



The state of health care and adult social care in England 2023/24



Care Quality Commission

The state of health care and adult social care in England 2023/24

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OGL

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Foreword

This year's State of Care draws on findings from CQC's national NHS patient survey programme and statutory reports, our inspection activity, bespoke research into people's experiences, insight from key stakeholders, and the evidence that our expert staff have collected throughout the year about the quality and safety of services in all areas of health and care.

Across our activity and analysis, it is clear that timely access to good care continues to be a struggle for many, and that inequalities in care persist. For example, in March 2024, 5 million people waited more than 2 weeks for a GP practice appointment, with 1.4 million waiting more than 4 weeks. The number of new requests for local authority adult social care support that resulted in no service being provided has increased by 27% over the last 5 years. In April 2024, waits for care home beds and home-based care accounted for 45% of delays in discharging people who had been in an acute hospital for 14 days or more, with nearly 4,000 people delayed on an average day.

And issues with getting access to services are often exacerbated by deprivation: in 2023/24, attendance rates for urgent and emergency care for people living in the most deprived areas of England were nearly double those for people in the least deprived areas. Furthermore, analysis conducted for CQC showed that for people attending for mental health reasons, the difference was over 3 times higher for those in the most deprived areas.

The safety and quality of some services is not good enough – our review of maternity services shows that women and babies are still not receiving the high-quality maternity care they deserve. Women from Black and ethnic minority backgrounds continue to be more at risk of experiencing poor maternity care and outcomes, and we found huge differences in the way trusts collect and use demographic data, particularly ethnicity data, to address health inequalities in their local population. We have made recommendations for both providers and the wider system, aimed at improving safety for every mother and baby.

We also have serious concerns about mental health services. Lack of resources, ageing estates and poorly designed facilities are affecting the safety of inpatient wards. In community mental health services, following our special review of the care provided by Nottinghamshire Healthcare NHS Foundation Trust, we also identified wider concerns. In response, we have made clear recommendations to improve oversight and treatment of people with serious mental health issues. We also called for national action to tackle systemic issues in community mental health – including a shortage of mental health staff and lack of integration between mental health services and other healthcare, social care and support services – so that people get the right care, treatment and support when and where they need it.

Getting the right care, at the right time and in the right place is important for everyone. However, for children and young people, delays can have especially significant and lasting consequences. Some treatments and interventions are less effective if not administered at a specific age or developmental stage

– and the opportunity to intervene can be missed completely if the wait for diagnosis is too long.

Many children and young people are not currently getting the support they need. We are highlighting this as a risk not just for today, but for the future. Children who do not receive the care they need today are at increased risk of becoming adults with long-term mental or physical illnesses, which could affect their quality of life and their ability to contribute to society tomorrow.

We have particular concerns about children and young people's mental health services, where demand continues to rise. In 2023, 1 in 5 children and young people between the ages of 8 and 25 were estimated to have a mental health disorder. While the mental health workforce has grown, problems with staffing and skill mix remain. Across the country, services are facing challenges in recruiting staff including nurses, psychologists, occupational therapists, and consultant psychiatrists – all of which are having an impact on capacity, and therefore on the availability and regularity of appointments.

Mental health difficulties experienced as an adult can begin in childhood or young adulthood, as pointed out by the Mental Health Foundation. Early intervention increases the prospects of good mental health in later life – but delayed or inadequate intervention decreases these chances.

To explore the experiences of children and young people when using mental health services, we commissioned work to gain further insight. From this, one young person describes the consequences of what they felt to be inadequate support from community services, leading to long-term hospitalisation: "I didn't know what to do because I didn't have any GCSEs and I thought no one's gonna want to give me a job and I'm not gonna be able to go to college...I wasn't a normal person of my age because I was in hospital and I missed out on all the things." Conversely, a young person who had a positive experience reflected: "I do still think back on my time at CAMHS and I was like, if I didn't [get that support], I would be in such a different place today... I got very lucky."

Sadly, for every child who gets 'lucky' by receiving timely, appropriate support, we know that there are many more who don't, potentially affecting their chances of a healthy adulthood.

We commissioned further research into attendances at urgent and emergency care settings by people with a mental health issue. This found that those aged 18 to 21 consistently have the highest rates of presentation for mental health issues at both emergency departments and urgent care centres. Not getting the right help at the right time can lead people's symptoms to deteriorate and then they can end up in crisis and/or in inappropriate environments, such as urgent and emergency care.

Our inspections in urgent and emergency care found issues around triage and patient flow that affect care for all patients. This includes the link between delayed hospital discharges and availability of home-based care and care home beds, which is acutely apparent.

Inspections in these settings also identified specific issues around care for deteriorating children. Low numbers of children's nurses and gaps in staff

training in safeguarding and recognising sepsis meant that in some services, there was a risk that a deteriorating child might not be identified quickly, with patients at risk of sepsis not being assessed and treated promptly. Actively involving parents in their child's care decisions and addressing their concerns promptly is critical to safety.

Last year's State of Care warned about movement to a two-tier healthcare system – where those who can afford to pay for treatment do so and those who can't face longer waits and reduced access. This remains a concern, starkly illustrated in dental care. We conducted a dental access survey of 1,000 people earlier this year, which found that people relied more on private care where NHS activity is lowest, and we also heard how access issues had a clear impact on children and young people.

Parents told us they felt pressured to go private and found it difficult to get appointments, even in emergencies, and we heard about children left in pain while waiting for an emergency appointment. It is notable that the tooth extraction rate related to decay is nearly 3 and a half times higher for children and young people in the most deprived communities, compared with the most affluent.

Another area of concern for CQC is about care for autistic people and people with a learning disability – both the quality of care and access to it. We are currently exploring the barriers and inequalities faced by these groups of people in accessing primary care, including the quality and consistency of annual health checks and action plans by GPs. The waiting time to begin assessment for a possible autism diagnosis is far too long, with average waiting times even longer for children and young people – 356 days in April 2024 compared with 238 days for adults. An autism diagnosis can be vital to getting the right help and support and can make a critical difference for children who are struggling at school.

Our inspections of providers revealed some examples where specialist services for children and families with complex needs were pivotal in leading multiagency working and sharing learning. Our work on formal integrated care system (ICS) assessments is currently paused. But in our limited review of ICS plans, we have seen some early positive signs, including transformation plans for children and young people's services. Some ICSs have children and young people scrutiny boards to provide governance and monitor planned implementation.

But waiting times for services remain a problem within ICSs, and the main challenge is demand versus supply – a significant increase in requests at the same time as workforce shortages. We found variation between some published ICS plans or a lack of clarity about their intended outcomes. But some ICSs had examples of action already taken – for example, one described virtual wards that had supported more than 1,150 children.

However, a greater focus on children and young people's services at both a national and local level is needed. This should include:

- consistent funding targeted to areas of early intervention
- a better understanding by systems of the gaps in provision of care and treatment for their population to ensure that local areas can meet the needs of their children
- improved management of demand
- better communication with children and their families.

The health and wellbeing of a nation's children has been described as the best predictor of its future prosperity; failing to ensure good, safe care for our children today also risks failing their future.



Ian Dilks OBE Chair

Summary

Primary and community care

More people are struggling to get appointments to see a GP at the same time as the number of people registered with a GP has increased. In our survey of 1,600 adults who had accessed care in the last year, the 2 services that people had the most difficulty accessing were GP services (59%) and dental services (23%).

Between March 2020 and March 2024, the number of patients registered with a GP in England has increased by 5%, from 60 to 63 million. The number of people waiting more than 2 weeks for a GP practice appointment increased by 18% from 4.2 million in February 2020 to 5 million in March 2024. The number waiting over 4 weeks also increased, from approximately 1 million in February 2020, to 1.4 million in March 2024.

The 10 integrated care system areas with the highest proportions of patients waiting over 2 weeks for a GP appointment were in comparatively rural areas – with half of these in the South West of England.

Demand and capacity pressures on NHS primary dental services contribute to problems in accessing care that are leading to the deterioration in people's oral health.

There is notable regional variation in the proportion of NHS dental work being completed – ranging from 48% to 97% – with rural areas tending to provide less NHS treatment.

Schoolchildren living in the most deprived areas were more than twice as likely to experience tooth decay than those living in the least deprived areas. And people in the most deprived areas of England were nearly 3 times more likely to be admitted to hospital for treatment that could potentially be avoided with timely and effective care in the community.

Our targeted assessments of the responsiveness of GP practices found that some practices demonstrated improved availability and accessibility of appointments and provided proactive outreach to patients.

Adult social care

The need for social care continues to increase, including when people are discharged from hospital. However, supply has not always kept pace, meaning more people are not getting the support they need.

The increase in the number of new requests for local authority adult social care support in 2022/23 was not matched by the number of requests granted with long-term care or short-term care to maximise people's independence. The number of new requests that did not result in a service being provided increased by 27% since 2017/18.

In April 2024, waits for care home beds and home-based care accounted for 45% of delays in discharging people who had been in an acute hospital for 14 days or more, with nearly 4,000 people delayed on an average day. Although

some of these delays will have involved waits for health rather than social care services, social care is likely to have been a significant factor in these delays.

For much of 2023/24, the North East and Yorkshire region had the highest proportion of delayed discharges from acute hospitals due to waiting for home-based care, and the North East region had the fewest homecare services per 100,000 population of older people. Meanwhile, London had proportionally the most delayed discharges from acute hospital due to waiting for a bed in a care home, and the fewest residential care home beds per 100,000 population of older people.

At 5.4%, staff vacancies in care homes at the end of 2023/24 were at their lowest rate for the last 3 years. Increases in international recruitment showed signs of levelling off over 2023/24, and there has been a steep fall in the number of overseas workers applying for health and care worker visas – representing an 81% decrease in the period April to July 2024 compared with the same period in 2023.

In 2023/24, we made 106 referrals to partner agencies regarding concerns about modern slavery and labour exploitation – nearly 3 times as many as last year.

Despite the challenges described in our report, outstanding adult social care providers are putting people at the heart of all decision making. Personcentred care, delivered with compassion and integrity, still makes a big difference to people's lives.

Mental health

The demand for adult mental health services continues to grow, and even more so for children and young people, with ever increasing numbers seeking care and support for their mental health.

Access to mental health services remains a challenge for many people. Research from the Strategy Unit (hosted by NHS Midlands and Lancashire) shows that people who live in deprived areas, women, and people from 'other' ethnic minority groups with mental health needs are more likely to attend urgent and emergency care departments.

Our regulatory activity, including our special review of Nottinghamshire Healthcare NHS Foundation Trust, has found evidence of people having to wait several months – and in some cases several years – for treatment in the community.

While the mental health workforce has grown, problems with staffing and skill mix remain. Across the country, services are facing challenges in recruiting staff – all of which are having an impact on capacity, and the availability and regularity of appointments.

The safety of mental health wards continues to cause concern. Lack of resources, ageing estates and poorly designed facilities can lead to issues around privacy and dignity for patients, as well as compromising the safety of both patients and staff.

Secondary care

High demand for services and ongoing pressure in all parts of the system mean that many people, including children, are not getting the care they need when they need it. This is leading to a deterioration in people's health conditions, which then need more intensive support and treatment, and results in longer stays in hospital.

Although demand has not increased dramatically, overall, the performance of services to meet the need for care is below the expected standard – and in some cases it is getting worse. By operating continuously in these environments, there is the risk that it becomes normal to accept care that is below standard.

People are facing long waits for diagnostic tests. As at March 2024, there were around 1.62 million people waiting for a diagnostic test or procedure. And waiting lists are increasing. In total, the waiting list for a diagnostic test or procedure has increased by 52% since 2019.

People continue to experience delays in referrals and diagnosis for cancer. Figures from NHS England show that the 3 waiting standard measures are not being consistently met, with the exception of the 28-day faster diagnosis standard, which was met for the first time in February 2024. Performance varies considerably between types of cancer and between regional health and care systems.

Areas of specific concern

In our 2023/24 report, we have highlighted some areas of specific concern. The concerns involve issues around safety, quality, workforce, and inequalities, including:

- Too many women are still not receiving the high-quality maternity care they deserve. Of the 131 locations we inspected in our national maternity inspection programme, almost half were rated as either requires improvement (36%) or inadequate (12%).
- We have concerns that children and young people are not always able to access services in a timely way – both planned and in an emergency.
 Anecdotal evidence suggests that parents and carers are well placed to recognise when their child is very unwell, but many feel they are not being listened to.
- The number of health visitors, who give individual support for young children and their parents, has declined by 45% over the last 9 years.
- Only around a quarter of people with a learning disability were recorded on the learning disability register, which means that many people are missing out on the proactive care and treatment they are entitled to.
- Despite fewer new referrals for autism diagnoses over 2023/24, the average waiting time to start an assessment reached a peak of nearly a year (328 days) in April 2024, rather than the recommended 3 months.
- People in Black or Black British ethnic groups are over 3 and a half times more likely to be detained under the Mental Health Act than people in white ethnic groups.

 Work on our cross-sector dementia strategy is highlighting the compassionate care and initiatives that are improving people's lives, but staff do not always understand the specific needs of people with dementia.

Deprivation of Liberty Safeguards

Too many people are waiting too long for a Deprivation of Liberty Safeguards (DoLS) authorisation, despite multiple examples of local authorities trying their best to reduce backlogs and ensure sustainable improvement.

We remain worried about the rights of people at the heart of the DoLS system. We continue to see people in vulnerable circumstances without legal protection, which not only affects them but also their families, carers, staff and local authorities.

The system has needed reform for over 10 years. Unless there is substantial intervention, we are concerned that these challenges will continue.

Local system response

Finance, joint forward planning and workforce depletion are among the main challenges for integrated care boards as people struggle to access the care they need.

Urgent and emergency care services in crisis are a symptom of complex system problems that need resolving, by providing more services for people away from hospitals.

Systems are focused on tackling health and care inequalities. They need to understand their populations to address issues that affect everyone, from children who need dental care to older people with dementia, but they face financial pressures and competing priorities.

There are mixed views among integrated care systems (ICSs) about their capability to address local health inequalities. There are challenges and barriers around data and analysis skills, governance and accountability, and capacity and capability in the system. CQC's formal work on ICS assessments is currently paused.

Carers play a vital role in millions of people's lives. At all the local authorities we have assessed so far, there is work needed to identify carers – and raise awareness that carers are entitled to an assessment and services to support them in their role. This was needed more for people in ethnic minority groups.

Local authorities have taken steps to address known inequalities and understand the demographics of local populations. But there is a need for better engagement with the voluntary sector and community groups, which have seen some success in identifying groups that are seldom heard and at greater risk of inequality.

Local authorities have a focus on safety through collaboration. Shared data and information is helping this, as it is made available across services and care pathways, improving safety for people moving between hospitals and the community.

Evidence used in this report

This report sets out the Care Quality Commission's (CQC's) assessment of the state of health care and adult social care in England in 2023/24.

In this report, we use evidence from our inspection and registration activities, along with other information and personal experiences, including from people who use services, their families and carers, to inform our view of the quality of care.

We have collected bespoke qualitative evidence to supplement our findings. This has enabled us to gather views from our inspection and assessment teams and subject matter experts on quality issues for specific types of health and social care services.

This report is also based on our wider horizon scanning activity. We have reviewed reports published by our stakeholders, drawn on findings from national surveys, and analysed publicly available datasets to supplement our understanding of the challenges facing health and social care today and the experiences of people using services. Where we have used data from other sources, these are referenced within the report. To aid readability, we have rounded many of these figures, so they may not match exactly with the published source.

To ensure that the report represents what we are seeing in our regulatory activity, analytical findings have been corroborated, and in some cases supplemented, with expert input from our Chief Inspectors, colleagues in our Regulatory Leadership directorate, specialist advisers, analysts and subject matter experts. Our analysis has also been supplemented with expert input from our Clinical Fellows, Katherine Bowman, Zahra Yasen, Saadiq Moledina, and Martha Martin.

Where we have used other data, we reference this in the report.

Here, we provide further detail relating to the evidence used in this report.

People's experiences and what they have told us

Our view of quality and safety has been informed by information that people have shared with us through our online <u>Give feedback on care service</u>, phone calls to our Customer Service Centre and social media. People's experiences and comments submitted through Give feedback on care enabled us to focus on the following areas:

• To deepen our understanding of the experiences of people who have accessed services for cancer, we carried out a thematic analysis of a sample of comments spanning the period 1 April 2023 to 31 March 2024. The sample was selected by searching all submissions in this period using 45 key words relating to cancer illnesses and treatments. This resulted in a total of 2,169 submissions. From this total, we analysed the data until no further significant themes emerged, a process called saturation. In total, we fully analysed 417 comments, coming from people using services, their family, friends and carers, and people working in services.

- To explore how people are accessing GP services and the quality of the care they receive, among other issues, we analysed 343 comments. These experiences were all shared between 1 April 2023 and 31 March 2024. A total of 3,420 comments were selected from this period, and all related to our programme of inspections looking at the responsiveness of NHS GP services, which ran from 30 October 2023 to 31 March 2024. We selected a sample of 10% of these comments (343) to represent all geographical regions in England in a proportionate way.
- To understand the experiences of people who are entitled to free NHS dental care, we thematically analysed 563 comments from the period 1 April 2023 to 31 March 2024. For the purposes of this research, we defined people who are entitled to free NHS dental care as: children and young people aged under 18 years or under 19 years and in full-time education, people on low income or receiving benefits, and women and birthing people who were pregnant or had given birth within the past year. We selected comments by searching the data for 12 key terms that would allow us to identify relevant respondents.
- To represent the experiences of autistic people when engaging with mental health services, we thematically analysed 212 comments using a key search term method to identify those that were relevant. As there were only a small number of relevant comments in the year from 1 April 2023 to 31 March 2024, the timeframe was expanded to include the previous year, meaning the analysis covers the period from 1 April 2022 to 31 March 2024.

