup>.

### Those lacking confidence they can get timely care from an NHS dental service



### Our calls for change

People want access to affordable, high-quality dental care.

At the time of writing, the government is promising to publish an NHS dental care recovery plan soon, but with no extra funding likely.

### The plan must:

- 1** Set out a clear vision for improving patient access to a local NHS dentist that provides preventative and emergency care.
- 2** Incentivise dentists to provide more NHS work, through major changes to the contract introduced in 2006.
- 3** Conduct a national assessment of the needs and gaps in oral healthcare for diverse populations.
- 4** Ensure Integrated Care Boards listen to local communities, include dental representatives in their decision-making, and use all opportunities to join up dental care with other local NHS and public health services.
- 5** Mandate collection of specific data to track the access and experience of people facing the worst barriers to care.



### On the ground

In 2022, Healthwatch Birmingham and Healthwatch Solihull released research<sup>40</sup> into people’s experiences of dental services across the area.

Since then, NHS England have taken steps to make change, including:

- Providing more space across seven practices for people to book weekend appointments.
- Funding a campaign promoting good oral health.
- Establishing an Oral Health Network.
- Funding the distribution of toothbrushing packs at food banks.
- Launching schemes to improve access for homeless people, refugees, and migrants.
- Offering additional emergency access within 24 hours of a 111 referral through ten providers.



# 03

## Getting mental health support

Mounting pressure on the system means people face longer waits for mental health support, and risk becoming more unwell.

# 69

**“Primary care told me I’m too complex for them and secondary care said I’m not complex enough, so I get zero help!”**

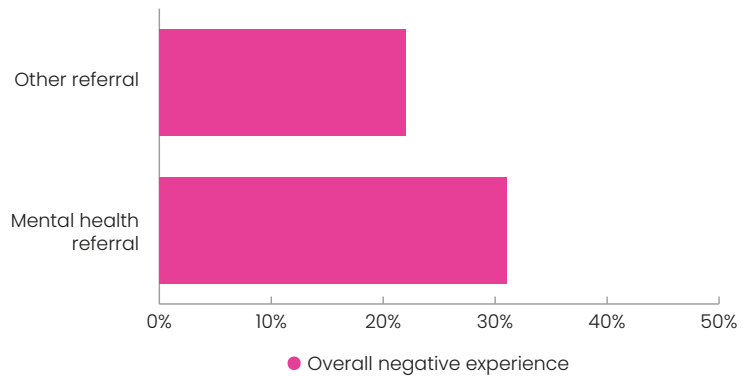
– Story shared with Healthwatch England



**Each year, around one in four people in England experiences some kind of mental health issue<sup>41</sup>. Last year, we heard how patient, kind, respectful staff made people seeking mental health support feel understood.**

But timely, appropriate support was not accessible for everybody.

People shared their frustrations at getting only short-term help. There were issues with referrals, including people being referred multiple times without success. When we looked at people’s experiences of GP referrals<sup>42</sup>, people trying to get a mental health appointment were more likely to report a worse experience.<sup>43</sup>



Even once referred, many faced long wait times – sometimes over a year.

In August 2023, 1,394,537 people<sup>44</sup> were waiting to hear back after a referral to community-based mental health or learning disability services.

Other research shows almost three in four<sup>45</sup> adult patients are waiting over four weeks to start community mental health care.

People’s mental health can worsen as they wait<sup>46</sup>, impacting relationships, finances, and work. And when they can’t get timely help, they turn to other parts of the system, including urgent and emergency care<sup>47</sup>.

The NHS has pledged to publish more mental health waiting times data, and encourage more services to track people’s experiences of care. We hope the government’s Major Conditions Strategy<sup>48</sup>, due in 2024, will do more to tackle the issues people have raised with us.

## Across society: Support for young people and neurodiversity

### Support for young people

Child and adolescent mental health services (CAMHS) support young people with a wide range of emotional, behavioural, and psychiatric conditions. Demand for their help rose by 53% between 2019–22<sup>49</sup>.

And we’ve heard from young people and their parents, guardians, and carers about difficulties getting support – including people who felt they had no option but to use private services.

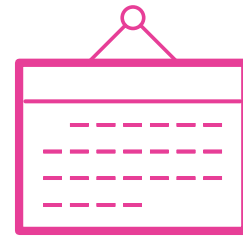
In recent polling we carried out, almost two in five young people reported that an NHS professional had advised them to consider paying for a private health service in the last year<sup>50</sup> compared to fewer than one in ten people aged 50+.

Without timely support, poor mental health can affect relationships, education performance<sup>51, 52</sup> and outcomes later in life, including employment<sup>53</sup>.

We support the call by a coalition of mental health charities for all pupils to have access to in-school mental health support, to ensure they can get timely help<sup>54</sup>.

This help is especially important for certain groups who are more likely to struggle with mental health difficulties. High risk groups include young people who<sup>55, 56</sup>:

- Are LGBTQ+
- Are autistic
- Have a learning disability
- Have caring responsibilities
- Are refugees or asylum seekers
- Have experienced food poverty



Almost

# 3 in 4

adult patients are waiting over four weeks to start community mental health care.<sup>45</sup>

# 69

**“Post diagnosis, my 17-year-old got no support. She was just discharged from CAMHS. She has severe social anxiety and had to leave sixth form due to stress and lack of support.”**

– Story shared with Healthwatch England

When it comes to getting support, Black and mixed ethnicity children may find getting help harder. Data indicates that they are less likely to access CAMHS, but more likely to be detained under the Mental Health Act. In adulthood, Black men are more likely<sup>57</sup> to present with major psychiatric conditions, be at risk of suicide, or suffer PTSD.

It's essential that the government moves forward with draft legislation that aims to tackle racial disparities in mental health care.

## Neurodiversity

A timely diagnosis for conditions like autism helps people get appropriate support, and reasonable adjustments that ensure continued access to healthcare, education, and employment.

But people with suspected autism and other conditions like attention deficit hyperactive disorder (ADHD) face long waiting times. Delayed assessment and diagnosis in turn delays much-needed support.

In our GP referrals research<sup>58</sup>, neurodivergent people were more likely<sup>59</sup> to seek a referral for a mental health issue. 51% of neurodivergent people reported a negative experience of getting a referral, compared to 34% of neurotypical people<sup>60</sup>. They faced communication barriers, like struggling to speak on the phone, and left GP appointments feeling their concerns weren't heard.

We've also heard how autistic people can struggle to access mental health support that suits their needs<sup>61</sup>.

**“When I raised a concern about struggling with the appointment because nothing was being explained and I was expected to conform, I was discharged because of my social anxiety! I'm autistic with severe depression and anxiety, so the very things I need treatment for are the reason I was discharged without treatment.”**

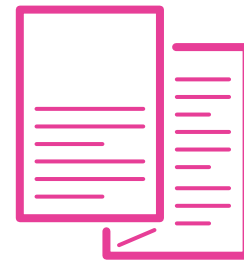
— Story shared with Healthwatch England



69

**“I have only just, after nearly three years, had a diagnosis for my son of ADHD and autism.”**

— Story shared with Healthwatch North Tyneside



51%

**of neurodivergent people reported a negative experience of getting a referral, compared to 34% of neurotypical people<sup>60</sup>.**





## Our calls for change

People want to access mental health services quickly to get the personalised support they need, and prevent further problems.

But mental health services face stark challenges, including a workforce shortfall of 17,000 nurses by 2036–37<sup>62</sup>. It could be many years before extra nurses and doctors promised by the NHS Long Term Workforce Plan are trained or recruited.

### We're calling for:

- 1** Provision of early or ongoing support through additional staff roles at every available opportunity. This includes through mental health practitioners, peer support workers, and school-based teams.
- 2** A parity of esteem definition that puts mental and physical health services on equal footing. The government must publish this as soon as possible.
- 3** The Major Conditions Strategy to include a roadmap that:
  - Reduces mental health waiting times for assessments, treatment, and crisis support.
  - Improves transitions from child to adult mental health services, based on need, not just age.
- 4** The Draft Mental Health Bill to be amended and pushed through without delay. The bill aims to ensure patients get more say over their treatment, improve access to advocates, and place a duty on doctors to consider patients' wishes before deciding on compulsory treatment. It also aims to reduce the disproportionate number of Black people who are sectioned.
- 5** Bespoke training for NHS staff, to equip them to better understand the needs of young people with learning disabilities and autism.



## On the ground

Healthwatch Cornwall spoke to 281 residents about local mental health and suicide support<sup>63</sup>. People valued the statutory support services offered. Practical activities, including exercise and art therapy, were particularly helpful. Community organisations also provide vital support.

But residents wanted more focus on what causes mental health issues, highlighting the need for targeted support for those struggling with gambling or at risk of self-harm, and for veterans. And people wanted more joined-up care, noting the difficulty of having to repeatedly share traumatic experiences with different health professionals.

# 04

## Cancer care

Delays at every stage of the cancer journey take an emotional as well as physical toll.