When people share their experiences through our Give feedback on care service they are consenting to giving us their feedback. This process means that we are told about the many different issues that people face as they interact with health and social care services in England. We tend to receive more negative comments than positive comments from the public. Positive comments are often less detailed than negative comments, which can mean that these experiences are more generic. People often include more detail in their negative feedback to us, which means we can say more about these experiences.

As in previous years, we have used findings from our published <u>surveys</u> to better understand what people think about the NHS services they use. Furthermore, we have used evidence from bespoke surveys and research projects that we commissioned or developed ourselves.

We used free text responses to the 2022 NHS adult inpatient survey to better understand the impact of waiting for care on people's health and wellbeing. We selected 945 respondents and analysed their responses using thematic analysis. We only sampled respondents who had said their health deteriorated while waiting for care. Approximately half of the respondents were from an ethnic minority background. This was to ensure that the sample highlighted the voices of people in these groups.

We used free text responses to the 2023 NHS community mental health survey to gather insights into the experiences of people accessing these services. We focused on 3 different groups: the general population, children and young people aged 16 and 17, and Black men (including men from a

mixed Black ethnic background). For all 3 groups, we used thematic analysis to understand their concerns and issues, which involved:

- a random sample of 667 respondents from the general population
- all 575 respondents aged 16 and 17 who had answered at least one free text question
- 195 Black male respondents who fitted our selection criteria.

To more fully understand people's experiences across a range of sectors, we commissioned market research company OnePoll and worked with them to produce 7 surveys:

- 3 related surveys explored people's experiences of medical and dental services, as well as specific issues while trying to access services. These were sent to:
 - 2,000 adults from the general population
 - 1,000 people with caring responsibilities
 - 1,000 parents.
- A survey focused solely on dental services was sent to 1,000 adults to look further at issues with access to dental services, and the impact on people if they couldn't access a dentist.
- With OnePoll, we surveyed 1,000 parents and carers of children and young people. This was to learn more about the experiences of parents and carers who raised a concern about their child to a healthcare provider during the period April 2023 to March 2024. We analysed open-ended responses from 99 of these participants using thematic analysis.
- To understand the impact of closures of community and retail pharmacy on people's health and wellbeing, we asked 575 adults about their experiences of using community pharmacies.
- We asked 720 adults about their experiences of intermediate care.

Where we highlight different responses to the same question from different groups, these are presented as descriptive statistics, without statistical significance testing.

We also commissioned Aqua, an NHS organisation that promotes improvement in health and quality of care, to gather case studies for us. Participants were selected from people who had responded to the NHS Community mental health and Adult inpatient surveys and who confirmed they were willing to participate in further research. The case studies focused on the experiences of children and young people, and of Black men using mental health services throughout their care pathway. Case studies were also developed for adult inpatients who had reported that their health deteriorated while waiting for care.

Providers of health and care services

We have used the data and insight gained through our routine monitoring of and engagement with providers, for example information collected through our surveys and our data from statutory notifications received. To identify common themes in urgent and emergency care services, we analysed a sample of 10 inspection reports that had been completed during 2023/2024.

To identify indicative common themes and examples of what good quality care in adult social care looks like, we analysed a sample of 10 inspection reports across different types of adult social care locations that had been rated as outstanding in 2023/24.

To help us understand how adult social care providers are responding to challenges and improving services, we qualitatively analysed information submitted through provider information returns (PIRs). We ask adult social care providers to submit a PIR form every year. As well as helping to monitor the quality of care, the PIR gathers qualitative data through a set of 12 open-ended questions, asking the provider about any changes that have been made in the past 12 months and how they are ensuring their service is safe, effective, caring, responsive and well-led. In this analysis, we used PIRs submitted between 1 April 2023 and 31 March 2024. We analysed a random sample of 110 PIR documents, using a mix of adult social care providers, including both residential and community services.

Quantitative data from PIRs were also used to estimate staff vacancy, turnover and bed occupancy rates in residential adult social care providers between 1 April 2021 and 30 April 2024. Additionally, this year we have included experimental analysis on the use of restraint and restriction in residential care homes, with a particular focus on residents who are autistic or have a learning disability. As providers are required to submit one return every 12 months, each monthly cut of data represents only a subset of providers and is not necessarily representative of the whole sector. Data are collected through an online self-completion questionnaire and, while we have applied cleaning rules as part of our analysis, the returns are not validated and may be subject to data quality issues.

This report also provides an analysis of data submitted to us by providers in our Market Oversight scheme, as well as information and insight gained from our engagement with providers that participate in the scheme. The scheme covers providers with a large local or regional presence which, if they were to fail, could disrupt continuity of care in a local authority area.

We have conducted quantitative analysis of our inspection ratings of more than 32,000 services and providers. Aggregated ratings for the main sectors and services we regulate are provided in the data appendix of this report. These are a snapshot of the latest ratings for all services that were active or registered on 1 August 2024.

In March 2020, we paused routine inspections and focused our activity where there was a risk to people's safety. Last year, we noted that we had also started to carry out inspections in low-risk services to quality-assure our risk identification process. From January 2024, we started to implement a new approach to assessment using the single assessment framework. The number of published assessments and ratings using the single framework is still small, so we only present ratings awarded under our previous frameworks this year. As we begin to publish more ratings under the new approach, and continue to improve and develop this, we will begin to include these ratings in our analysis of aggregated ratings.

As we are in a transition period with ratings, we will be unable to make comparisons with those from previous years.

Quantitative analysis of inspection ratings includes information on the proportion of services that are categorised as having 'insufficient evidence to rate'. This rating can be used when, on inspection, we have not been able to collect enough information to give a rating. Charts in our data appendix visualise the proportion of all active services with a current rating of either outstanding, good, requires improvement or inadequate. We indicate the proportion of services where there was insufficient evidence to rate in a note below the chart, where applicable.

Earlier this year, we convened an event for senior leaders and specialists from across England to understand their local experiences around congestion in urgent and emergency care services – and the impact for providers and people using these services. The findings are summarised in the report.

We worked with the Strategy Unit (hosted by NHS Midlands and Lancashire), a specialist NHS analytical team, to understand the scale of people attending emergency departments (A&E) because of a mental health crisis and whether this highlighted any inequality.

To do this, the Strategy Unit analysed patient-level data in the Emergency Care Dataset (ECDS), NHS 111 dataset and the Mental Health Services Data Set (MHSDS). They looked at attendance and call rates, and how these varied by characteristics such as age, gender, ethnicity and deprivation. They also examined the characteristics of people's contact with the service, such as the time and mode of arrival, their presenting mental health condition and whether they were already known to mental health services.

(For our own analysis of attendances in emergency (A&E) departments, we used published data from NHS England. These use different data sources (MSiteAE and ECDS), which leads to some differences in figures.)

Local health and care systems

Working with the Nuffield Trust, we surveyed integrated care systems (ICSs) to understand what integrated care boards (ICBs) perceive as the main challenges or barriers to addressing inequalities in health care.

The Nuffield survey was for people with responsibilities for addressing health inequalities in their ICSs. Responses covered 23 individual ICSs (55% of all 42 in England). Several ICSs submitted responses from people across a range of different roles, including chief executives, chief medical officers, directors of population health, public health, and strategy, and from health inequalities leads, GP and clinical leads, pharmacists, and one patient.

With such small numbers involved, it is difficult to tell whether these answers represent a broader picture. Therefore, the results should be interpreted with caution as small changes to answers will significantly change the proportions. More in-depth work with people involved in different health inequalities roles would be important to further understand these early perspectives.

To help us understand approaches of regional and local health systems to service improvement and its impact on health, a group of CQC operational colleagues carried out a desktop review of key documents. They reviewed:

- joint forward plans for 2023/24 and 2024/25
- ICS strategy documents
- Health and Wellbeing board strategies, plans and case studies.

Last year, we formed an initial view of the performance of local authorities regarding their adult social care duties by carrying out a desktop assessment of selected publicly available information for all 153 local authorities in England. This year, we have begun baseline assessments of local authorities and have used findings from 11 such assessments to inform our view of local authorities' performance against their statutory duties.

Statutory responsibilities

We report on our own data for notifications of the outcome of an application to deprive a person of their liberty under Deprivation of Liberty Safeguards (DoLS) received between 1 April 2023 and 31 March 2024. This excludes Court of Protection applications and notifications from primary medical services, but due to changes in our systems, we cannot exclude Court of Protection from other DoLS notifications for the last 6 months of the reporting year (this number is small, typically less than 1,000 in a 6-month period). We also report on the annual data publication for DoLS from NHS England published on 22 August 2024.

To gather insight, we conducted a survey and a focus group with our inspectors.

In June and July 2024, we conducted a survey of the National DoLS Leads Network. This was to learn more about local authorities' experiences as supervisory bodies and the ongoing challenges they face in this area. A thematic analysis of the 51 responses aimed to identify common experiences and trends across local authorities.

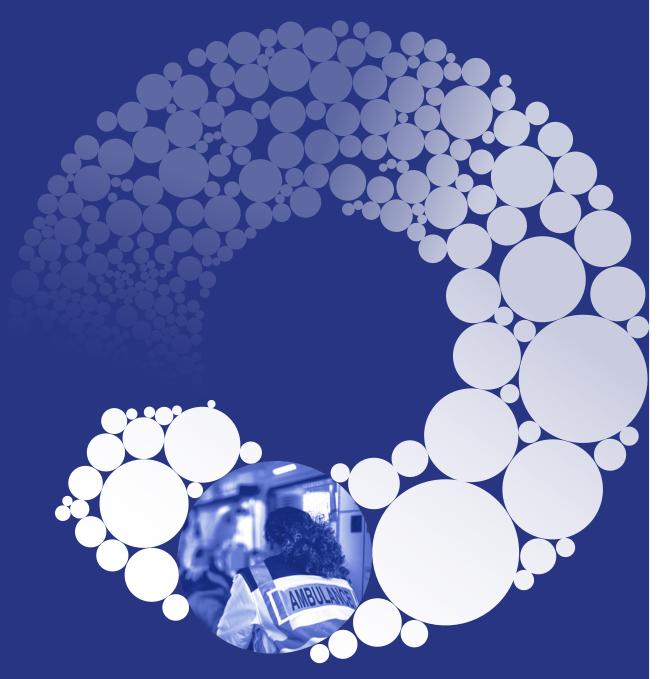
During June 2024, we conducted a survey of an external stakeholder group comprising:

- people with professional experience in caring for and supporting people who have been deprived of their liberty under DoLS
- people with a special interest in DoLS in a personal or professional capacity
- people who had cared for or supported friends or family who have been deprived of their liberty under DoLS.

Participants answered questions relating to their experience of the operation of DoLS across the period 1 April 2023 to 31 March 2024. We analysed responses from 46 people to understand themes and trends.

Evidence in this report, alongside our annual report and accounts, enables us to fulfil our legal duties to report on equality issues and on the operation of DoLS.

State of Care



Challenges affecting access and quality in health and social care services

Primary and community care
Adult social care
Mental health
Secondary care

Primary and community care

Key findings

- Between March 2020 and March 2024, the number of patients registered with a GP in England increased by 5%, from 60 to 63 million.
- The number of people waiting more than 2 weeks for a GP practice appointment increased by 18% from 4.2 million in February 2020 to 5 million in March 2024.
- The 10 integrated care system areas with the highest proportions of patients waiting over 2 weeks for a GP appointment were in comparatively rural areas with half of these in the South West.
- There is notable regional variation in the proportion of NHS dental work being completed – ranging from 48% to 97% – with rural areas tending to provide less NHS treatment.
- In our survey of 1,600 adults who had accessed care in the last year, the 2 services that people had the most difficulty accessing were GP services (59%) and dental services (23%).
- People in the most deprived areas of England were nearly 3 times more likely to be admitted to hospital for treatment that could potentially be avoided with timely and effective care in the community.
- Schoolchildren living in the most deprived areas were more than twice as likely to experience tooth decay than those living in the least deprived areas.
- Our targeted assessments of the responsiveness of GP practices found that some practices demonstrated improved availability and accessibility of appointments and provided proactive outreach to patients.

Primary care workforce

Between March 2020 and March 2024, the number of patients registered with a GP in England increased by 5%, from 60 to 63 million.

Looking further back, this figure has increased by 10% between March 2016 and March 2024, from 57 to 63 million. But GP numbers have not increased to meet this higher demand. NHS England figures show that over the same 8-year period since 2016, the number of fully qualified GPs for every 100,000 patients has reduced by 15%, from 51 to 44 full-time equivalents.¹

This increased need for GP services is putting unsustainable pressure on the workforce. The <u>latest poll of members</u> of the Royal College of General Practitioners in July 2024 echoed this, with a warning that "over three-quarters of GPs (76%) say that patient safety is being compromised by their excessive workloads".

This excessive workload comes, in part, from pressures in hospitals, which are passed on to primary care. For example, more unsuccessful referrals from a GP to a hospital can mean that people need to be cared for by a GP for longer while they wait for hospital treatment to go ahead.

The need for more GPs is well recognised and there has been a consistent drive to increase capacity over the years. The proportion of GPs in training increased considerably from less than 1 in 6 (15%) full-time equivalent GPs in March 2016 to more than 1 in 4 (26%) by March 2024.

The numbers of other staff providing direct patient care, for example healthcare assistants and paramedics among others, has increased dramatically, from 17 full-time equivalents for every 100,000 patients in March 2016, to 80 in March 2024. This represented a 372% increase. We recognise that new staff joining a practice will require supervision and support to carry out their roles.

There are different types of staff in a GP practice following the introduction of the Additional Roles Reimbursement Scheme (ARRS). This was introduced in England to reimburse salaries for new roles within the multidisciplinary team. But a survey by the British Medical Association found that a third (33%) of locum doctors have made definite plans to change work or career paths, with 71% blaming ARRS for creating unemployment among GPs.

Subsequently, the Department of Health and Social Care has <u>announced</u> that practices will be allowed to use funding from ARRS to recruit newly-qualified GPs in 2024/25, as an emergency measure. The announcement states that "more than 1,000 newly qualified GPs will be recruited" this year as a result.

Access to GP practice appointments

In this report, the section on <u>GP responsiveness</u> discusses what we found from our targeted assessments of GP practices. This was part of our work to understand how practices are trying to meet the need from patients to access appointments and to gain a better understanding of the experiences of both people who use GP services and of providers themselves.

We acknowledge the efforts of staff to increase the number of appointments for their patients. For example, primary care networks have been able to introduce new roles within the multidisciplinary team, selected to meet the needs of the local population. However, the rising need from patients continues to be one of the key challenges practices often say they are struggling to meet.

During our targeted assessments, we could clearly see that access to GP services continues to be an area of concern. We regularly receive feedback from people telling us of difficulties in getting GP appointments, which is also reflected in a continued decline in the proportion of positive experiences in local and national patient survey data.

Difficulties accessing GP services can have a significant impact on both short-term and long-term care. For example, we have also seen in our analysis of people's experiences shared through our Give feedback on care service that difficulties accessing GP services may also have an adverse impact on cancer screening and other health checks.

These issues around access to services are reflected in data from <u>NHS</u> England:

- The monthly number of GP practice appointments attended in England increased by 24% between February 2020 and March 2024, from 22 million a month to 27 million a month.²
- In March 2024, 17% of appointments in GP practices took place more than 2 weeks after booking.
- The number of people waiting more than 2 weeks increased from 4.2 million in February 2020, to 5 million in March 2024 – an increase of 18%.
- The number waiting over 28 days also increased, from approximately 1 million in February 2020, to 1.4 million in March 2024.

Analysis of the data from the 42 integrated care systems (ICSs) in England shows that people in different areas of the country are affected differently by waits for GP practice appointments – most notably in terms of rural versus urban area.

In March 2024, of the 10 ICSs with the lowest proportions of patients waiting over 2 weeks to be seen:

- 5 were in London
- 1 bordered London
- 4 were located around Birmingham or the wider West Midlands region.

Of these 10 ICSs, 7 were in urban areas.

It is also interesting to note that the ICSs with the highest number of registered patients for each GP were mainly in London or bordering areas.

By contrast, the 10 ICSs with the highest proportions of patients waiting over 2 weeks to be seen were in comparatively rural areas – with half of these in the South West.³

People's experience of GP services

The <u>2024 GP patient survey</u> received responses in the first 3 months of 2024 from nearly 700,000 people about their experience of local NHS GP practice services.

It found that nearly three-quarters (74%) of respondents said their overall experience of their GP practice was good, with 13% saying it was poor.

However, the survey's findings about contacting and accessing services tend to show a lower level of satisfaction. For example:

- 67% said their overall experience of their last contact with their GP practice was good and 19% said it was poor
- 66% said the wait for their last GP practice appointment was about right and 34% said it was too long.

Accessing GP appointments

We carried out a survey specifically for this report in July 2024, which received responses from 1,600 people who had accessed health and adult social care services in the past 12 months.

When asked 'which services have you had difficulty accessing, arranging, or attending?', most people said NHS GP services (59%) followed by NHS dental services (23%).

When asked about the causes of these difficulties, of those who had difficulty accessing, arranging or attending services:

- 58% said it was the availability of appointments
- 39% said it was problems when trying to book an appointment, such as being put on hold.

Some of these difficulties are also reflected in people's experiences of GP practices, which we received through our Give feedback on care service in 2023/24.

Accessing GP services was a common topic of feedback. A lot of people spoke about it positively, including booking appointments, as well as actions their practice had taken to improve physical access to the building.