“

**“The breast clinic staff are amazing in all departments. Gentle and reassuring. They take their time and explain everything, then phone two days later.”**

– Story shared with Healthwatch Norfolk



**One in two<sup>64</sup> people will develop cancer during their lifetime in the UK. In a recent national survey<sup>65</sup>, on average, NHS cancer patients rated their care close to nine out of ten.**

And over the last year, we've heard from people with cancer or suspected cancer who got treatment or diagnostic tests quickly. They shared the support they received, and the positive impact this had.

But patients struggled to access primary care. Trouble getting face-to-face GP appointments left them feeling unsupported. People having cancer treatment that affects their teeth found it difficult to get dental care.

Others shared poor experiences of emergency care, including people on chemotherapy not getting the antibiotics they need quickly enough after being hospitalised.

And we've also heard about the lack of bereavement support for people who've lost someone to cancer.

**“I had a lumpectomy and radiotherapy. The aftercare has been non-existent. I have been very low and unable to have a face-to-face with a doctor.”**

– Story shared with Healthwatch England

## The impact of waiting

People may face long waits at different stages of their cancer journey. This can have an emotional toll.

We’ve heard from people who had urgent referrals for diagnostic tests, only for the test not to go ahead in the specified time frame. Others had their test when expected, but faced a long wait for results.

For some, the wait came later. They spoke positively about the speed of diagnosis, but faced delays getting treatment.

**“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

Our work this year<sup>66</sup> drew attention to the hidden waiting list behind referrals, particularly for suspected cancer.

We heard from people who had faced delays in getting a referral, including those who were only referred after visiting their GP multiple times. They felt their concerns weren’t taken seriously.

People facing delays told us about seeking alternative routes into the health system, including visiting A&E. Others felt they had no option but to access private services.

### Across society: Where are you from?

The NHS tracks performance at an Integrated Care Board<sup>67</sup> (ICB) level against key waiting time targets<sup>68</sup>.

NHS data<sup>69</sup> from the last year shows a wide range in the performance of ICBs against different standards.

In the worst performing area, 44% of appointments, diagnoses, or treatment start dates happened later than they should, compared to just 15% in the best performing area<sup>70</sup>.

Data shows people living in more deprived areas are more likely<sup>71</sup> to get cancer. This means regional disparities may disproportionately affect those living in deprived parts of the worst performing ICBs.

The two-week wait target showed the largest regional variability, particularly for those referred for suspected breast cancer. In June 2023<sup>72</sup>, the best performing ICB met the target for over 99% of suspected breast cancer patients. The worst met the target for just 13%.



**“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



**In the worst performing area,**

**44%**

**of appointments, diagnoses, or treatment start dates happened later than they should, compared to just 15% in the best performing area<sup>70</sup>.**





## Our calls for change

No matter where they live, patients want to have the same quick access to cancer diagnosis and treatment.

But people still contact us about poor experiences of cancer care – from referral through to aftercare.

### We're calling for:

- 1** First appointments that meet people's preferences and needs, including longer appointments where necessary.
- 2** Improvements to online referral trackers, so those waiting know what is happening with their care.
- 3** Personalised aftercare support, including post-treatment plans, appropriate home adaptations, and a single point of contact with care teams.



## On the ground

Smears Means Years is a community-led initiative that Bolton GP Federation runs with support from Healthwatch Bolton and Answer Cancer.

It provides an informal space to learn about cervical screening through community-based drop-in screening clinics. It also promotes cervical screening in communities with low screening rates. They offer language support in Urdu and Gujarati.

Healthwatch Bolton published a report<sup>73</sup> that showed 75 women had had cervical smears through the programme. Many were overdue or had never had a screening.

In 2024, we'll make recommendations on improving cervical screening uptake and earlier diagnosis, looking at experiences of disabled women and women from ethnic minority backgrounds.

# 05

## Waiting for elective care

The waiting list for planned care is at an all-time high. But poor communication makes it harder for those waiting for treatment.

# 69

**“When I arrived on the morning of surgery, the process was very smooth and calm. The surgical team were very reassuring”**

– Story shared with Healthwatch England



**Over the last year, we've heard about excellent elective care experiences.**

People told us about consultants who helped them navigate the health and care system, including chasing referrals. Services helped create good overall experiences by keeping patients informed as they waited.

But for many, those waits are long, and make the experience harder. People told us about being removed from waiting lists, sometimes without being told why – or without being told at all.

**“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

Others had appointments continually postponed or cancelled.

By the end of September 2023, the total national waitlist reached a record 7.7 million appointments<sup>74</sup>. This includes people with multiple conditions waiting for more than one appointment.

And though the deadline for eliminating waits<sup>75</sup> over 18 months for elective care expired in April 2023, 10,201 people were still waiting beyond this in September<sup>76</sup>.

## Communication

Last year's Elective Recovery Plan accepted our recommendations<sup>77</sup> for people to get regular updates and accessible communications while they wait for appointments.