"I've always got a quick, same-day appointment with warm staff that always want to help."

However, many people also had difficulty in accessing GP services. Contacting the practice by phone was an issue for many people.

"You have to phone the doctors at 8am if it is urgent. Good luck with that as you have to wait on the line in a queue which could be 20 to 30 minutes if you're lucky, by which time there are no appointments available."

Some people had such difficulty contacting their GP practice that they gave up trying or felt that the practice did not want them to access services.

"Nowadays I feel like a burden whenever I try to speak to anyone there, which puts me off even trying. Not sure if that's what they're hoping for? As it certainly feels like it sometimes."

Difficulties contacting a GP practice

Bethany told us that her GP practice was not very good at calling her back. She had recently had a urinary tract infection and rang her GP first thing in the morning to arrange for some medicine to come with her afternoon medication delivery. After waiting over 6 hours for a call back from her GP and becoming more unwell, Bethany rang her pharmacist who then rang an ambulance to take her to hospital. This attendance at A&E may have been avoided if the GP had called her back and assessed her earlier. Bethany has arthritis and has a lot of experience of using health services, including waiting 2 years for a knee replacement operation. She said it was the care and services from primary care that she had been most unhappy about.

(Interview with a member of the public)

The ease of booking appointments also depended on the options available to people. Many felt that booking through online systems was a quick and efficient way to contact their practice.

"I used the online service to seek medical advice for my daughter. I was contacted within 30 minutes offering a same day appointment."

In a few cases, though, people struggled to use online systems, either because it didn't appear to work or because it was difficult to use and navigate the system.

"Trying to get [an] appointment with this surgery is a nightmare, they say fill in the form on [their] website to request an appointment. My wife and I have tried to find the form but it's just not clear how to find it."

The difficulty in using online systems can be further exacerbated when people do not speak English as their first language.

This was one of the findings from our inequalities local outreach project in 2024. During the project, we contacted local voluntary and community sector organisations to collect feedback from people from ethnic minority backgrounds across England about their experiences of care and treatment for a long-term condition in primary and secondary care. Some people from ethnic minority groups, including a group that supports families from overseas who do not speak English as a first language, told us how the people they represent find it difficult to use apps or systems to make appointments, read letters or submit medical information. For example, they said

- information about appointments delivered by email and text message is hard to understand because of their limited English language
- they don't trust translation software when using digital apps
- language is a barrier because they would need an interpreter to book an appointment when using an app.

Waiting for a GP appointment

The Department of Health and Social Care's <u>2022 plan for patients</u> sets out an expectation that patients should get an appointment with their GP practice within 2 weeks, and that patients with urgent needs should be seen on the same day.

Many people used our Give feedback on care service to give positive feedback about their GP practice for getting an appointment quickly. For some, a key strength was the ability of receptionist or triage staff to listen to what the problem was and prioritise accordingly. A few people felt that the online systems speeded up the triage process and allowed them to access the care they needed efficiently.

"The receptionist was committed to finding a suitable appointment time that worked for me and explained the next steps."

However, reflecting the NHS England data referenced in the section on 'Access to GP practice appointments', some people told us they waited between 2 to 4 weeks for an appointment, which exceeds the recommended 2-week wait.

"I asked for an appointment to see a doctor on 15 January and was told that I would be contacted. I heard nothing more until 8 February when I had a phone call to offer me an appointment on 16 February. While I accept, and indeed said, that my request was not urgent, to wait for a month to see a doctor is disappointing to say the least."

A few people said that, even though appointments were available, it did not necessarily mean they were available at times that worked for them.

"Poor opening hours. I can only call on day of appointment at 8:30am. Unable to book appointments in advance or, if any available, it's a long wait of at least 3 weeks. No walk-in service, or early mornings/evenings for those who work."

Emergency appointments

In the 2024 GP patient survey, 31% of respondents said they had contacted or used an NHS service when their GP practice was closed. Of those:

- 47% phoned NHS 111
- 24% went to an emergency department (A&E)
- 16% went to a pharmacy
- 13% went to an urgent treatment centre.

Similarly, people's experiences through Give feedback on care also mention turning to other NHS services to seek emergency care when they couldn't access GP services.

For many people, accessing emergency GP appointments at their practice was relatively straightforward. Those who were able to contact their practice and request an emergency GP appointment often received one the same day following a triage process.

"Called the surgery at 8am for an emergency appointment for my child. I was surprised that I was offered an appointment and seen within the hour – quick and efficient service!"

However, some people found it difficult to get an emergency GP appointment, which meant they had to access urgent and emergency care services, such as NHS 111 and emergency departments.

"The main problem with this practice is getting an urgent appointment to see a doctor. My last 3 requests have had to be via NHS 111. The last urgent request via 111 ended with an ambulance being called, followed by 24 hrs observation in hospital. The doctors are all very efficient when you can get an appointment, the problem is just getting the appointment to see them."

GP responsiveness

We recognise the work of GP practices to continue to provide safe, good quality care, despite the pressures of increasing patient numbers. To understand what practices are doing to improve patients' access to primary care, we carried out a programme of over 250 targeted assessments of GP practices between October 2023 and March 2024.

We found that the services identified by inspectors as showing innovative or outstanding practice were either:

- improving the availability and accessibility of appointments
- providing proactive outreach to patients.

Steps to increase the number and availability of appointments included offering new and wider services.

Efficiencies were often supported by improving or introducing technology to tackle issues the practice had identified. These included improved online accessibility options and new systems for booking appointments and online consultations. We acknowledge that these solutions may not benefit all people, and can restrict those who do not have access to digital technology or, as we mention earlier, people who do not speak English as their first language.

Examples of providing proactive outreach to patients, specific groups of people and wider communities included setting up a women's health hub, supporting migrant patients, and engaging with local homelessness charities. Practices sought to address specific health concerns, such as referral delays for suspected cancer and issues around mental health and isolation, by working together with partners in the local system. This included cancer alliance partnerships and mental health charities.

Examples from a GP practice assessed and rated as outstanding for providing responsive services

As well as operating a telephone system that monitored call performance, the practice used an online service to enable patients to book and cancel appointments, order repeat prescriptions, access care records, request fit notes, and get answers to general enquiries. Nearly 70% of its patients had signed up to this. The practice continuously reviewed its appointments system in response to feedback and demand, and planned ahead to ensure appointments were available.

The rural location meant that some patients found it difficult to travel to the local hospital. To address this, the practice tried to provide services in-house as much as possible, such as phlebotomy, minor surgery and a diabetic screening service.

The practice also reviewed the results of the national GP patient survey every year, listened to patient feedback and adjusted its services as necessary, for example by offering more early morning and lunch-hour appointments for working-age patients. There were also more reception staff at busy periods.

The practice held a register of patients living in vulnerable circumstances, including homeless people and Travellers. It also focused on supporting patients with mental health needs, including offering priority appointments to those experiencing poor mental health, with the practice nurse checking that these patients attended their appointment and following up if they failed to attend.

Access to dental care

NHS dental activity

NHS primary dental care is facing a crisis. The <u>Dentists' Working Patterns</u>, <u>Motivation and Morale survey</u> for 2022/23 paints a worrying picture since the last survey:

- motivation and morale levels have fallen for most groups of dental staff
- recruitment and retention issues have become increasingly prevalent
- around two-thirds of dentists across the UK often think of leaving dentistry.⁴

Demand and capacity pressures on NHS primary dental services contribute to problems in accessing care that are leading to the deterioration in people's oral health.

The proportion of adults who have seen an NHS dentist in the last 24 months and children who have seen an NHS dentist in the last 12 months is lower than in 2019/20. At the end of March 2024, 40% of adults had seen a dentist in the last 24 months and 56% of children had seen an NHS dentist in the last 12 months, compared with 49% of adults and 59% of children at the end of March 2020.

This <u>data</u> shows a variation at integrated care system level, of over 20 percentage points between the highest and lowest proportions of both adults and children seen by a dentist.

Similar to the figures for longer waits to see a GP, of the 10 areas with the lowest proportion of adults who have seen an NHS dentist, half are in the South West of England.

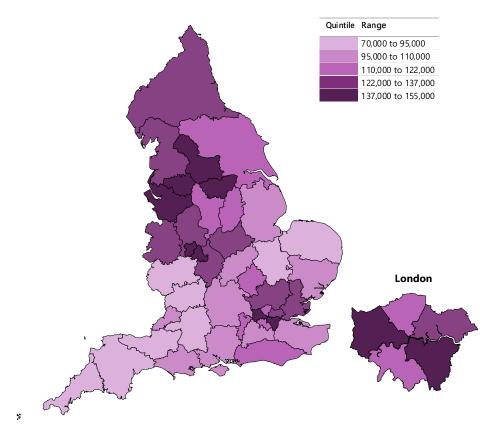
This is reflected in <u>data</u> on the amount of NHS dental treatment being delivered in England (measured in units of dental activity). Although there has been some improvement, figures have not recovered to those seen before the pandemic.

There is notable regional variation in the proportion of NHS dental work being completed in each integrated care system area relative to the budgeted units of dental activity allocated to it. In 2023/24, this varied from as low as 48% to as high as 97%.

Another way of looking at the rate of activity during the same period is by the number of units of dental activity completed for every 100,000 population. This measure also showed high variability from around 70,000 to more than double at 155,000.

Our analysis indicated a link between the level of dental activity per head of population and whether an area can be classified as urban or rural. It showed that ICS areas with higher levels of NHS dental activity tended to be more urban than areas with lower levels of activity (figure 1).

Figure 1: Units of dental activity per 100,000 population by ICS area, 2023/24 (darker areas have a higher amount of activity completed per head of population)



Source: Dental activity delivery <u>data</u> from Department of Health and Social Care (Dental Service Profiles) and ICS population data from the Office of National Statistics

Areas with a low proportion of dental activity completed against budgeted allocation could affect patients' access to an NHS dentist and result in some areas becoming 'dental deserts'.

When we compared regional rates of units of dental activity with scores from the 2024 NHS GP Patient Survey about dental services, we found a correlation between the proportion of completed NHS dental activity and patient satisfaction. Answering the question, "Overall, how would you describe your experience with NHS dental services?", of the 5 integrated care system areas with the lowest rates of positive answers, 4 were in the South West.

Alternatives to NHS primary dental care

Some of the findings above align with the results of a survey of 1,000 people on dental access, which we carried out in March 2024. This found that people relied more on private care in areas where NHS activity is lowest. The survey found that London had the lowest proportion of respondents who said, "I am a private only patient" (16%), whereas the South West had the highest proportion (49%). This survey also showed that the highest proportion of respondents (72%) who said "I am only an NHS patient" were in the North West, where there is a high level of NHS dental activity.

As private dentistry is often perceived to be cheaper outside of the UK, many people now travel abroad to access a course of dental treatment. However, continuity and maintenance of care may not always be considered for these courses of treatment, and patients may have to seek support from UK services when they return.

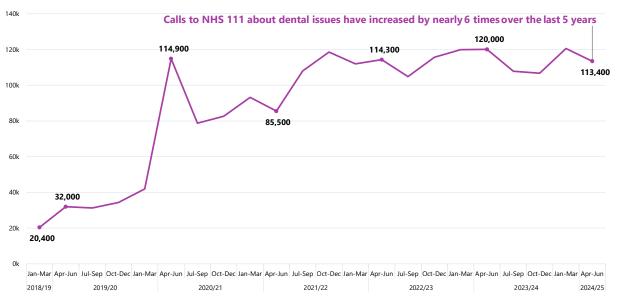
As we reported last year, for patients who are on long waiting lists due to a lack of access to NHS dental services and who can't afford private dental care, 'DIY dentistry' is becoming increasingly common. According to a recent survey, 9.4 million UK adults have performed a dental procedure on themselves. This appeared to be particularly exacerbated by the pandemic, with 82% of UK dentists reporting cases of DIY dentistry since lockdown. 6

Our survey of 1,000 people also reflects this, as it found that 10% of all respondents had resorted to 'DIY treatment', with those aged 25 to 34 the age group with the highest rate at 18%. These treatments include temporary crowns, fillings or adhesives, as an alternative to seeing a dentist.

One potential indicator of whether people can access the routine dental care they need is the number of calls to NHS 111 that are about dental issues. According to NHS England data, this number has grown by nearly 6 times over the last 5 years and was at over 120,000 calls in the 3 months to March 2024 (figure 2).

This could indicate that more people are contacting NHS 111 because of issues with accessing NHS dental services, as they have left routine care for so long that they need more urgent attention, or that NHS 111 is now the most accessible option to them.

Figure 2: Number of calls to NHS 111 about dental issues in England 2019 to 2024



Source: NHS England data

Looking at the rate of calls across ICS areas, we compared the number of NHS 111 contacts with the population of each area to give a rate of dental calls for every 100,000 people.

We found that the 5 areas with the highest rates of dental calls are in the North of England. These are followed by areas that have low rates of completed dental activity, including those in the South West and East of England.

Another indicator that people are not able to access the oral health support they need is the number of people attending emergency departments because of dental issues.

A target for many integrated care boards (ICBs) is to reduce the number of admissions to hospital from an emergency department. A lack of access to timely preventative dental care can result in a greater number of dental emergencies requiring admission, increasing the burden on emergency departments, oral and maxillofacial units and wider hospital services.

But NHS figures from the Emergency Care Data Set show that the number of patients attending emergency departments where a dental condition is the primary diagnosis has increased in England by nearly 45%, from 81,773 in 2019/20 to 117,977 in 2023/24, with increases across all 7 NHS regions.

This increase in emergency attendances can lead to poorer patient experience. For example, while patients can receive pain relief or antibiotics in this setting, medical professionals in emergency departments are not trained or equipped to carry out the interventions needed to prevent the issue from recurring.

Looking at the number of people attending emergency departments with a diagnosis of a dental condition per 100,000 population in each region, we can see links to the data on dental activity. Generally, attendance rates were higher in ICS areas with a lower percentage of dental activity completed.

This indicates that people in 'dental deserts' may be more likely to resort to emergency departments because they haven't been able to maintain their oral health due to access issues.

People's experience of dental care

We have heard a lot from people in 2023/24 through our Give feedback on care service about the availability of NHS dental appointments and the ability to book them.

In our analysis, which focused on people who are entitled to free NHS dental care, we saw that some people had good experiences where they found it easy to book appointments using several booking options, including telephone and email, or there was flexibility around availability.

But more people have mentioned lengthy wait times for appointments, sometimes waiting months and years before an appointment is available with an NHS dentist, which could lead to poor oral health.

A few people said they had to travel long distances to see an NHS dentist, as they were unable to get appointments at a more local practice.

Despite patients being eligible for free NHS dental care, some practices appear to offer a private appointment sooner than if they waited for an NHS appointment.

In most of these cases, people told us they were offered 2 options – either wait for the next available NHS appointment, in which case oral health may deteriorate further, or pay for a private appointment. Some patients told us about a third option, which is to leave the practice and try to get an NHS appointment at a different practice.

We were also told of appointments often being cancelled without a reason. However, some people linked cancellations to staffing issues, with examples of practices telling patients they no longer have an NHS dentist at the practice to carry out NHS dental work.

As part of our analysis of feedback about people's experiences of dental care, we heard about the impact of access issues on pregnant women and children and young people (both are protected characteristics).

Pregnancy

A few pregnant women who submitted feedback said they were in need of dental attention due to the impact of pregnancy on their teeth, but were unable to get an appointment and were therefore not treated, as the following experience showed:

"Throughout my pregnancy, I suffered with bleeding gums, a crumbling tooth, a build-up of plaque, but they refused to see me because I wasn't in 'agony'. They still won't see me and tell me that they are only seeing people for absolute emergencies and cannot give a timescale as to when they will be able to see their patients routinely again."

This was also reflected in our survey of 2,000 adults about their experiences of accessing health and adult social care services, with one person saying that difficulty in getting free dental entitlement was particularly hard when combined with reduced income:

"I had a baby this year so have been entitled to free NHS dentistry but have not been able to get an appointment. The NHS dentist I was registered with closed and my only option available within 50 miles is private dental care. This is particularly difficult at a time when I am on a reduced income due to maternity leave."

Cancelled appointments was one of the most common issues mentioned by people through Give feedback on care, who told us about trying to access NHS dental services, often citing frustration, anger, and feeling at a loss:

"I'm sick and tired of being cancelled on. I am pregnant and need to be checked over as I'm having issues with my teeth this time around. They don't give a reason for cancelling. They cancelled my appointment on 8 December and now can't see me until February, which I have no doubt that they'll cancel again. I'm worried they will cancel my appointments so many times that they remove me from the system. Others have warned me of this."

Patients have also reported being removed from practices' NHS dental lists:

"I missed one appointment due to going into labour, was 3 minutes late to another appointment because I was 2 weeks postpartum, then missed an appointment back in June as I forgot the date and had so much on my mind, then to top it off [staff member] from [the] dental practice refuses to see me and says he is taking me off his books."

Cancelled appointments led some patients to feel pressured to book privately for their dental needs. One person told us about their appointment being cancelled and having to go private because of the pain, therefore forgoing their maternity exemption certificate, which had a financial impact on them.

Access to emergency dental appointments for people who need them and who were entitled to free NHS dental care, including pregnant women, has often led to a deterioration in oral health, as the following experience shows:

"I phoned [the dental practice] to let them know I had an abscess and needed an emergency appointment. I informed the receptionist that I was pregnant and was concerned about the infection becoming dangerous and affecting the health of myself and my baby. The receptionist informed me that they had no available appointments until September. I then queried this as this was an emergency appointment. She then told me there were no available appointments until August."

We highlight other issues around maternity care later in this report.

Children and young people

As well as our general survey of 2,000 adults asking about their experiences of accessing health and social care services, we also asked the same questions of a separate group of 1,000 parents and carers of children under 18. Patterns of access were similar to the larger adult group, but notably the proportion of parents and carers saying they had difficulty accessing NHS dental services for their child was higher (31% for parents compared with 23% of the general population).

Widescale issues around the availability of appointments can be aggravated when there is a lack of flexibility for children and their carers. Some people told us through Give feedback on care that they are limited to appointment times that are typically inconvenient for children and working parents or guardians, such as during the school day:

"It's not possible to have an NHS appointment other than in the middle of the day, making it extremely difficult for people that have children in school and also for those who work. They can only offer a convenient appointment if you pay privately."

The issue of some practices appearing to steer patients towards more expensive private care is also seen in dental care for young people:

"My husband has tried to book an appointment for my 15-yearold daughter. When he called today, he was told that they had no appointments until September, but if he went private and paid £30 she could have an appointment this week. Is this ethical?"

Parents and carers are also telling us about issues with emergency dental care, where reception staff tell them there are no emergency appointments and provide little support moving forward. We hear of instances where dental practices have told parents to give their children painkillers or where children have been left in pain while waiting for an emergency appointment:

"I rang as my 9-year-old child cracked her adult tooth. Only to be told that the appointment would have to be in 2 weeks and to give her [children's paracetamol] for the pain. Even though I was told she would need an emergency appointment, they wouldn't see her any quicker. It's disgusting."

Access to emergency dental services, and availability of appointments more generally, has contributed to some people needing to access urgent and emergency care:

"Tried to call for my daughter and ended up having to take her to A&E because she was in so much pain."

We discuss the care and treatment of young people more in our section on 'Children and young people's health'.

Improving access to dental care

Healthwatch's <u>report on NHS dentistry</u> highlights the many problems people are having with access to NHS primary dental care, and how much this varies across England.

Access to NHS dental care continues to be one of the main issues Healthwatch hears about through its network of 153 local groups, often affecting people in the most vulnerable circumstances in society. Healthwatch reports a number of key findings from its work:

- The cost-of-living poll in January 2024 found that 21% of people surveyed were put off going to the dentist because of cost. This was up from 15% in a similar poll in March 2023.
- In November 2023, 69% of people who accessed private dental care in the past 12 months had no dental insurance.
- Disabled people and those with long-term health conditions were more likely to avoid going to the dentist because of the cost, according to January 2023 findings.⁷

To gain an understanding of the issues, we approached representatives from all 7 NHS regions, including commissioners and local dental committees. They told us that additional commissioning is needed to address an unmet need in urgent dental care and to help resolve the issues of access and health inequality. We heard about initiatives introduced through flexible commissioning, using dental budget under-spend to address unmet needs in urgent dental care, and to resolve the issues of access and health inequality.

Examples of initiatives in an integrated care board

At Greater Manchester ICB, 3 members of the dental provider board attend twice-weekly meetings held by the primary care board. This means that primary care dentistry is well represented, not only in discussing dental service provision, but also when considering wider healthcare issues, such as primary care pressures and clinical effectiveness.

The primary care board has set out a 5-year plan for improving access to primary care across the area. One of its aims is to improve access to NHS dental care and to improve the oral health of the population through various schemes.

One scheme, introduced in June 2023, offers financial incentives for providers to increase access and treat new patients. Participating practices are expected to indicate on the NHS website that they are accepting new patients, and to deliver dental care to an agreed number of new patients. They are also expected to become part of the wider urgent dental care network, to accept patients on an emergency basis through their helpline. This means that gaps in clinical diaries can be used for emergency patients. Practices are paid over their contract value, with the extra being funded by under-spend of the dental budget.

230 practices signed up to deliver this scheme, and 38 additional urgent dental care hubs, initially set up in response to COVID-19 pressures, were commissioned to continue to offer urgent dental services. This has resulted in a large number of new patients benefitting from NHS dental appointments.

The local medical committee believes that dental-related attendances at GP practices have reduced, and that triage nurses in emergency departments are seeing a large reduction in the number of dental-related attendances.

The local dental networks have also taken initiatives to improve the quality of care, and to address health inequalities for groups of people in more vulnerable circumstances. These include introducing 'dementia-friendly' practices by improving staff understanding of dementia and making simple adjustments within the dental practice to improve the general experience for people with dementia and their carers.

Access to community health services

<u>Community health services</u> cover a wide range of services and provide care for people of all ages in their homes, as well as in community hospitals, clinics and schools. Services also include health promotion services such as school health services and health visiting services.

Many services involve partnership working across health and social care teams, made up of a wide variety of professionals including district nurses, mental health nurses, therapists and social care workers.

But access to community health services is also an issue for people, shown by the size of waiting lists:

- for adults needing community health services, the waiting list has increased from January 2023 to April 2024 by 22%, from 648,400 to 795,270
- for children and young people (under 18 years) needing community health services, the waiting list has increased more in the same period by 32%, from 214,220 to 282,240, although this is partly because services were added to this list in February 2024.

We discuss community health services more in the section on 'Children and young people's health', with a focus on health visitors, who give individual support for young children and their parents.

Access to community pharmacy

Community pharmacies are a crucial part of the health and care system. Their location on many high streets or in large supermarkets enables people to have an accessible source of support with their medicines, advice on minor illnesses, or for ongoing long-term conditions.

This also has the potential to relieve pressures on the rest of primary care and the wider health service – especially with the introduction in January 2024 of <u>Pharmacy First</u>, which aims to enable people to get certain medicines directly from a pharmacy, without a GP appointment.⁸

However, the <u>Health and Social Care Committee report on Pharmacy</u> in May 2024 concluded that "the sector needs better support if that potential is to be delivered".⁹

Analysis by the CCA (Company Chemists Association) reported a net loss of 432 pharmacies in England in 2023/24. Since 2015, core funding for community pharmacy has been cut in real terms by 30%, seeing a net loss of nearly 1,200 pharmacies. Between April 2015 and February 2024, closures have had a disproportionate impact on the most deprived neighbourhoods, with 35% of permanent closures taking place in the top 20% of deprived communities.

We ran a public survey in 2024 to further understand the impact for people when there are changes to and closures of community pharmacies. We do not regulate community pharmacies, but we wanted to explore how it might affect access in other services. In the previous 12 months, from 524 respondents:

- 17% saw a reduction in their local community pharmacy's opening hours
- 12% said their usual pharmacy had closed.

Changes happening to community pharmacy may be adding to the challenges in the wider healthcare system. Of the 176 survey respondents who reported a change to or closure of their usual pharmacy:

- 35% could not access a pharmacy when they needed to
- 42% reported a worse experience than before.

When asked "what healthcare services have you visited or used since the changes to your usual pharmacy?", of the 176 respondents:

- 44% visited a GP
- 24% visited an urgent treatment centre
- 24% visited an emergency department (A&E).

Of the 134 people who had visited either a GP, emergency department (A&E), private service, urgent treatment centre, or called NHS 111, 35% said they did this as they had no other option.

Primary and community care in areas of deprivation

Effects on hospital admissions

A recent <u>report from the Joseph Rowntree Foundation</u> paints a stark picture of the impact of deprivation and hardship on people and its effect on primary and community healthcare, stating "people going without essentials piles pressure on GP surgeries, diverting resources and adding to workloads".

The report also says that the "barriers to accessing healthcare due to hardship may mean that some patients do not present to their local GP or other services for help at all, even if they need it, or potentially end up facing health crises, and having to present to emergency services such as A&E."

We have talked about the barriers to accessing services above. <u>Data published by NHS England</u> shows a concerning link between people living in areas of deprivation and the rate of unplanned hospital admissions for chronic ambulatory care sensitive conditions.

These are hospital admissions related to long-term conditions, such as chronic obstructive pulmonary disease (COPD), asthma and diabetes, that could potentially be avoided with timely and effective community care.

The rate of unplanned hospital admissions for these chronic conditions was 302 per 100,000 for the most deprived areas, compared with 104 for the least deprived. In other words, according to the most recent data, people living in the most deprived 10% of areas in England were nearly 3 times more likely to be admitted for potentially avoidable hospital care than those in the least deprived areas.

This pattern was reflected when looking at local authority areas. The 10 local authorities with the highest rates of unplanned hospital admissions for chronic ambulatory care sensitive conditions were all areas of comparatively high deprivation:

- 7 were in the North
- 3 were in the West Midlands.

The 10 local authorities with the lowest rates of unplanned hospital admissions were nearly all in comparatively affluent areas, and were all in London or the South East.

Effects on oral health

The effects of health disparities are also seen in people's oral health. According to the <u>Oral health survey of children in year 6</u>, schoolchildren living in the most deprived areas of the country were more than twice as likely to have experience of tooth decay (23%) as those living in the least deprived areas (10%) between September 2022 to July 2023.

Consequently, according to <u>official statistics published by the Office for</u>
<u>Health Improvement and Disparities</u>, the tooth extraction rate related to decay was nearly 3 and a half times higher for children and young people in the most deprived communities, compared with the most affluent.

There were also differences in the prevalence of tooth decay by ethnic group, with the 'other' ethnic group (22%) and Asian and British Asian group (18%) significantly higher in than in the white (16%) or Black or Black British ethnic groups (13%).

The combined effects of deprivation and poor access to dental care have been reflected in some of the feedback we have received from the public through our Give feedback on care service. Some patients who are entitled to free NHS dental care have told us that they had been removed from NHS patient lists but were then told that they could remain at the practice as a private patient. A few patients said they could not afford this, instead being left to find a new dental practice and without the required dental treatment.

"I was a patient here for years. Then out of the blue they rang and told me they were no longer treating NHS patients and I could take out a dental plan with them. I cannot afford this as I am on disability benefits and entitled to full free NHS dental treatment. They said they could do nothing to help and couldn't help with recommending another dentist. I need urgent dental care right now and have tried unsuccessfully to get a new dentist."

Adult social care

Key findings

- The increase in the number of new requests for local authority adult social care support in 2022/23 was not matched by the number of requests granted with long-term care or short-term care to maximise people's independence. The number of new requests that did not result in a service being provided has increased by 27% since 2017/18.
- In April 2024, waits for care home beds and home-based care accounted for 45% of delays in discharging people who had been in an acute hospital for 14 days or more, with nearly 4,000 people delayed on an average day. Although some of these delays will have involved waits for health rather than social care services, social care is likely to have been a significant factor in these delays.
- For much of 2023/24, the North East and Yorkshire region had the highest proportion of delayed discharges due to waiting for home-based care, and the North East region had the fewest homecare services per 100,000 population of older people.
- Meanwhile, London had proportionally the most delayed discharges from acute hospital due to waiting for a bed in a care home, and the fewest residential care home beds per 100,000 population of older people.
- At 5.4%, staff vacancies in care homes at the end of 2023/24 were at their lowest rate for the last 3 years.
- Increases in international recruitment showed signs of levelling off over 2023/24, and there has been a steep fall in the number of overseas workers applying for health and care worker visas – representing an 81% decrease in the period April to July 2024 compared with the same period in 2023.
- In 2023/24, we made 106 referrals to partner agencies regarding concerns about modern slavery and labour exploitation – nearly 3 times as many as last year.

Waiting for adult social care

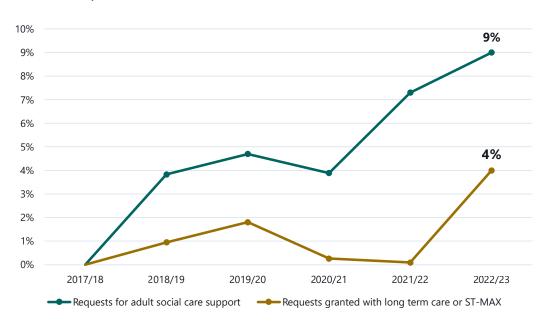
In this section, we see how the need for social care continues to increase, including needs when people are discharged from hospital. However, supply has not always kept pace, meaning more people are not getting the support they need.

The <u>Autumn Survey Report 2023</u> from the Association of Directors of Adult Social Services (ADASS) highlighted that the number of people waiting for an assessment of their needs, including needs relating to care, support, carers, occupational therapy or Deprivation of Liberty Safeguards, was just under a quarter of a million as at 31 August 2023.

Encouragingly, in its subsequent 2024 Spring Survey report, ADASS noted that the number of people waiting for an assessment of their needs had reduced to just over 227,000, a reduction of 8.9%. This reflected a general improvement in all waiting times in 2023/24, with a total reduction of 11% in the number of people waiting for assessment, care or direct payments to begin or a review of their care between the end of August 2023 and the end of March 2024 (from over 470,500 to just over 418,000).

However, where people's care is funded by local authorities, the availability of services is increasingly struggling to keep up with the overall level of demand. The latest available data from NHS England shows that in 2022/23, for the first time, local authorities received over 2 million requests for adult social care support from new clients (people who are not currently receiving long-term support). Our analysis shows that since 2017/18, the number of new requests for support has increased by 9%. However, the number of these requests granted with long-term care or short-term care to maximise independence has not kept up, as it increased by only 4% (figure 3). Meanwhile, the number of new requests that received no service increased by 27%.

Figure 3: Requests for local authority support and number of requests granted with long-term care or short-term care to maximise independence, relative to 2017/18



Source: NHS England Adult Social Care Activity and Finance Report

Last year's Review of Adult Social Care Complaints by the Local Government and Social Care Ombudsman gives case summaries that illustrate the real-life experiences of people who use services. Failures to provide timely and effective assessment and care planning featured in 4 of the public interest reports it issued during the year.

Example of a failure to carry out a timely care assessment

The investigation into a complaint about a county council found that a woman whose sight was impaired was left without social care support for 21 months, despite having eligible care needs. The council failed to comply with timescales for conducting a care assessment and preparing a care and support plan. The investigation found fault with the financial assessment and delays in arranging personal budget payments.

As a result, the woman was left at risk of falling and burning herself when cooking. She also suffered from increased isolation as she was not provided with support to access the community.

As a result of the investigation, the council:

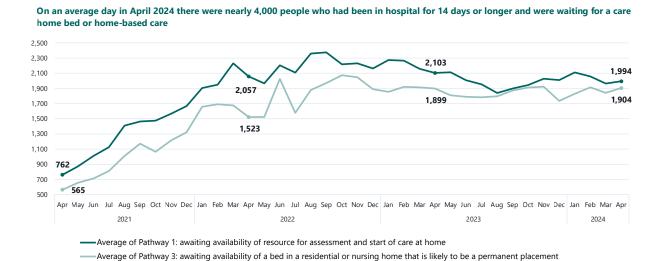
- agreed to review its processes for preparing care and support plans for residents with eligible care needs, and reminded frontline staff of the required timescales for these
- provided training for staff on financial assessments
- carried out an audit to identify residents who might have missed out on support following their care assessments because of delays in preparing care plans.¹¹

In April 2024, data published by <u>NHS England</u> shows that the combined waits for care home beds and home-based care accounted for an average of 45% of delayed discharges from acute hospital of people who had been in hospital for 14 days or longer. This was equivalent to nearly 4,000 people on an average day (figure 4). Of these people:

- nearly a quarter (23%) were waiting for an assessment to start a care package in their own home (daily average of just under 2,000 people) an increase from 18% in April 2021
- 22% were waiting for a long-term care home bed to become available (daily average of just over 1,900 people) – an increase from 14% in April 2021.¹²

It should be noted that waits for care home beds are predominately in adult social care but can include some NHS-funded nursing beds or continuing healthcare. Waits for home-based care can involve NHS and housing services as well as adult social care services.

Figure 4: Average daily number of patients with a length of stay of 14+ days whose discharge was delayed due to waiting for a care home bed or start of home-based care, April 2021 to April 2024



Source: NHS England Discharge Delay data

There is regional variation in the proportion of delayed discharges from hospital due to waits for care home beds or home-based care.

For example, the London region generally had the lowest proportion of delayed discharges that were due to waits for **home-based care**; these accounted for an average of just under 17% of delayed discharges in April 2024 (a daily average of just over 250 people). Meanwhile, for most of 2023/24, the same region had the highest proportion of delayed discharges that were due to waits for **care home** provision (residential and nursing care); in November 2023, delayed discharges that were due to this reached over a third (36%) of the region's total delayed discharges from acute hospital (a daily average of nearly 500 people).

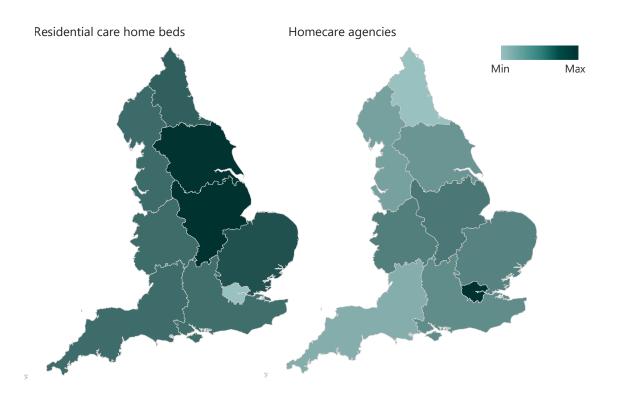
In comparison, for most of 2023/24, the North East and Yorkshire region had proportionally more delayed discharges because of waiting for an assessment to start home-based care than any other region in England. The daily average in April 2024 shows that, in this region, this was the cause of a third (34%) of delayed discharges of people who had stayed in hospital for 14 days or longer (daily average of over 400 people).