But poor communication, both between services and with patients, still negatively affects people's experiences of waiting for care.

People have told us about missing appointments because their appointment letter got delayed, or being incorrectly told their appointment had been cancelled. They've told us about getting phone numbers to check the progress of their referral – only to find they don't work or play a pre-recorded message, leaving them with no point of contact.

## Across society: Inequity in waiting

There is a longstanding link between deprivation and waiting times for treatment, tests and scans<sup>78</sup>. People in the most deprived areas are twice as likely to wait over a year compared to those in the least deprived areas.

Last year, we looked at disparities in experiences of waiting for planned care<sup>79</sup>. Those struggling financially, disabled people, and women had worse experiences. Longer waits may particularly impact those from ethnic minority backgrounds in worse financial situations.

This year, we looked at the impact of postponements or cancellations<sup>80</sup>. We found people were most likely<sup>81</sup> to experience multiple cancellations or postponements, and experience negative consequences caused by postponements if they were:

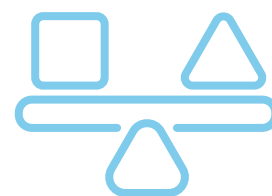
- Aged 25-34
- From ethnic minority backgrounds
- Disabled
- Neurodivergent
- Struggling financially

LGBTQ+ people were also more likely to experience postponements, and carers were more likely to experience negative consequences caused by postponements.



**“Why do I have to wait six to eight weeks for results? No one tells you. If I don't hear it's up to me to chase, which is very stressful just trying to phone.”**

– Story shared with Healthwatch Solihull



**People in the most deprived areas are**

**twice**

**as likely to wait over a year compared to those in the least deprived areas.**



## Our calls for change

People don't always mind waiting for care, but want clear timelines, and support while they wait if they need it.

The NHS aims to make sure nobody will wait over 12 months for appointments by March 2025. But long waits will remain the norm until NHS capacity can meet the demand for planned care. The experience of waiting must be as comfortable as possible.

### We're calling for:

- 1** More proactive NHS communications with patients while they wait for treatment.
- 2** 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.
- 3** More personalised support for those waiting, such as access to pain management, physiotherapy, and mental health support.
- 4** Transport and accommodation costs to be covered by the NHS where patients choose to travel for quicker treatment at another NHS setting.
- 5** Better use of all available data sources, to reduce last-minute cancellations and understand what drives non-clinical, clinical, and patient-led reasons for NHS delays.



## On the ground

Over 2,000 people across Hampshire and Isle of Wight told local Healthwatch about their experience of waiting for hospital care<sup>82</sup>.

They found waits of any length added to patients' worries, especially if they didn't know how long the wait would be. They also found that as waiting times increased, so did the detrimental effects, and the likelihood that patients would turn to other services like A&E.



# 06

## Social care

Both people who need social care and unpaid carers are struggling with long waits and a lack of support.

“

**“[The staff] all play such a fundamental role in supporting individuals [to] live, excel and enjoy their lives in a safe and respectful environment.”**

– Story shared with Healthwatch Lincolnshire



**Over the past year, we've heard about positive experiences in care homes, and the impact of good care planning – particularly around hospital visits and supporting people's health journeys.**

People shared stories about caring, compassionate staff, and highlighted the importance of person-centred care.

**“Limitless provide respite care for my daughter. ... Her care is very individual and her needs are well met.”**

– Story shared with Healthwatch England

But we've also continued to hear about the problems people face across social care<sup>83</sup>. We've heard about assessments being delayed, repeated, or not carried out when scheduled. And once people were assessed, they may have faced a further wait.

National data shows social care waiting lists at 430,000, with the level and complexity of people's needs increasing<sup>84</sup>.

In their feedback, people mentioned staff shortages or the impact of staff turnover. We also heard about lack of social workers leading to delayed hospital discharge.

The latest workforce data from Skills for Care<sup>85</sup> shows record vacancies, with 152,000 posts vacant, and staff turnover rates at 28%.

People told us about providing interim support for loved ones until they couldn't provide the level of care required. Delays in getting the right support in place affected not only those that need care but those close to them too.

Pressure elsewhere in the health and care system caused knock-on effects, including late diagnosis preventing people getting appropriate, personalised care.

We also heard how pressure to discharge people from hospital meant patients felt they were being sent home too early, without a care assessment, and without the right support in place.

### Coordinating care

The experiences people have shared with us point to the lack of joined-up working, highlighting communication issues between teams, services, and organisations.

This adds to the challenges those responsible for navigating the health and care system already face, leaving people frustrated, isolated, and unsure where to turn for help.