Although other factors may be involved, these differences could in part be explained by regional variation in the provision of social care. For every 100,000 people aged 65 and over, the London region has by far the most homecare services and the fewest residential care home beds. This may also partly explain why data from our provider information return shows that London also consistently has higher rates of care home bed occupancy than the rest of the country, as there are relatively fewer beds available. As at April 2024, there were less than half the number of registered residential care home

beds for every 100,000 people aged 65 and over (nearly 1,300) in London, than there were in Yorkshire and Humber and East Midlands (both nearly 2,700).

In the same way, there is potentially a link between the North East and Yorkshire region having the most delayed discharges from waiting for home-based care services to start and the North East having the fewest homecare services per 100,000 population aged 65 and over. As at April 2024, the North East had just over a third of the number of registered homecare agencies for every 100,000 people aged 65 and over (just over 70) as London (just over 200) (figure 5).

Figure 5: Maps showing registered residential care home beds and homecare agencies per 100,000 people over 65, April 2024



Source: CQC registration data

Although nationally the numbers of care homes, as well as beds, has fallen slightly over the last few years, the number of registered homecare services increased by a third (34%) between April 2020 and April 2024 to nearly 13,250 registered services. While the growth in adult social care services to provide people with care in their own homes is positive, it is important that there is sufficient capacity in care homes for people who need that kind of support and that regionally there is equal access to the right care to suit people's needs.

Spotlight on intermediate care

The <u>Intermediate care framework</u> defines intermediate care as involving community-based assessments and interventions provided to people in their own home, or in short-term community-bedded settings. Home-based intermediate care is the default pathway, as with the 'home first' approach.

Intermediate care services can be entirely health care, entirely social care, or ideally have elements of both delivered by multidisciplinary teams working in integrated ways. They may be commissioned by the NHS or by local authorities, and delivered by a range of providers across the health, social care, housing, independent and voluntary sectors.

Intermediate care is expected to result in improved outcomes, experiences and independence for people, as well as reducing avoidable re-admissions to hospital and avoidable or premature long-term care provision. Further expected benefits include improved flow and discharge from acute and community hospitals, and freeing up NHS hospital capacity for those who need it most.¹³

The most recent available data for 2022/23 shows that the number of new local authority requests for adult social care support that were met with short-term adult social care to maximise independence (support intended to reduce or prevent longer term reliance on social care) was the highest it's been in recent years, at nearly a quarter of a million (245,000). However, there is a lack of growth in the rate of provision – for every 100,000 adults in 2022/23, 5 fewer requests for support were met with local authority-funded short-term care to maximise independence than in 2018/19 or 2019/20.¹⁴

We wanted to hear from people who use services and organisations that represent them to find out:

- what good intermediate care looks like in the adult social care sector
- the barriers to achieving this
- what impact this can have on people who use services and on providers.

To do this, we carried out a survey of 720 people to understand their experiences of intermediate care services. Of the 245 respondents who said they or a loved one had received intermediate care, the majority (59%) were positive about their experience, with 38% saying it was 'good' and 21% saying it was 'very good'. However, a quarter (25%) of respondents described the care as 'average' and just over 1 in 10 (10%) said it was 'poor' or 'very poor'.

Nearly two-thirds (64%) of respondents felt their care had a positive impact on recovery or return to normality for them or their loved one.

We also spoke with people who had first-hand experience of using services and family carers through interviews and workshops.

Most of the people we spoke with were grateful for the care they received, with some saying, "I couldn't fault it", "The carers were excellent", "the physio was really encouraging".

However, we also heard that for some people, the discharge from hospital was "rushed", and that "Hospitals are desperate to discharge at any costs".

We also heard that "discharge had to be delayed due to a lack of reablement facilities" and, in some cases, there was a lack of local provision. This is supported by data from NHS England, which shows that in April 2024, 20% of people who had been in hospital for 14 days or longer and whose discharge was delayed were waiting for a rehabilitation bed in a bedded setting, such as a care home or community hospital.¹⁵

On a number of occasions, family carers told us that the hospital had spoken about discharge and what happens next with the patient, but did not include family carers in these conversations, which made it difficult for them to help and support their family member.

We also consistently heard that people were not aware of a care plan or did not have the opportunity to feed into their family member's care plan, so were unclear what was happening.

People expressed the importance of having joined-up services, with the need for clear communication with people using services and their carers, as well as between different services.

People also emphasised the importance of staff having an understanding of the communities they will be visiting, to enable them to deliver personcentred care, as the following experience describes:

"Being from a minority, often marginalised protected group – it was refreshing for the health professionals to not only ask about my life experiences and treat me as an expert about my own body and problems, but to also listen, respond and adapt care that felt holistic in nature by looking at the bigger intersectional picture – not simply a diagnosis and a singular health issue to work around."

Positive experience of intermediate care after an operation

Marianne, aged 81, was scheduled for a hip operation before Christmas last year. Before the operation, a package of support was arranged for her.

The occupational health team sent Marianne a form to complete, which asked questions on details such as the height of her bed and the distance from her bedroom to her bathroom, so they could work out what equipment she would need in her home after the operation. She was then visited before the operation to make sure she had all she needed, and that the equipment was set up correctly.

After a discussion with Marianne on the type of support she would need, the hospital arranged personal care support for her, such as help with showering and dressing. The package included 2 visits a day for the first week, and a morning visit in the second week. Her package of care also included a physiotherapist who would visit 3 times in the fortnight, and a district nurse to change her dressings.

On the whole, Marianne was impressed with how seamless her intermediate care was and how the system worked together. She is recovering well from her hip operation and pleased with the compassion that her carers showed to her.

(Interview with a member of the public)

Adult social care workforce

Vacancy and turnover rates

Data that care homes have submitted to us through our provider information return shows that estimated staff vacancy rates in care homes continued to fall throughout 2023/24, reducing to 5.4% by the end of the year. This is the lowest rate of staff vacancies in care homes in the last 3 years.

Regionally in England, staff vacancy rates in 2023/24 did not vary significantly. They were lowest in the Midlands, averaging at 5.6%, and highest in the South East at 7%. However, the South East had also seen the biggest reduction in staff vacancy rates since the previous year, when its vacancy rate of 11.6% was noticeably higher than most other regions.

Skills for Care estimates for 2023/24 show a similar picture to our provider information return, with the rate of vacancies in care homes at 5%. However, the overall vacancy rate across all adult social care stands at 8.3%, with the vacancy rate for homecare over double that for care homes – at 12%. Skills for Care makes the point that, despite recent reductions driven mainly by international recruitment (see below), the sector still has a vacancy rate around 3 times higher than the wider economy.¹⁶

Our provider information returns show that staff turnover rates in care homes also fell during 2023/24, and between January to March 2024 were nearly 10 percentage points lower than their peak between January to March 2022. However, with turnover at 27%, this means that at the end of 2023/24 over a guarter of staff in care homes had left their roles within a year.

Staff turnover rates in London across the last 2 years have been significantly lower than in other regions, and between January and March 2024 were just below 20%.

Skills for Care reports particular difficulties in retaining younger staff across the sector. Its estimates for 2022/23 show that London had the highest average age of direct care workers (45.5 years compared with a national average of 43.4 years) and that London also had the lowest proportion of direct care workers aged under 25 (6% compared with a national average of 9%). As London has fewer younger staff, this might then explain why the region has a significantly lower turnover rate than the rest of the country.

The age of the workforce is a concern across all regions: nationally, 27% of workers who provide direct care are aged over 55, and therefore likely to leave the workforce relatively soon.

It is worth noting that London is also an outlier regarding the rate of zerohours contracts, where the employer is not obliged to provide any minimum working hours. Skills for Care estimates show that the highest rate is in London, with 6 times the proportion of direct care workers on zero-hours contracts, compared with the North East, which has the lowest rate (62% versus 10% in 2022/23). Nationally, more than 1 in 4 direct care workers (28%) was on a zero-hours contract in 2022/23. This compares with a rate of just 3.5% in the wider English economy, according to the Labour Force Survey from January to March 2023.¹⁷

Impact of recruitment issues

Our provider information return for adult social care asked providers to describe the challenges they face in providing good quality care. They told us about difficulties in recruiting new staff, with one saying:

"The high demand for care services coupled with the perception that caregiving roles are low-paying and physically demanding can deter potential candidates."

Through focus groups with our inspectors, we heard that high staff turnover can lead to poor practice as there are not enough established staff to mentor new staff.

Vacancy rates and high staff turnover can place a great deal of pressure on existing adult social care staff. <u>A GMB Union survey</u> shows that 70% of social care workers say understaffing is negatively affecting their mental health.¹⁸

We saw these pressures illustrated during an inspection of a care home this year, which was rated as requires improvement for the well-led key question.

Managerial and staffing pressures at a care home

At the time of our inspection, there was no registered manager in post. The interim manager who was covering was clearly committed to providing high standards of care, but acknowledged they did not have time to complete some aspects of their managerial role.

Records showed that on the week of our inspection visit, the interim manager had worked for 7 days, including 2 days supporting people to help cover shortfalls in the staff rota. Although working support shifts enabled the interim manager to have a good understanding of the challenges for staff, it did not support their wellbeing.

Records also showed that other members of staff were working very long hours without the government-recommended breaks between shifts. This was a particular concern because of the potential risks when providing the complex support people needed.

The provider had appointed a new manager and assured us that the rota would be monitored better to ensure staff had the recommended breaks when they volunteered to pick up additional hours at work.

As well as pressures on providers and existing staff, high turnover can also have an impact on people who are using services. One homecare provider told us, through our provider information return, how "staff have left and clients who had built good relationships with them have understandably not welcomed the change. We have had to carefully phase staff in and out, especially for clients with a learning disability."

International recruitment

Large numbers of staff have been recruited into adult social care since care home and homecare workers were added to the government's Shortage Occupation List and the Health and Care worker visa route from February 2022.

Estimates from Skills for Care suggest that in 2023/24, 105,000 people had been recruited from overseas into direct care roles, compared with 80,000 in 2022/23. However, increases have showed signs of levelling off: in 2022/23 there were 4 times as many people recruited from overseas compared with 2021/22, but in 2023/24 international recruitment increased by just under a third (31%).

Many of these workers came to work in London and the South East, with roughly 18,500 people recruited internationally for direct care roles in London and 18,000 in the South East in 2023/24.

Recent provisional <u>Home Office figures</u> indicate a steep fall in the numbers of overseas workers applying for health and care worker visas. There were 10,800 applications between April and July 2024 – an 81% decrease compared with the same 4 months in 2023, following the policy changes affecting social care workers and their family members.¹⁹

Although international recruitment has been the main driver behind the overall increase in filled posts and reduction in vacancies in adult social care, focus groups with our inspectors for this report have highlighted challenges faced by some staff, for example:

- some overseas workers have had to work very long hours to gain the minimum wage required by the sponsorship contract, leading to stress and mental health issues
- when groups of international staff start work at the same time, this puts pressure on existing staff to induct them
- staff have experienced racist abuse.

Unethical recruitment and exploitation in health and social care

We have been building our understanding and regulatory response to the emerging issue of modern slavery and exploitation of workers within the health and social care sector.

Aligned with our commitment to regulating to protect people's human rights, we fully support the government's objective to eradicate modern slavery and human trafficking. Modern slavery and unethical international recruitment practices can be present in any health and social care setting.

Late in 2023, we set out our regulatory policy position on modern slavery and unethical international recruitment and reviewed our modern slavery and human trafficking statement.

We recognise that workers recruited from overseas are a hugely valuable and important part of the UK's health and social care workforce. International recruitment itself is not a risk that leads to modern slavery. Regrettably, unethical international recruitment practices are now evident, particularly the exploitation of workers using the immigration system and being sponsored to obtain a skilled care worker visa to work in the social care sector.

Although we do not have the authority to investigate concerns relating to modern slavery and unethical international recruitment directly, we do share relevant concerns from our work to help partners ensure compliance with the Human Rights Act 1998. These include the right for people to be free from slavery and forced labour under Article 4 of the European Convention on Human Rights, as incorporated into the Human Rights Act 1998.

In 2023/24, we made 106 referrals to partners agencies who have the duty to investigate concerns regarding modern slavery and labour exploitation. This is nearly 3 times as many as the previous year – we made 37 referrals in 2022/23 and 8 referrals in 2021/22.

The referrals we made related to:

- modern slavery
- labour exploitation
- debt bondage
- · controlling, coercive behaviours
- visa exploitation
- sexual exploitation.

Future of the adult social care workforce

We support and value the huge contribution of the adult social care workforce to care services and people's lives every day.

Over successive years, we have called for a national workforce strategy that:

- recognises the importance of effective and consistent leadership
- raises the status of the adult social care workforce
- ensures that career progression, pay and rewards attract and retain the right professional staff in the right numbers.

Skills for Care has overseen work on developing the <u>Workforce Strategy for Adult Social Care in England</u>, which we welcome and have contributed to. We support the need for a national workforce strategy for social care, alongside the NHS workforce strategy, to give parity of approach.

To achieve this, we will work closely with Skills for Care and other key partners to ensure that we have a healthy, skilled and enabled workforce – now and in the future – to continue delivering high-quality and compassionate care.

Complaints about adult social care

We can see the impact on people when they use poor adult social care services in the complaints investigated by the Local Government and Social Care Ombudsman, as the following examples highlight.

Examples of complaints investigated by the Local Government and Social Care Ombudsman

One investigation referenced in the Ombudsman's annual report for 2022/23 was of a homecare agency commissioned by a local authority in the North West. It found that staff were not staying long enough to deliver sufficient care to an older woman who had dementia. Care workers were sometimes staying for only 3 minutes, despite the family paying for the full 15-minute visit – which is in itself little time to complete the care tasks many people need.

As a result of the investigation, the local authority apologised to the family, made a payment for the distress caused and reviewed other cases with 15-minute care calls. The review found that over 300 people in the area were also receiving short calls, so the local authority agreed to review a sample of these cases to work out the wider extent of any shortfall in care being provided.

In another investigation, the Ombudsman found that a local authority took too long to arrange an assessment of the needs of an autistic man, and then failed to provide the support he needed for a further 16 months.

The man was not offered an advocate and, because the social worker did not have a good understanding of autism, his assessment was ineffective. This meant the services provided were not sufficient and his partner had to provide additional support. The local authority did not properly assess his partner's needs as a carer or provide her with support, and also failed to deal properly with the complaint.

One of the Ombudsman's recommendations related to ongoing autism awareness training for staff.

The pressure on carers highlighted in the second investigation is also reflected in a <u>survey of over 40,000 unpaid carers who are known to their local authority in England</u>. When asked how much time they have to look after themselves – in terms of eating or getting enough sleep – the proportion of carers who said that they feel they look after themselves has reduced from 52% in 2018/19 to 47% in 2023/24, and the number who felt they were neglecting themselves increased by 2 percentage points during this period.²⁰

Capacity and stability in adult social care

In previous State of Care reports, we have reported on financial concerns for providers because of relatively low levels of care home beds occupied during the pandemic, but that this has since been recovering. Estimates from our provider information returns indicate that the recovery in bed occupancy continued through 2023/24, nearly reaching 84% by the end of 2023/24.

Bed occupancy in care homes was consistently higher in London than in other regions, averaging nearly 86% across 2023/24. The Midlands had the lowest bed occupancy rates over 2023/24, with an average of just over 82%. It also had one of the lowest recoveries in bed occupancy since 2021/22, increasing by just under 4.5 percentage points.

Increased bed occupancy has helped to improve the profitability in adult social care providers in our <u>Market Oversight scheme</u>. The scheme monitors the financial sustainability of adult social care providers that have a large national, local or regional presence which, if they were to fail, could disrupt continuity of care in a local authority area.

A key measure of profitability we monitor is 'EBITDARM', which is a high-level measure of profit that excludes key expenses such as rent, depreciation and interest charges. This shows that profitability in care homes for older people was 26.9% in March 2024, representing a recovery from 22.5% in March 2022.

As well as increased occupancy, various factors have contributed to this recovery, such as fee increases and stabilised costs. But we have particularly noted the impact of reducing costs for agency staff on overall staffing costs.

Figure 6 shows that care homes for older people saw the greatest reductions in agency staffing costs as a percentage of total staffing costs, falling from nearly 14% at the end of March 2022 to under 5% by March 2024.

Over the same period, agency staff costs for specialist care home and homecare providers fell from just over 11% of total staffing costs to just over 7%. These providers deliver services to people with complex needs, including autistic people and people with a learning disability, and people with mental ill-health and physical disabilities.

There is a more stable picture for homecare services, as agency staff costs fell from 3.4% of total staffing costs to 2% between the start of 2022 and the start of 2024. Profitability in this sector was at 17% in March 2024, an improvement of over 4 percentage points in the last 12 months.

16% 13.7% 14% 12.6% 11.3% 12% 10% 7.3% 8% Specialist providers 6% Care homes for older people 3.4% 4% 2.8% 2.0% 2% 2021/22 2023/24 2022/23

Figure 6: Agency costs as a percentage of total staff costs for providers in CQC's Market Oversight scheme

Source: CQC Market Oversight data

The move to reduce the proportion of agency staff used is also reflected in responses to our provider information return. As well as the cost benefits described above, providers tell us how depending less on agency staff maintains consistency of care and establishes relationships, which benefits the people using their services and improves communication within the team. One care home provider told us:

"We are actively working to reduce the use of agency staff within the service to ensure we can build our team, which will in turn be more effective for the service with better teamwork and communication."

International recruitment was noted as an initial driver in reducing use of agency staff, but this is showing signs of levelling off in 2023/24. Subsequently, providers of care homes for older people within the Market Oversight scheme have reported improvements in recruitment and retention of people within the UK, which has contributed to lower spending on agency staff. However, specialist providers continue to refer to workforce as a key challenge, and are experiencing lower increases in profitability compared with the other types of providers in the Market Oversight scheme.

Increased fees paid by local authorities in 2023/24 also contributed to improved profit margins in older people's care homes and in homecare providers. But providers in the scheme are telling us that the increases for 2024/25 do not fully meet increased costs, for example increases in the National Living Wage. This is supported by the 2024 Spring Survey from the Association of Directors of Adult Social Services, which states that, "The one-year funding settlements from Government that have been the norm for several years have failed to create the conditions for adult social care to thrive."²¹

Providers are telling us that the amount of homecare commissioned by local authorities is less than the available capacity. Where comparisons can be made, data from providers in the Market Oversight scheme over the last 2 years suggests there is a reduction in the number of homecare hours that have been provided.

This echoes findings from a survey we carried out last year, which found the most common reason from care providers for unused capacity was a lack of commissioning opportunities.

While there are promising signs in terms of increased occupancy and profitability, there are still some concerns around the sustainability of the adult social care market. Providers have faced higher costs in recent years due to inflation and workforce challenges and this has affected their financial position, for example leading to a reduction in reserves. This means some providers may have lower resilience to deal with any future financial and operational challenges.

We spoke with ARC England, a membership organisation for providers of services for people with a learning disability and autistic people about the financial pressures its members are operating under.

We heard how many local authorities are not paying an hourly fee rate that allows providers of services for people with a learning disability and autistic people to pay their staff the National Living Wage, which is shown in ARC's analysis.²²

ARC told us that increases in fee rates over the last 6 years have been lower than the actual inflation rate when salary costs are taken into account. This is illustrated by the example of supported living services, which we highlighted in our State of Care report last year, where more than 85% of providers' costs can be staff wages. This means that when national wage rates are increased without an accompanying increase in local authority fee rates, services quickly become financially unsustainable.

According to ARC, one impact of this long-term underfunding of its members is a loss of services, driven by providers handing back contracts and declining to offer a service that they would otherwise be well-placed to deliver. ARC told us about an example where one of its members used their fee-rate maps to make the decision not to expand into their neighbouring counties because the fee rates being offered by the relevant local authorities were too low to allow them to offer a good enough service.

ARC also commented that unsustainable fee rates create the longer-term effect of "opportunity loss" because providers are not being paid to develop existing services or to design new models of care. One of the consequences of this, that ARC and its members are especially concerned about, is that the progress made in recent years to support people in ways that increase choice and control in their lives, and which promote their independence, is placed at risk.

Medicines support in adult social care

Elsewhere in this report, we highlight how closures of community pharmacies have had a disproportionate impact on people in the most deprived neighbourhoods.

Access to medicines is also an issue for services. For example, we have seen through our conversations with providers how care homes and homecare services are struggling to get certain medicines that have been prescribed, which means they then spend more time going back to the GP to ask for an alternative.

To help us understand this issue, we commissioned Ipsos to carry out research with adult social care providers to look at how medicines were being managed in adult social care settings and the support they received from other health and care providers in their area.

As part of the research, a survey with 2,331 respondents in February and March 2024 showed that 34% of adult social care providers said the support they receive from their usual supplying community pharmacy has got better, and just over 1 in 10 (13%) said the support they receive has declined over the last 12 months.

Care homes with nursing, which are potentially more likely to require pharmacy support, were more likely to say the support they receive has declined over the past 12 months (18% compared with 13% overall). Also, adult social care providers in the South West of England, a region we have highlighted in this report as having issues with access to primary and community care, were also more likely to say their support has declined (24% compared with 13% overall).

The survey also highlighted some opportunities for improvement:

• Less than a third (30%) of adult social care providers said they received support from community pharmacy or other healthcare professionals to help them encourage people they care for to self-administer their medicines, and 25% said it was not applicable to their service at all. NICE guidance states that social care providers should assume that people can take and look after their own medicines unless a risk assessment indicates otherwise.

- Only 1 in 5 (20%) reported that medicines tasks were delegated to care workers in their service. Nurses can delegate more complex medicines tasks to care workers, provided that <u>certain requirements are met</u>. This can free nursing time and ensure people get their medicines in a timely way.
- Only a third (36%) said they used NHS Mail. Most (85%) of those who
 used it said it was useful. NHS mail provides a safe and secure method
 of exchanging sensitive information and <u>is available</u> to all homecare,
 residential or nursing care providers.

Outstanding adult social care providers

Personalised care

Despite the challenges described in this report, outstanding adult social care providers are putting people at the heart of all decision making. Analysis of a small sample of inspection reports published in 2023/24 of services rated as outstanding highlights that person-centred care, delivered with compassion and integrity, still makes a big difference to people's lives.

One prominent theme from our analysis was that these outstanding services placed a focus on understanding people on an individual level to provide care and support that best meets their needs.

Several inspection reports outlined examples of this person-centred ethos. It often involved services encouraging people to be involved in decisions about their care, so that they could make meaningful tailored adjustments to the support they provide. This was highlighted in a service for people with a learning disability, autistic people, and people with mental health support needs:

"One person had previously lived in secure hospital settings for years and had become institutionalised. However, since moving into [the care home], we saw how staff had responded to this person's needs and worked collaboratively with them to implement a comprehensive support plan which, over time, increased their independence. This culminated in this person enjoying their first holiday in over 10 years!"

We saw that a compassionate and empathetic approach to care was nurtured through training. A member of staff at another service described to our inspectors how dementia training had:

"...changed the way I supported people. It exposed my mind to how we see people and I'm putting myself in their shoes so I can feel what they feel. This made a big impact on how I support people."

One homecare service rated as outstanding told us how it had rolled out a 'Care Ambassador programme', giving specialist staff oversight in areas such as dementia and care at the end of life, to enable them to help with recruitment and training of new staff. These Ambassadors also play a key role in filling out 'All About Me' pages, which highlight important details such as people's life history, preferences, likes and dislikes.

Adapting the environment

Inspections also highlighted the important role of the physical environment in enabling services to meet people's personal choices and needs well.

One care home had taken steps "to recreate the layout" of the ordinary homes people lived in before moving into the service:

"There were meetings to ensure people and their relatives agreed what furniture could be moved, including matching paint and other items such as artwork and curtains to further create a familiar environment. People and their relatives praised how they were involved and how the smooth transition reduced any fears or anxiety of moving home."

This commitment to creating a welcoming and tailored environment extended to the door to each person's room, which displayed a bespoke piece of art that meant something unique to that person, designed by the in-house artist. For example, one person had a piece of art inspired from an old Valentines card that had significant sentimental value to them.

Activities, goals and interests

Outstanding services also acknowledge the importance of holistic approaches to support and care, for example including people's goals and personal interests, and involving them in communities. To support these aspects of people's lives effectively, staff often need to build a personal understanding of the people they support.

One inspection report commended a service for having "gone the extra mile to find out what people had done in the past and accommodate activities around this". One such activity was a trip to an airfield for a former Spitfire pilot who wanted to see his favourite aircraft again for a special birthday with his relatives. This helped him to fulfil "a long-term ambition".

An outstanding homecare service supporting autistic people and people with a learning disability told us through its provider information return how it supported a person to regain their cooking ability. This person had a fear of cooking, but staff supported them to build their confidence to the extent that they often chose to cook for the whole house.

Innovations and technology

Some inspection reports captured innovative approaches to providing personalised support, which was sometimes helped by using new technology. For example, a service promoted independence and privacy by using a lighting system and acoustic monitoring technology to help people have a restful night without the need for staff to disturb them, while ensuring people's privacy and dignity was upheld. One relative told us the equipment helped to reduce any falls as it enabled their family member to be more independent.

We support the Department of Health and Social Care's <u>Digitising Social Care</u> <u>programme</u>, which has been providing additional funding to care services to support them to move towards digital record keeping. CQC collects data

on uptake of digital social care records as part of our provider information returns. Analysis of this data, published by the Department, shows a huge increase in the estimated percentage of providers with digital social care records, which has increased from 41% of care services in December 2021 to 70% in the latest publication in May 2024.

It is encouraging to see other areas of research and innovation in social care that have the potential to bring real improvements to people using services.

Examples of joint working on innovative care for older people

Monitoring infections in care homes

The <u>UK Health Security Agency</u> has announced funding for a pilot scheme to monitor infections in care homes in England. The pilot builds on the Vivaldi study, which began during the pandemic to monitor COVID-19 infections. The Vivaldi social care project is a collaboration between University College London, The Outstanding Society, Care England, and NHS England. It will work with over 500 care homes in England to monitor infections such as COVID-19, flu, norovirus and urinary tract infections. The results will be analysed to help reduce infections in care homes for older adults.

Reducing risk of falls while improving care

Another <u>example</u> from collaborative work started when University Hospitals of Leicester NHS Trust (UHL) noticed an increase in toileting-related inpatient falls. It asked the question whether reducing caffeine intake can reduce the number of falls, as it has a mild diuretic effect and can increase urinary frequency and urgency. It offered decaffeinated drinks to patients, and early results showed a 30% reduction in the number of falls.

Recognising that falls are the most common cause of injury-related deaths in people over 75, Care England worked with UHL to find adult social care providers willing to take part in a care home trial. Over a 6-month trial of introducing decaffeinated hot drinks as the default in its homes, one care home provider (Stow Healthcare) observed a 35% reduction in toileting-related falls. It has continued to offer decaffeinated drinks as default, with the option of caffeinated beverages available.

This was a small study, but the researchers have suggested that extending it across the sector could save £85 million a year in prevented falls and hospital admissions – and, of course, reduce the number of people whose lives are affected by falls.

Mental health

Key findings

- The demand for adult mental health services continues to grow, and even more so for children and young people, with ever increasing numbers seeking care and support for their mental health.
- Access to mental health services remains a challenge for many people.
 Research from the Strategy Unit (hosted by NHS Midlands and Lancashire) shows that people who live in deprived areas, women, and people from 'other' ethnic minority groups with mental health needs are more likely to attend urgent and emergency care departments.
- Our regulatory activity, including our special review of <u>Nottinghamshire</u> <u>Healthcare NHS Foundation Trust</u>, has found evidence of people having to wait several months, and in some cases several years, for treatment in the community.
- While the mental health workforce has grown, problems with staffing and skill mix remain. Across the country, services are facing challenges in recruiting staff – all of which are having an impact on capacity, and the availability and regularity of appointments.
- The safety of mental health wards continues to cause concern. Lack of resources, ageing estates and poorly designed facilities can lead to issues around privacy and dignity for patients, as well as compromising the safety of both patients and staff.

The level of demand for adult mental health services continues to grow. Data from the Mental Health Services Data Set (MHSDS) shows there were 600,000 more people in contact with secondary mental health services in June 2024 than there were in June 2019. This reflects a 45% increase in 5 years, which cannot be accounted for by population growth alone.

In June 2024, for every 1,000 people, 34 were in contact with services compared with 24 for every 1,000 people in June 2019.

While the number of people in contact with mental health services is increasing, figures show that there has not been a corresponding rise in the number of interactions people have had with services. This could potentially suggest that not everybody is getting the same level of care.

We can see from data that between June 2022 and June 2024, there was a 21% rise in the number of adults aged 18 to 64 in contact with services, but the number of interactions they had with services only increased by 9%. The picture is worse for children and young people: in the same period, the number of children and young people in contact with mental health services increased by 29%, but the number of interactions they had with mental health services only increased by 11% (figure 7). As well as supporting a growing number of people, mental health services are also receiving an increasing number of referrals from other services.

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Figure 7: People in contact with mental health services by age group, April 2022 to June 2024

Source: Mental Health Services Data Set (MHSDS)

Being able to get the right mental health care, as early as possible, can have a significant impact on the trajectory and severity of a person's illness.²³ However, we are concerned that access to mental health services remains a challenge for many people. As highlighted in this section, research from the Strategy Unit (hosted by 'NHS Midlands and Lancashire') shows that people who live in deprived areas, women, and people from 'other' ethnic minority groups with mental health needs are more likely to attend urgent and emergency care departments.

Long waits for community mental health care

As reported in last year's State of Care, we continue to be concerned that a high demand for community mental health services – without the capacity to meet it – is affecting people's ability to get the help they need, when they need it. Our regulatory activity has found evidence of people having long waits from referral to receiving treatment in the community.

Access to care was one of the key concerns we raised in our special review of Nottinghamshire Healthcare NHS Foundation Trust (NHFT).²⁴ In this review, we found that high demand and lengthy waiting lists meant that people were not able to get the care they needed when they needed it. Many people told us they were unhappy with access to community mental health and crisis services at NHFT, with many reporting that they felt frustrated by "immense" or "extraordinary" waiting times:

"I have now been on it [waiting list] over 1 year, and was told when I first asked for help, that it would be 3 to 4 months. I was totally forgotten after my initial assessment, which was traumatic... I have had to chase numerous times to get feedback, updates etc, I have gone backwards on the waiting list."

Our findings from Nottingham are not unique. Our analysis of free text responses to the 2023 NHS Community mental health survey found that people reported having to wait several months, and in some cases several years, between referral, assessment, and treatment.

While a few people described seeking alternative private health care, this was not an option for many people. This can lead to inequity between those who can afford private care and so avoid the waits, and those who cannot.

Results from the survey show that children and young people had a worse experience than adults, and faced long waiting times at all stages of care. This included waits for initial assessments, diagnoses, medicines, and therapies. Of the respondents who had used children and young people's mental health services, 61% (327 out of 534) said they waited too long for their first appointment for treatment.

Waiting times for children and young people are variable. This is supported by findings from the March 2024 Children's Commissioner's report on children's mental health services. This reported that in 2022/23, the average (median) waiting time of the 305,000 children and young people entering treatment (receiving their second contact from children and young people's mental health services) was 35 days or 108 days (mean). The median wait varied widely between integrated care board (ICB) area from 5 days to 79 days. This disparity suggests that services are operating in a complex and demanding environment, and are continually having to prioritise.

For the 270,300 children and young people recorded as still waiting at the end of the year for their second contact, they waited on average 142 days (median) or 359 days (mean).²⁵

Some young people who responded to the NHS Community mental health survey also described being denied support on multiple occasions before being accepted by mental health services:

"I was turned away the first time because I wasn't bad enough! Which is ridiculous because I had expressed suicidal thoughts."

We are also concerned that because support from children and young people's mental health services typically ends at 18 years old, there is an increased risk that older teenagers (people aged 16 to 18) may fall through the gaps. For example, one person described how, "[I was] told that I was nearly 18 so no point in starting treatment."

Jamie's story

Jamie, who is autistic, told us about their experiences of seeking help from mental health services. In 2020, on the cusp of lockdown, the specialist school that Jamie attended went into liquidation. After some time at home and an unsuccessful placement at another school, Jamie started at a new specialist school closer to home in January 2021. However, the pandemic and disruption to their education was beginning to have an impact on their mental health.

Jamie began to suffer with increased anxiety, trouble sleeping, and nightmares, so they contacted the GP who made a referral to children and young people's mental health services. Unfortunately, this first referral was not accepted by the service, with no reason given, so Jamie sourced some counselling privately, which they did not find helpful.

A few months later, a second referral was made, which was accepted. Jamie was assessed by a mental health practitioner and offered 10 to 12 sessions of therapy to address their anxiety. This therapy didn't seem to help, so Jamie was upgraded to a higher tier of support. It was acknowledged that Jamie would likely benefit from medication, but they were told it would not be prescribed unless they tried cognitive behavioural therapy (CBT) first, despite having tried it twice without success in the past.

Jamie was eventually seen by a psychiatrist who diagnosed them with generalised anxiety disorder and prescribed anti-anxiety medication. However, Jamie later had to stop taking the anti-anxiety medication because of the side effects – they started to get mood swings and hear voices, which further worsened their mental health.

Jamie was then discharged from children and young people's mental health services when they turned 18:

"And then they just discharged me like that. That was it, there was nothing else, there was no continuation of care, there was nothing. And my mental health has just deteriorated since then. My mood swings have got worse, I've started hearing stuff, I can't sleep... I just felt like, well, what the hell am I meant to do?"

Jamie asked about an onward referral from the children's to the adult community mental health team, but was told that it was not appropriate because their condition was not severe enough. They have since been back to their GP and have been placed on a new medication, which is helping a little with their anxiety, but the mood swings are still present. The GP has now also made a referral to adult community mental health services, and Jamie is waiting for an assessment to decide if they will be offered any support. Daily life continues to be a struggle while they are waiting:

"I'm not really going out a lot. I get quite depressed when I'm in depressed moods. I do neglect myself a lot, like not clean my room or not clean my teeth or wash. I can't really look after myself."

(Interview with a member of the public)

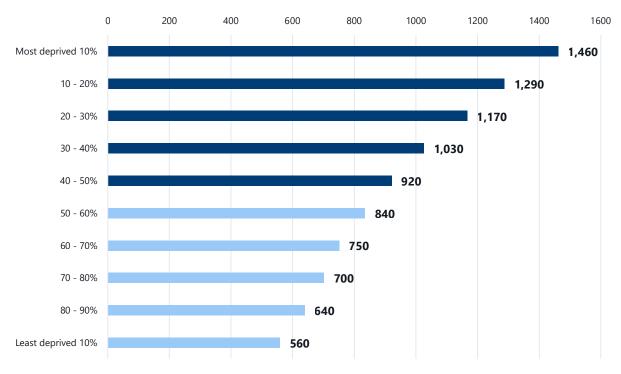
The consequence of not getting support is highlighted by findings from the research we commissioned from the Strategy Unit into mental health attendances in urgent and emergency care settings. This found that people aged 18 to 21 consistently have the highest rates of presentation for mental health issues at both emergency departments and urgent care centres. In addition, they found that children and young people aged 0 to 17 were the only age group to have an increase in attendance rates at type 1 urgent and emergency services (A&Es) since 2019/20.