**“Nothing joins up, you repeat over and over what has happened ... realising you are on your own and no one cares.”**

— Story shared with Healthwatch England

We've also heard from people who have been told they're eligible for support, yet can't seem to get any. This includes being continually signposted to services that just directed them elsewhere, or turned away by people they feel should be able to help them.

**“[The local] council spend a lot of time explaining what they do not do, as opposed to how they could help.”**

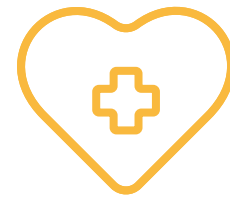
— Story shared with Healthwatch England

Estimates suggest 1.6 million people aged 65 and over currently have unmet needs<sup>86</sup>.

69

**“My [son is] trying to live independently but even with our support we need help. We contacted social services, and it has taken six months [and] four different departments to be assigned a social worker to start to look at his unsuitable housing.”**

— Story shared with Healthwatch England



**The value of labour unpaid carers provide amounts to**

**£445m**  
per day<sup>87</sup>



**1.6m**

**people aged 65 and over currently have unmet needs<sup>86</sup>.**

## Across society: Support for carers

Over five million people<sup>89</sup> provide unpaid care across England and Wales. This report highlights just some of the issues that disproportionately affect them.

Carers may struggle with:

- Physical and mental health, particularly LGBTQ+ carers<sup>90</sup>.
- Finances, especially those from ethnic minority backgrounds<sup>91</sup>.
- Social isolation and loneliness, with young carers particularly at risk during the summer when their caring responsibilities can increase<sup>92</sup>.

And family and unpaid carers bear the brunt of an overstretched system, with more carers now needing support themselves<sup>93</sup>.

We found<sup>94</sup> the cost of living crisis is disproportionately affecting carers. In our research, they were more likely<sup>95</sup> to have had to look for cheaper accommodation, buy less healthy food than usual, and reduce or cancel their phone or internet contracts.

Similarly, carers were more likely<sup>96</sup> to worry about going into debt, not being able to socialise, and not being able to travel for healthcare because of the rising cost of living.

Alongside this, carers struggle to get the support they need. Recent research found:

- Only 27% of carers that had applied for direct financial support received it<sup>97</sup>.
- 80% of carers of people with dementia are close to crisis point<sup>98</sup>.
- 61% of carers said they were uncertain about what practical support would be available to them over 2023<sup>99</sup>.
- 41% reported not taking a break from their caring role<sup>100</sup>.
- Only 10% of people surveyed on access to holiday clubs for disabled children were able to find something suitable for their child during the summer<sup>101</sup>.

Last year, people shared how voluntary and community organisations provide essential support, improving the lives of carers and those they care for.

But they also told us about the reduced availability of local support groups after COVID, poor signposting to community resources, and lack of provision.

69

**“[My son] used to be able to go to all kinds of different activities in the borough on the weekends. But everything we used to do has either been closed down or he’s not allowed because he’s not considered to be a child anymore.”**

– Story shared with Healthwatch Greenwich



Only

**27%**

**of carers that had applied for direct financial support received it<sup>97</sup>.**

**80%**

**of carers of people with dementia are close to crisis point<sup>98</sup>.**



## Our calls for change

People want easily accessible and affordable social care.

Getting the right social care support can make a huge difference for people who need help to live independently. But with workforce and funding pressures, and such a complicated system, people can't always access the care they need.

### We're calling for:

- 1** Renewed focus on implementing previously announced reforms to cap the amount people have to spend on social care costs over their lifetime.
- 2** Further reforms to boost investment in services, address workforce challenges, and support councils to provide more proactive social care information and advice services. These should cover both pre- and post-assessment.
- 3** People in health and care settings to have a legal right to a Care Supporter – a person important to them, like a relative or friend – who can visit to provide emotional support, advocacy, and essential human contact.



## On the ground

Collaborating with Citizens Advice in Eastbourne, Diversity Resource International, and Care for the Carers, Healthwatch East Sussex developed<sup>102</sup> eight case studies that highlight unpaid carers' experiences. The case studies highlight:

- The impact of caring on carers' lives.
- The lack of support from across the whole system, and how hard it is to navigate.
- The desire to see better collaborative working across agencies and services.

This report fed into the plan for implementing Sussex Health and Care's integrated care strategy.



# 07

## Hospital discharge

A lack of support during the discharge process is causing frustration, confusion, and even emergency readmissions.

“

**“When my spouse was discharged, they made sure to tell us both about what to do about the dressings and what to do if [my] spouse started bleeding again, making sure they changed the dressing just before [my spouse] left the hospital.”**

– Story shared with Healthwatch Lincolnshire



**Over the past year, people have shared what they've found positive about the process of leaving hospital.**

They've told us about staff members arranging the next steps, and feeling involved in decisions. They highlighted the importance of feeling their discharge wasn't rushed, and leaving with clear information.