These findings show that not getting the right help at the right time can lead to symptoms getting worse and people ending up in crisis and/or inappropriate environments, such as urgent and emergency care. We heard that deterioration in people's conditions can be compounded by poor communication from providers while waiting. One respondent to the NHS Community mental health survey described how, "...not knowing feeds my anxiety and depression. Instead of helping they are making it worse."

Figures from NHS England's Mental Health Services Data Set (MHSDS) show that the number of adults with a serious mental illness who accessed community mental health services increased from nearly 560,000 to just over 600,0000 between June 2023 and June 2024 (an 8.9% increase).

People's need for mental health services varies depending on where they live. Data from MHSDS shows that people with a serious mental illness who live in deprived areas are more likely to be in contact with services (figure 8).

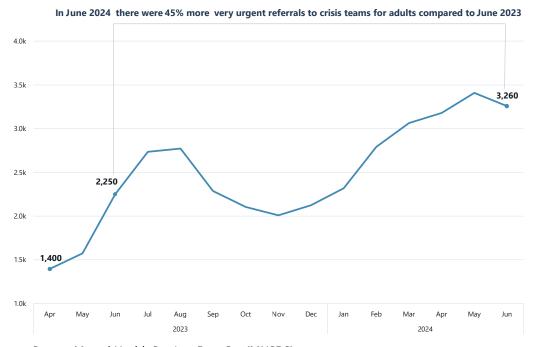
Figure 8: Adults per 100,000 population with serious mental illness who received 2 or more care contacts by deprivation decile, 2022/23



Source: NHS Digital, Mental Health Bulletin

In June 2024, very urgent referrals to crisis teams for adults were 45% higher than in June 2023 (figure 9). These figures support the findings from our special review of Nottinghamshire Healthcare NHS Foundation Trust, where we identified high levels of need for the trust's crisis service. This was potentially being exacerbated by the waiting times for people who need longer-term support from the community teams.

Figure 9: New very urgent crisis team referrals for people aged 18 and over



Source: Mental Health Services Data Set (MHSDS)

Best practice guidelines from the Royal College of Psychiatrists state that crisis teams should see very urgent referrals within 4 hours, and urgent referrals within 24 hours. In June 2024, only 20% of adults with a very urgent referral were seen face-to-face within the 4-hour standard.

When people reach crisis point but can't get help from specialist crisis services, they may need urgent care in hospital. The research by the Strategy Unit shows that across England in 2023/24, people with a primary diagnosis of a mental health condition made 200,000 attendances to emergency departments and 20,000 attendances to urgent care (type 3) units.

This research also showed that some people are more likely to need help from urgent and emergency services than others. People who live in deprived areas, children and young people, people from 'other' ethnic minority groups, including Chinese and Arab people, and women all present at urgent and emergency care departments at higher-than-average rates. In particular, it highlighted that urgent and emergency care attendance rates are over 3 times higher for people who live in the most deprived areas than for people from the least deprived areas. While the majority of these patients are known to specialist mental health providers, a substantial minority (20% attending type 1 emergency (A&E) departments) are not.

As we highlighted in our 2020 report <u>Assessment of mental health services in acute trusts</u>, emergency departments are often not suitable environments for people experiencing a mental health crisis. While they may be able to provide a safe physical environment, they are not therapeutic for people with mental health needs and can make people's mental and physical health worse.

Despite this, the Strategy Unit research shows that in 2023/24, people presenting with mental health issues waited longer in the emergency department for assessment, treatment and discharge. The average emergency department 'pathway' was almost an hour longer for mental health patients.

People are still facing long waits in an emergency department while they wait for a mental health bed to become available. This issue was raised by people in their comments through Give feedback on care:

"My daughter was admitted to [the ward] around 9pm, having waited 5 days in A&E for a place."

"I joined the 10 to 15 psychiatric patients waiting in A&E for psychiatric beds. I was informed that there were 60 patients on the bed list and no beds available."

Marlon's story highlights the importance and positive impact of getting access to the right care, in a timely way.

Marlon's story

Marlon came to the UK from Jamaica in 1990 and happily worked up until his recent retirement. Within the space of a few years, he had experienced retirement, the loss of his mother, and a terrible experience with Covid where he had to be admitted to hospital as his oxygen levels were alarmingly low. These stresses took a toll on him and 18 months ago his mental health deteriorated.

During this time, he became paranoid, believing he and people he loved were being followed and might be harmed. He noticed something wasn't right and eventually admitted he felt very ill and needed help. His wife was scared of what was happening to him, and he was taken to A&E where he was assessed by the mental health team and then admitted to hospital.

Marlon's recovery went well, and he describes the care and treatment he received as exceptionally good, and his consultant as extremely helpful in helping him to get back on his feet. He did experience terrible side-effects from his medication following discharge from the ward, so he went to his GP who, rather than stopping the medication, offered further medication to dampen the side-effects. He described going back to the consultant rather than taking more tablets, and at that point was told to stop the medication, which led to him feeling a lot better and being free of side-effects.

His follow up from hospital discharge was within weeks, and after an assessment, he was offered support from a different service. He felt the therapy service, which was near to his home, was right for him. He started therapy within weeks and attended a peer support group, as well as other activities at the hub. "The therapy helped me more than anything else because you get to meet other people in similar situations."

Marlon has now become a volunteer where he received support, and it is one of the things he looks forward to doing each week. He can give back, and he also gets informal support if he ever needs to check in with the staff.

Although his experience was strange and frightening for him and his family, he felt the NHS dealt with it very well and in a timely way. He describes very positively the support he has received and continues to in his role as a volunteer.

(Interview with a member of the public)

Lack of inpatient beds

High levels of bed occupancy in mental health hospitals are a known indicator of pressure in other parts of the system. Over the last 13 years, mental health bed occupancy has increased from around 86.6% to 90.4%.

Lack of inpatient beds, combined with a lack of capacity across the system, including community care, can lead to people being sent to a hospital miles away from home. We know that these <u>out-of-area placements</u> can be hugely detrimental to people's recovery. Not only can it leave people feeling isolated

because friends and family are often not able to visit, but it can also increase the risk of closed cultures developing in services. In addition, as reported in our 2022/23 Mental Health Act annual report, it can increase challenges around communication with community mental health teams and securing appropriate community support back in the person's local area.²⁶

Despite the previous government's commitment in 2021 to ending out-of-area placements, more than 1,500 people were in an inappropriate out-of-area placement at the end of June 2024. This, together with the high occupancy rates, suggests there isn't enough capacity in inpatient settings to meet the needs of patients being referred from the community.

Lack of capacity in the system has also led to people under the age of 16 being placed in inappropriate settings (wards designated for the treatment of adults). Figures from MHSDS show the number of adult bed days within a reporting period that are used by children, but they do not show the number of children. For example, 10 bed days could mean that 1 child may have been on an adult ward for 10 days in a month, or 10 children may have been on an adult ward for 1 day each. In 2022/23, across England children and young people spent on average 313 bed days a month on adult wards, reflecting the high need for specialist mental health beds for children and young people under 18 years.

<u>Guidance from NHS England</u> is clear that people should be discharged to a less restrictive setting as soon as the purpose of their admission is met and they no longer require care and treatment that can only be provided in hospital.²⁷

The NHS Long Term Plan set out the ambition that people should have inpatient stays of no longer than 32 days.²⁸ However, figures show that for adults discharged in June 2024, nearly 2,500 had stays of 60 days, down from a recent high of over 3,200 in March 2024. Nearly 1,400 had stays of over 90 days also down from nearly 1,900 in March 2024. Longer stays may be due to people being more ill on admission, which may take longer to treat, as well as other factors such as being placed out of area, or other issues such as housing.

Issues with staff shortages may also have an impact on the length of inpatient stays. Our 2022/23 Mental Health Act annual report shows the findings from our monitoring activity. We've seen how staff shortages have affected patients' access to therapeutic activities, stopped them from taking planned leave, or even prevented them from accessing fresh air – all of which are vital in creating therapeutic environments and supporting people's recovery.

Data from NHS England shows that people aged 18 to 64 from the most deprived areas of England are far more likely to have longer stays in hospital. It shows that for every 100,000 people from the most deprived areas:

- 65 people have stays longer than 60 days compared with 14 people from the least deprived areas
- 37 people stay longer than 90 days compared with 7 people from the least deprived areas.

There are also stark differences for some people from ethnic minority backgrounds, especially for people in Black ethnic groups. The data shows that in 2022/23, for every 100,000 of the population:

- 100 Black people stayed in hospital for longer than 60 days, compared with 25 white people (the group with the lowest number of people)
- 55 Black people stayed in hospital for longer than 90 days, compared with 15 white people (the group with the lowest number of people).

Quality of mental health care

Generally, when people can get access to mental health services, they are often satisfied with their treatment, and grateful to staff.

However, people are still struggling to get person-centred care at a time that works for them.

The impact of staffing on the quality of care

The mental health workforce grew by nearly 40,000 full time equivalent (FTE) members of staff (35%) between March 2019 and March 2024. While this is a positive improvement, we remain concerned about the impact of difficulties in recruiting staff to specific, skilled roles.

Problems with staffing and skill mix was a key concern identified through our special review of services at Nottinghamshire Healthcare NHS Foundation Trust (NHFT). Evidence from our regulatory activity shows that services across the country are currently facing many of the same challenges in recruiting staff, including nurses, psychologists, occupational therapists and consultant psychiatrists – all of which are affecting the capacity to deliver services.

During our <u>review of NHFT</u>, people using services told us they felt there were not enough staff across many locations. We found several vacancies for psychologists across all teams, and not all teams had access to the same number of practitioners. In addition, issues around caseloads and the make-up and size of the teams meant that people were facing lengthy waits to receive care and treatment.

Availability of appointments

We have also heard how staffing numbers and staff turnover is affecting the availability and regularity of appointments. Respondents to the NHS Community mental health survey reported difficulties in making regular appointments, as well as problems with not receiving treatment for a long enough period to meet their needs. People described the impact this had on them:

"Since February I've been left with no therapy, messed around and have declined ever since. I was promised I'd have therapy back in a short amount of time after [my therapist] left, and it's currently been 8 months and no sign of help."

"I have had so many experiences of being promised support and not getting it – and then being essentially told off for being upset – that I have no faith in the mental health service. There is no trust, and I find interaction with the team triggers anxiety and distress to the point that I avoid interaction. There is no continuity of care and I've rarely seen the same clinician twice."

This was a particular concern for young people, with only 39% (468 out of 1,211 respondents) saying they were given enough time to discuss their needs and treatment, compared with a national average of 50%.

Issues around access and availability of appointments have had negative effects on people. We heard from people who suffered negative impacts such as worsening their condition and negatively affecting personal relationships. We also heard instances of people gaining weight or self-medicating to cope.

Feeling that there is no support could also risk people withdrawing from the mental health system altogether. As highlighted in our <u>Special review of mental health services at Nottinghamshire Healthcare NHS Foundation Trust: Part 2</u>, disengagement with services is common for people with mental health problems. Through our special review, we found that the people who had disengaged from mental health services had experienced large gaps in support from community mental health teams, with gaps between visits ranging from several weeks to over 2 months in one case.

Children and young people are more at risk of disengaging from services. Data from MHSDS shows in 2023/24, over a million children and young people each year did not attend their care contact, with half missed with no advance warning. Reasons for this could include their needs not being met or a deterioration in their mental health condition. Not attending appointments increases risks to children and young people and could lead to worse outcomes for them.

Nevertheless, at the same time, some young people who responded to the NHS Community mental health survey have described positive experiences around availability of appointments. These included examples of staff being flexible with appointments and arranging home visits – in one case by arranging home visits to accommodate the individual needs and disabilities for one person.

The type of appointment offered can also have an impact on care. Respondents to the NHS Community mental health survey described problems such as being given phone-based appointments when they struggle to communicate by phone. For example, through our online Give feedback on care service, autistic people described being offered telephone or online consultations, which they found challenging:

"I am struggling with phone appointments as I struggle to have these very personal conversations over the phone and I am not able to open up fully."

Many young people said they would prefer to have more face-to-face appointments, rather than the telephone or video calls that were offered. For example, one young person said that a face-to-face appointment, "gives patients a physical connection and builds trust with their therapist. Online just feels insensitive in serious cases."

Are people being kept safe?

Staffing levels

As we reported in last year's <u>Mental Health Act Annual report</u>, not having the right levels of suitably qualified staff can have a huge impact on the safety of people who use services and the quality of care they receive. Through our monitoring activity, we saw examples of staffing shortages preventing people from accessing therapeutic activities, stopping them from taking planned leave, or even preventing them from accessing fresh air.

We have similar concerns for people who need community mental health care. As highlighted in the section on quality, problems with recruitment have led to issues with capacity in some services. Long waits and not being able to access care when people need it increases risks. For example, during our special review of services at Nottinghamshire Healthcare NHS Foundation Trust we found that too many patients did not have a care co-ordinator. Without this oversight, staff and services cannot monitor any deterioration of people's condition, putting them at risk of harm.

Although vacancy rates have been decreasing across the NHS, they are still persistently higher in mental health services compared with NHS hospital and community health staff as a whole. Concerns about vacancies within multidisciplinary teams has been a theme in some of our inspection reports. In particular, in line with our findings from the special review of Nottinghamshire Healthcare NHS Foundation Trust, we have found that many services have experienced difficulties in filling posts for psychologists and occupational therapists.

Not having enough staff puts additional pressure on the existing workforce. Results from the 2023 NHS staff survey showed that 58% of the mental health workforce reported working unpaid hours on a weekly basis – higher than the national average of 53%. These figures were even higher for roles including occupational therapists, nurses, clinical psychologists, consultants and psychotherapists, with clinical psychologists and consultants having the highest proportion of respondents who reported working unpaid hours (70% and 79% respectively).

Working under sustained pressure poses a challenge to the safe, effective care of people using mental health services. Results of the NHS staff survey continue to show poorer results from mental health workers when asked if they would want their friends and relatives to be treated in their organisation (64% in 2023, compared with a high of 70% in 2020), showing that they feel the standard of care is not high enough.

Ward environments

The safety of mental health wards continues to cause concern. Lack of resources, ageing estates and poorly designed facilities can lead to issues around privacy and dignity for patients, as well as compromise the safety of both patients and staff.

Under the Standards of the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, patients have a right to a suitable standard of environment.²⁹ However, during inspections, we have found wards that were not clean, with food on floors, ripped furniture and a failure to ensure appropriate hygiene in food preparation areas. In some cases, wards have closed due to the environments being unsafe.

The environment of inpatient wards was a particular concern that autistic people raised with us through Give feedback on care. Many people (including autistic people and their loved ones) told us about poor ward conditions, including environments that had a negative effect on their sensory perceptions, such as lights, noise and temperature:

"She is in a big room with lots of lights, it's too hot, there's lots of noise and strange people are sitting at the bottom of the bed staring at her all the time."

"I can't sleep because of the noise here, I have very sensitive hearing and hypervigilance; the office door slamming shut constantly is stopping me falling asleep, I wear ear plugs for bed, I've even [taken] some meds for sleep and I still can't sleep; I don't think the lack of sleep is helping at all."

Not only does this indicate that reasonable adjustments for autistic people are not always considered on inpatient wards, but it may breach service provision requirements under the Equality Act 2010.

The poor quality of seclusion rooms within forensic services has been highlighted in a number of our inspection reports. On one inspection, we found a seclusion room with no natural light and intercom facilities that did not work, which made it difficult for patients to communicate with staff.

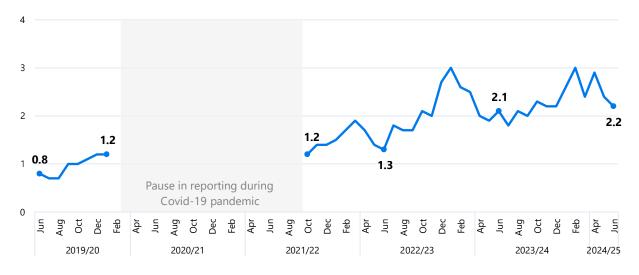
We are also concerned about the rise in the number of mixed sex accommodation breaches, which have safety implications for patients. People affected by mental ill health can at times act in disinhibited ways or may lack the mental capacity to make sound decisions about relationships. They may also have experienced abuse in the past, which might have contributed to their mental ill health, and which might leave them at risk of being exploited by others.

The Mental Health Act Code of Practice highlights that women-only environments are important because of this increased risk of sexual and physical abuse, and previous trauma. It also states that consideration should be given to the needs of transgender patients.³⁰

<u>The NHS Constitution</u> is clear that people admitted to hospital will not have to share sleeping accommodation with patients of the opposite sex. It has been mandatory for providers to report all mixed sex accommodation breaches since 2011. In the last 5 years, we have seen a gradual increase in the number of mixed sex accommodation breaches reported in mental health services, with 47,489 breaches between July 2023 and June 2024, compared with 42,200 breaches between July 2022 and June 2023.

The increase is also reflected in the rate of breaches for every 1,000 finished consultant episodes, which has increased every year from 1.3 in June 2022, to 2.1 in June 2023 to 2.2 in June 2024 (figure 10). Alongside this increase, research shows a rise in the number of sexual safety incidents, including sexual assaults, in mental health wards.

Figure 10: Mixed-sex accommodation breaches per 1,000 finished consultant episodes



Source: NHS England Mixed-Sex Accommodation Data. February 2020 data is excluded from the chart as data for this month was unusually high as it included additional breaches that had been under-reported in previous months.