But they've also told us about delayed discharge, medication shortages, issues with coordination between the hospital and social care, and the shortage of community beds.

**“[I was] Told I was being discharged if bloods were fine. All packed up, ready to leave. No one told me there was a problem. Doctors have gone home. No senior nurse to speak to.”**

– Story shared with Healthwatch Halton

Health and care data highlights the challenges:

- In June 2023, people who could have been discharged were using around one in eight general and acute beds<sup>103</sup>.
- During winter 2022–23, waiting for a care package at home remained the most common reason for delayed discharge<sup>104</sup> for those in hospital over seven days.
- Waiting for permanent care or a nursing home was the most common reason for delayed discharge for those in hospital over 21 days<sup>105</sup>.

We’ve heard about the impact of poor communication, both with patients and their loved ones. This includes family members and carers not getting prior notice of discharge, nor being involved in conversations about the support available at home.

Other research has also highlighted this issue. In the latest Adult Inpatient Survey, 25% of people<sup>106</sup> said they had little to no involvement in decisions about their discharge.

People also told us about being discharged without adequate support or a discharge assessment, which can result in emergency readmissions. Some felt their discharge was rushed.

Other people shared stories about being discharged without appropriate transport and in the middle of the night.

**“At 1.30 in the morning my wife was discharged and told she could go home. There was no patient transport, and we couldn’t get a taxi ... . It was a total stranger who overheard our conversations who was at the hospital who volunteered to give us a lift home.”**

– Story shared with Healthwatch Halton

### Across society: The impact on older patients

Last winter, there was a rise in patients staying in hospital for three or more weeks<sup>107</sup>. When admitted, older patients usually stay in hospital for longer and are more likely to experience delayed discharge<sup>108</sup>. One in six patients over 75 is readmitted within 30 days of discharge<sup>109</sup>.

**“They still discharged me, not listening that I wasn’t well enough and lived alone with no help.”**

– Story shared with Healthwatch England

In our own data, we have heard about the impact of social isolation<sup>110</sup>, and the assumption that people will have support networks that can provide care when required. This led to people being discharged without adequate support.

**“I have no relatives available to help with transport. I am worried about getting to and from a Liverpool hospital as I have been informed I cannot use my own car.”**

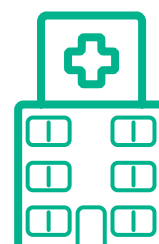
– Story shared with Healthwatch England

An increasing number of people in mid to later life live alone, without social and familial support structures around them<sup>111</sup>. Around 17% of older people<sup>112</sup> are estimated to have contact with family, friends, or a neighbour less than once a week.



**“We were just left to cope and called an ambulance the next day. We felt like the hospital needed the beds free.”**

– Story shared with Healthwatch Warwickshire



# 25%

**of people<sup>106</sup> said they had little to no involvement in decisions about their discharge.**

# 1 in 6

**patients over the age of 75 is readmitted within 30 days of discharge<sup>109</sup>.**



## Our calls for change

Patients need a holistic approach to improving their discharge.

The Department of Health and Social Care is due to update its guidance on hospital discharge, which we hope will address some of the issues people have told us.

### We're calling for:

- 1** An urgent focus on workforce and capacity solutions in secondary care and social care.
- 2** More consistent implementation of latest hospital discharge guidance<sup>15</sup>, including:
  - Support to help people make informed choices, by providing contact information and advice, and asking about transport home.
  - Better signposting to support services, such as voluntary organisations and services that support unpaid carers.
  - Clear responsibility for who will arrange people's transport home, with dedicated staff to make travel arrangements.
  - Single points of contact for people to use if their condition gets worse.
  - Greater involvement of family and carers in decisions about discharge.



## On the ground

Homeless people in Leicestershire shared their stories with local Healthwatch about their experience of hospital admissions and discharge<sup>16</sup>.

They found high levels of staff commitment and good examples of collaboration between services. However, most people did not leave hospital with a clear plan, and ongoing support with mental health was a particular problem.



# 08

## Health and care in a changing world

The cost of living, a shift to digital technology and the need for accessible information have continued to impact people's experience of the healthcare system in 2023.

# “

**“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



### Cost of living

**In our research into how the cost of living is affecting people's health choices<sup>117</sup>:**

- 15% of respondents said they'd avoided going to the dentist because of the cost of check-ups or treatment.
- 7% avoided buying over-the-counter medication they normally rely on.
- 5% avoided getting an NHS prescription because of the cost.
- 6% had avoided booking an NHS appointment because they couldn't afford the associated costs.

Over the last year, we've continued to hear about the health impact of the rising cost of living. Costs can be a direct barrier to accessing health and care, particularly dentistry and eye care.

**“My GP advised me to go to the opticians ... . I haven't done this as there's no way I could afford glasses.”**

— Story shared with Healthwatch Hertfordshire

Costs indirectly affect access too, such as through travel costs and phone or internet bills. People have also told us costs have kept them from activities that help manage health conditions, such as swimming.

Our research<sup>118</sup> has highlighted the relationship between rising costs and the exacerbation of health inequalities.

- People on disability benefits are over twice as likely to have avoided their usual over-the-counter medication.



- One in five people on means-tested benefits have avoided booking an NHS appointment due to associated costs.
- People aged 18 to 24 are twice as likely to have avoided an NHS appointment due to travel costs.

Those in employment or with more financial resources appear to be less impacted. 40% of people in work that describe themselves as financially 'very comfortable' can access free or discounted private GP appointments through work – significantly<sup>119</sup> more than those describing themselves as 'really struggling' (11%).

And people in better financial positions are more likely to have access to gyms, exercise equipment or exercise classes through work, helping them live healthier lives<sup>120</sup>.

Polling by The Health Foundation supports our findings<sup>121</sup>. It found 57% of people think rising costs are a threat to health. Being unable to afford healthy food or to heat their home can directly affect people's health<sup>122</sup>. Lack of financial security can also have a substantial effect on mental health, particularly when this leads to homelessness<sup>123</sup>.



## Our calls for change

We want action to help ensure those who are most financially disadvantaged get the care they need.

The cost of living crisis continues to affect people's access and care, as well as the things that help them live healthy lives.

### We're calling for:

- 1** Over-the-counter medications to be offered on prescription for patients eligible for free prescriptions, and for those struggling financially who pre-pay for prescriptions.
- 2** Clearer information about annual and pre-pay prescription options.
- 3** NHS England to restart their review of the health travel costs scheme, and introduce a reimbursement scheme that covers travel to primary care appointments.
- 4** Inclusion of GP phone numbers in the freephone service.
- 5** Healthcare benefits that keep pace with inflation in real terms.
- 6** Extended Statutory Sick Pay for those on NHS waiting lists.



## On the ground

One third of people in Barnsley who local Healthwatch spoke to had to go without essential hygiene or sanitary products<sup>124</sup>.

**"My daughter has started her period and I am not in a position to be able to buy her products."**

—Story shared with Healthwatch  
Barnsley

In partnership with the local council, Healthwatch Barnsley helped distribute hygiene packs to those experiencing this problem.

## Digital transformation

**Over the last year, the NHS has continued on the path set out in the Long Term Plan<sup>125</sup>. This outlined a vision for digital technologies to play a central role in preventing and managing ill health.**

We've seen upwards trends<sup>126</sup> in people using the NHS app to book GP appointments and order repeat prescriptions. Around 4.3m people<sup>127</sup> are using the app every month.

Public feedback has highlighted ways that digital technology is benefiting people's health and wellbeing. We've heard from people who are visiting their GP less, because they're using at-home monitoring.

They've also shared how technology can provide flexibility that makes it easier and more convenient to access help.

But feedback around online consultation and booking services remains mixed, with access tools being switched off by GP practices, and frustrations when technology doesn't work.

**"[They] Just constantly send you round in circles for appointments. You try online and it doesn't let you. You try the link they send ... and it doesn't work. ... I can only imagine how hard this must seem for someone that isn't technology-wise."**

– Story shared with Healthwatch Tower Hamlets

People have continued to share stories about digital exclusion, and concerns about having to use technology they don't understand.

**"When I phone up for an appointment, I'm told there are no appointments. I struggle with technology and have no help."**

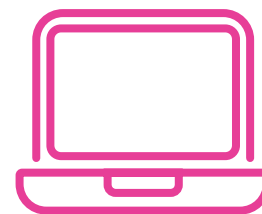
– Story shared with Healthwatch Lancashire

Our insight shows that older people, people with sensory impairments, people that speak little or no English, and people on low incomes continue to be at risk of digital exclusion.



**"I made an appointment via [eConsult]. The system allowed me to upload photos of the problem ... lead[ing] to me being referred ... very quickly."**

– Story shared with Healthwatch Knowsley



**Older people, people with sensory impairments, people that speak little or no English, and people on low incomes continue to be at risk of digital exclusion.**



## Our calls for change

Patients want digital systems that work for them and make accessing services easier. Some people also want help to use new systems if they lack the skills. People also want the choice to still speak to or see professionals if they prefer this approach.

### We're calling for:

- 1** Traditional models of access and care to remain alongside digital methods.
- 2** Involvement of patients in designing new technological solutions.
- 3** Built-in patient education (tutorials, how-to guides, digital community champions) with any new digital healthcare rollouts.
- 4** Funded, accessible community courses or training for those with low digital literacy.
- 5** A universal right to internet access, with cross-government action to work towards this.



### On the ground

Over 500 people shared their experiences and views on digital exclusion with Healthwatch North Tyneside.

They found<sup>128</sup> most people struggle with technology at some point, regardless of age, level of skill or confidence. Those who needed help feel technology is leaving them behind. And the cost of getting online can be a limiting factor.

## Accessible information

**Over the last year, people have continued to share experiences of being unable to get information in a way that works for them.**

We heard from autistic people, visually impaired people, deaf people, people with dyslexia, people struggling with illiteracy, and people that rely on translators about the challenges they face getting information.

We’ve heard how people were unable to use the NHS app and other online tools. We’ve heard how hard it can be to arrange translators. We’ve heard about cancellation letters being delivered in an inaccessible way, leading to people attending appointments that don’t exist.

Services continue to overlook individual communication needs<sup>129</sup>, leaving people to rely on family, friends, carers, or the goodwill of helpful staff.

**“My son is dyslexic. He went in person to the GP surgery. ‘We can’t do anything,’ the receptionists said, ‘you have to do it online’. ‘I can’t read,’ he [said], handing the receptionist his phone, ‘and I can’t spell’. So the receptionist filled in his form for him on his own phone while he was standing in the doctor’s reception office.”**

— Story shared with Healthwatch England



### Our calls for change

Patients want to receive health and care information in a way they can understand, so they can make decisions about their care and get the most out of services.

In partnership with leading charities, we launched Your Care, Your Way, a campaign calling for improvements in accessible information across the NHS and social care<sup>130</sup>. As a result of the experiences people shared with us, the NHS has reviewed and strengthened the legal right people have to accessible information. However, further steps are necessary.

### We’re calling for:

- 1** Action by Integrated Care Boards to ensure providers implement the Accessible Information Standard (AIS).
- 2** Routine checks of AIS compliance during Care Quality Commission inspections.
- 3** All health and adult social care providers to undertake the new voluntary self-assessment of AIS compliance, and work with local Healthwatch and people with extra communication needs on ways to improve accessible information.



**“It is frequently impossible to access services or information ... other than by telephone. This is profoundly inaccessible for many autistic people, touching on multiple areas of difficulty at once.”**

— Story shared with Healthwatch England



### On the ground

Healthwatch Sandwell ran focus groups with people with different accessibility needs. They released their research<sup>131</sup> on accessible information and communication in March 2023.

- Most blind and visually impaired people they spoke to said they hadn’t been asked about their information or communication needs.
- Deaf people said their communication needs were not being met, particularly around access to BSL interpreters.
- People with a learning disability had low awareness of the different methods they could use to access help.



# Thank you

**This report reflects the time and dedication of many individuals and organisations who are working for a better, fairer health and social care system.**

We'd like to give our particular thanks to:

- Every member of the public who shared their experience with us over the past year.
- Our fantastic colleagues and volunteers at local Healthwatch across England.
- The public, non-profit and research organisations to whose work we have referred.

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61. [Recommendations | Autism spectrum disorder in adults: diagnosis and management | Guidance | NICE](#)
62. [NHS Long Term Workforce Plan | NHS England](#)
63. [Cornish Communities in Mind | Healthwatch](#)
64. [Cancer | NHS](#)
65. [Latest national results | National Cancer Patient Experience Survey](#)
66. [The hidden wait for cancer care | Healthwatch](#)
67. An ICB is a “statutory NHS organisation responsible for developing a plan for meeting the health needs of the population, managing the NHS budget and arranging for the provision of health services in the ICS area.” [What is integrated care? | NHS England](#)
68. Prior to October 2023, this included waiting no more than two weeks to see a specialist after seeing a GP with symptoms of cancer; a 28-day wait for a communication of a cancer diagnosis or cancer being ruled out; starting treatment within 31 days of a decision to treat cancer; and starting treatment within 62 days of receiving an urgent two-week referral.
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87. [Valuing Carers 2021 | Carers UK](#)
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91. [Key facts and figures | Carers UK](#)
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98. [Unpaid Carers are Filling Gaps & Reaching Crisis | Dementia Carers Count](#)
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100. [State of Caring survey | Carers UK](#)
101. [Holiday Club Survey, 2023 | Contact and the Disabled Children’s Partnership](#)
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