Secondary care

Key findings

- High demand for services and ongoing pressure in all parts of the system mean that many people, including children, are not getting the care they need when they need it. This is leading to a deterioration in people's health conditions, which then need more intensive support and treatment, and result in longer stays in hospital.
- Although demand has not increased dramatically, overall, the performance
 of services to meet the need for care is below the expected standard,
 and in some cases getting worse. By operating continuously in these
 environments, there is the risk that it becomes normal to accept care that
 is below standard.
- People are facing long waits for diagnostic tests. As at March 2024, there were around 1.62 million people waiting for a diagnostic test or procedure. And waiting lists are increasing. In total, the waiting list for a diagnostic test or procedure has increased by 52% since 2019.
- People continue to experience delays in referrals and diagnosis for cancer.
 Figures from NHS England show that the 3 waiting standard measures
 are not being consistently met, with the exception of the 28-day faster
 diagnosis standard, which was met for the first time in February 2024.
 Performance varies considerably between types of cancer and between
 regional health and care systems.

There is still a high level of demand for services and ongoing pressure in all parts of the healthcare system, which means that many people are not getting the care they need when they need it. This is leading to a deterioration in people's health conditions, which then need more intensive support and treatment, and result in longer stays in hospital.

Although the level of demand has not increased dramatically since last year, the performance of services to meet the need for care is below the expected standard, and in some cases getting worse. By operating continuously in these environments, there is the risk that it becomes normal to accept care that is below standard.

In last year's State of Care report, we highlighted how problems in the wider health and care system were increasing pressure on urgent and emergency care services. This pressure continues to rise, with ongoing high demand for NHS 111 and ambulance services, and people using the emergency department (A&E) to get the care they cannot access elsewhere.

High demand for NHS 111

Evidence of ongoing pressure on the wider system is reflected in calls to the NHS 111 service. The annual volume of calls in 2023/24 remained relatively stable, reaching a high of over 2.1 million calls in December 2023. However, the speed at which calls are answered continues to be below expected standards.

Long waits for calls to be answered lead to delays in people receiving appropriate triage and treatment, which in turn can have an impact on their outcomes. NHS 111 response rates have been consistently poor: between April 2021 and April 2024, the standard of answering calls within an average of 20 second was not met during any month, and in 2023/24, calls took on average 2 minutes 59 seconds to be answered.³¹

When people have to wait a long time for their call to be answered, there's a risk that they will either:

- abandon the call and not receive advice on appropriate care or treatment
- seek care from a service that cannot meet their needs appropriately, or face delays in receiving the correct care
- not seek treatment at all.

Between April 2023 and March 2024, on average 10% (over 172,000 calls) to NHS 111 were abandoned each month.

Another safety risk is the delay in people being able to speak with a clinician. Despite a general increase in the number of triaged 111 calls since 2019/20, the proportion of calls assessed by a clinician or clinical advisor has decreased from 53% in 2019/20 to 44% in 2023/24 – this is below the standard of 50%. People are also having to wait longer to receive a callback from a clinician. While 90% of callbacks should happen within 20 minutes, on average only 31% of callbacks in 2023/24 were made within 20 minutes.

People have told us about the impact of delays in callbacks from NHS 111 through our Give feedback on care service:

"Called [111] for an emergency prescription due to GP errors ...
Called... at 17:11 [and was told] that my GP would call me back
within 2 hours. I advised that my GP was closed. Still had to wait the
2 hours. I then called back after not receiving a call back at 22:50...
I woke up [the next day] still no call back. I called back at 9:40am to
be prescribed over the phone there and then! I go to [the] pharmacy
and was told the prescription was sent the night before [and] the
pharmacy closes at 7pm. However, I was [not] informed, and [had
been] left in pain all night and not able to sleep due to pain and
waiting for a call back that never happened!"

"I called [111] at 7.30am this morning about my 2-year-old daughter. After the initial assessment I was told that she needed attention within 2 hours of the call and so a clinician could call us back... After 2 hours passed I hadn't heard back so called back again at 9.30am. [The call handler] confirmed we were in a queue and would be called as soon as possible... because I was told multiple times and reassured that we would get a call back, I didn't take my daughter to a walk-in centre. I called again at 5.20pm [as] I had still not received a call... This was 10 hours after the initial call...[I called] again at 7pm – 12 hours after my

initial call... Eventually I received a courtesy call at 9.40pm to say that we were still in a queue. I [cancelled the] call now given the time, and [said] that I would need to urgently have my daughter seen the next day at our GP."

Ongoing pressure on ambulance services

The number of calls to the ambulance service decreased by 2% in 2023/24 compared with 2022/23, with 13 million calls made. The proportion of answered calls has fallen over the same period from 76% to 74%, and continued to decline in April to June 2024 to 73%. However, the average time taken for a 999 call to be answered has improved significantly from 39 seconds to 9 seconds, this improvement has continued, with April to June 2024 averaging 5 seconds to answer.

Ambulance response times continue to fall below the expected standard, despite small improvements from last year. On average, ambulances should respond to a Category 1 incident within 7 minutes, and the standard is to respond to 90% of these within 15 minutes. Category 1 incidents are lifethreatening events that need immediate intervention and/or resuscitation, such as cardiac or respiratory arrest. Between April 2023 and March 2024, the average response time for Category 1 calls was 8 minutes 27 seconds. Although this is 51 seconds faster than the same period in the previous year, it was still not meeting the standard. But there was better performance against the 90% standard between April 2023 and March 2024 compared with the previous year, with 90% of category 1 calls answered in 15 minutes 2 seconds – just 2 seconds over the 15-minute standard.

The picture is worse for Category 2 calls: these are emergency events that need intervention and/or taking to a hospital, including injuries such as burns, epilepsy or strokes. Category 2 represents the highest volume of calls with increased acuity and therefore more complex care needs. All ambulance trusts should respond to Category 2 calls in an average time of 18 minutes and respond to 90% of calls in 40 minutes. Due to ongoing pressures, in January 2023, NHS England reduced this to a temporary objective to respond to Category 2 incidents in an average time of 30 minutes over 2023/24.³² This target remains in place for 2024/25.³³

Between April 2023 and March 2024, the average response time for Category 2 calls was 36 minutes 23 seconds, which is 13 minutes 37 seconds faster than the same period in the previous year. The picture is continuing to improve, with a national monthly average recorded of 32 minutes 35 seconds between April and June 2024.

However, performance varies across the country. Between April 2023 and March 2024, the average response time across integrated care system (ICS) areas varied, with only 9 out of 42 areas meeting the interim 30-minute standard. The fastest average response time within an ICS area was 22 minutes 59 seconds, while in the worst performing system, the average response time was 1 hour, 8 minutes and 12 seconds.

The high level of demand is sustaining pressure on services, which is having an impact on ambulance staff. In the 2023 NHS staff survey, 39% of ambulance staff respondents said they often or always felt burnt out because of their work. This was even higher for control room staff (44%), ambulance technicians (45%) and paramedics (45%).

Ambulance handovers

Our State of Care reports from the last 2 years have both highlighted the effects of handover delays – where delays in emergency departments lead to people being held in ambulances outside departments. This affects the care they're able to provide and how quickly they're able to respond to new emergencies.

The NHS Standard Contract states that targets for handovers between ambulances and emergency departments should be:

- 100% within 60 minutes
- 95% within 30 minutes
- 65% within 15 minutes.

We have seen ambulance crews still struggling to meet the required standards. Between October 2023 and June 2024, there were 3.7 million handovers, which took an average of 35 minutes 1 second. During this time, over 900,000 hours were lost due to handovers taking more than 30 minutes.

Nevertheless, as with ambulance response times, handover times have improved, with 72% made within 30 minutes in June 2024 (compared with 67% in January 2024). However, this is still far from the standard of 95%. Between October 2023 and June 2024, the average response time was below the standard of 95% within 30 minutes across all ICS areas, with performance varying from 31% to 93%.

Relieving the pressure on ambulances and urgent and emergency care

Earlier this year, we convened an event for senior leaders and specialists from across England to understand their local experiences around congestion in urgent and emergency care services – and the impact for providers and people using these services. This was an opportunity to learn from their experiences and understand common pressures across systems, as well as sharing experience of what initiatives might work to alleviate pressures.

We know that many people end up in an emergency department when they could be better served in other parts of their local health and social care system. Keeping people away from emergency departments and out of hospital – unless it is the best place to meet their needs – was the focus of many examples from senior leaders and specialists. Some spoke about the tension created among staff when emergency departments were at capacity, but ambulances needed to leave to respond to other emergency calls.

There were some success stories, and specialists explored innovative models and ideas. One of these was an initiative where the ambulance service provided cars to enable mental health practitioners to respond to people having a mental health crisis rather than dispatching an ambulance. The event

also explored solutions to the barriers to improving care, such as insufficient integration across systems leading to lost opportunities to make sure people get the care they need without ending up in hospital.

Through our regulation, we have seen evidence of providers taking other steps to address the pressures described above. For example, some ambulance providers have a hospital ambulance liaison officer (HALO) based in the emergency department who works with ambulance crews and hospital staff to enable a smooth handover and reduce the time that an ambulance spends at the emergency department.

Less pressure on ambulances and a faster response to falls

The private ambulance provider, Cornwall Ambulance Service Limited, introduced an urgent falls response team, which enabled an urgent response to patients after a fall, with fast assessment and treatment in either the patient's home or the community. The urgent falls response (a paramedic in an ambulance car) is available from 8am until 2am, 7 days a week.

This alleviates pressure on the NHS emergency ambulance service and meets the needs of patients who do not need an emergency ambulance, but are not suitable for routine patient transport services. The urgent response falls car had attended over 1,300 patients from March 2022 to March 2023.

One of the commitments set out in the <u>NHS Long Term Plan</u> was a new NHS offer of urgent community response to boost 'out-of-hospital' care, and therefore release pressure on secondary care, including ambulance and urgent and emergency care. This support aims to meet patients' urgent care needs at home with a view to improving patient outcomes, preventing avoidable hospital admissions and delivering NHS strategic priorities.

A key component of this commitment is the achievement of a 2-hour urgent community response standard. This response is delivered by a community-based service, typically provided by a multidisciplinary team, to adults with an urgent care need in their usual place of residence, and involves an assessment and short-term intervention.

It is encouraging to see an increase in the number of care contacts delivered by urgent community response support within the 2-hour target following an urgent referral from a GP, NHS 111 or elsewhere. Between April 2022 and March 2024, the number of urgent community response referrals in scope of the 2-hour standard increased by over 3 times – from 17,520 to 54,715. Performance against the response time standard of reaching 70% in 2 hours has improved from 79% in April 2022 to 84% in March 2024.

Reducing the number of admissions to an emergency department

Approaches to reduce ambulance callouts and admissions to an emergency department are being developed. These include the Norfolk & Waveney Unscheduled Care Coordination Hub, made up of multidisciplinary teams from the local health system, which aims to ensure patients get the right care, in the right place, whenever they need it.

If someone calls 999, but they do not necessarily need the skills of a trained paramedic, they are reviewed by the Hub, who then works out what service would be best and facilitates the right response. This could be a 2-hour urgent community response visit to help someone up after a fall, or an out-of-hours GP appointment.

Some people will still need to see a specialist at a hospital, but rather than getting there through the emergency department, the Hub can arrange for them to go in a planned way, with support, freeing-up ambulances to respond to those with more urgent needs.

Increasing pressure on urgent and emergency services

The 3 main types of urgent and emergency care services in England are:

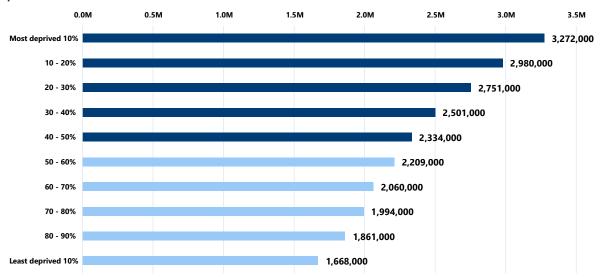
- type 1 consultant-led 24-hour emergency departments with full resuscitation facilities and patient accommodation (also referred to as accident and emergency (A&E) or casualty)
- type 2 consultant-led single service facilities for specific conditions, for example eye conditions or dental problems and patient accommodation.
- type 3 GP-led urgent treatment centres, also called minor injury units.

In 2023/24, the total number of attendances for all types of urgent and emergency services rose by 4% compared with the previous year, increasing from 25.4 million in 2022/23 to 26.3 million. The greatest increase in attendance was seen in type 2 and type 3 services, which both saw increases of 7%. Attendances in type 1 units only increased by 2% in the same period. The pressure on services has continued to increase in 2024, with levels of attendances across all service types 7% higher from April to June 2024 than the same months last year, suggesting pressure remained high on urgent and emergency care services going into the summer.

The level of demand for urgent and emergency care services continues to vary across England. In 2023/24, attendance rates for people living in the most deprived areas were nearly double those in the least deprived areas (figure 11). As we raised in last year's <u>State of Care</u>, and highlight in the section on primary care, we are concerned that these figures suggest people in deprived areas may be more likely to end up in hospital because they can't get the help they need, early enough, in the community.

Figure 11: Number of attendances at urgent and emergency care services by deprivation, 2023/24

In 2023/24 people living in the most deprived areas were nearly twice as likely to attend A&E than people living in the least deprived areas

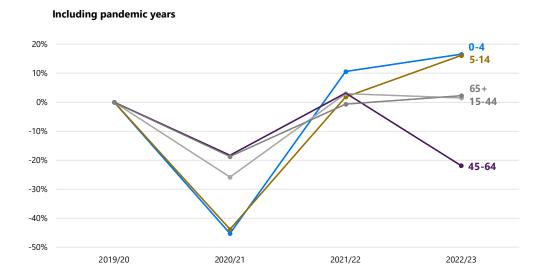


Source: NHS England, Hospital Accident & Emergency Activity

Levels of demand also vary across age groups. In 2022/23, we saw that attendance rates at urgent and emergency care services for children in the age groups 0 to 4 and 5 to 14 years had increased, compared with 2019/20.

In 2023/24, attendance rates for children aged 0 to 4 years had reduced, while rates for the groups aged 15 and over increased. Attendance rates for all these age groups are now approximately 9 to 12% higher than they were in 2019/20. Attendances at emergency departments have remained higher for children aged 5 to 14 years, at 18% above their 2019/20 level (figure 12).

Figure 12: Percentage change of attendance by age category in urgent and emergency care services compared with 2019/20



Source: NHS England, Hospital Accident & Emergency Activity

Waiting too long for urgent and emergency care

Once people have arrived at an urgent and emergency care service, it is important for their safety and health outcomes that they are seen promptly. Delays in getting care in urgent and emergency care services have been linked with increased mortality and illness.³⁴ For example, a 2021 study looked at the effect of delays in admitting people from an emergency department on patient outcomes; this showed an 8% increased risk of death within 30 days for people who waited for more than 6 to 8 hours.³⁵

The NHS Constitution pledges that people should wait no longer than 4 hours from arrival to admission, transfer or discharge in urgent and emergency services.³⁶ In 2010, operational standards stated that at least 95% of patients should be seen within 4 hours. Due to ongoing pressures, NHS England reduced this to a temporary standard of 76% in December 2022, which was to be met by March 2024. The current objective is that by March 2025, 78% of patients will be seen within 4 hours.

However, the number of people waiting less than 4 hours to be either admitted, transferred or discharged continues to remain below these targets. Across all types of urgent and emergency services, during 2023/24 performance was closest to the standard in April 2023 at 74.6%, and lowest in December 2023 at 69.5%. Performance had improved slightly as at June 2024 to 74.6%.

Type 1 services (emergency departments) tend to have the poorest performance for waiting times. In December 2023, only 54.7% of people attending an emergency department were seen within the 4-hour target. This means that in December 2023, there were over 627,000 people waiting for over 4 hours in a department for a decision to be made about their care. Again, this varied depending where in the country people lived.

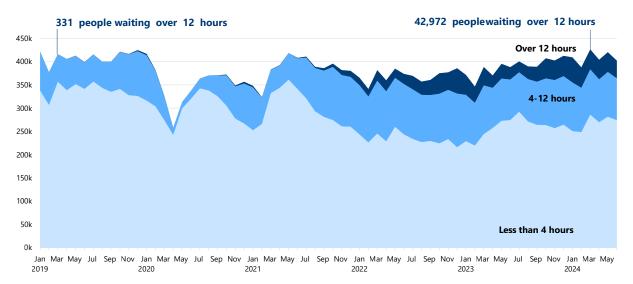
As highlighted in our section on mental health care, research by the Strategy Unit shows that long waiting times are a particular concern for people presenting with mental health issues, with the average emergency department 'pathway' almost an hour longer for mental health patients.

Our analysis of a sample of urgent and emergency care inspections found that challenges for the workforce, including low staffing levels and inadequate levels of core training, is a contributing factor to emergency services being overstretched. Some services did not have enough medical staff to keep people safe. Some inspection reports also described a high degree of risk around burnout and overloading of staff due to the high numbers of patients attending the emergency department. This is supported by the findings of the NHS staff survey, where 30% of respondents said they felt burnt out because of work.

Once the decision is made to admit a patient to hospital, it is important that the resulting action is taken quickly. Not acting quickly enough can increase the risk to patients. The proportion of people attending all urgent and emergency care services who wait over 12 hours from a decision to admit to being admitted indicates how quickly hospitals are able to act. This measure is sometimes referred to as 'trolley waits' and can indicate an inability to admit patients who need care in the hospital. Again, this is a particular concern for people presenting with mental health issues, including children and young people – see section on mental health.

Since 2019/20, the number of emergency admissions has grown more slowly, at less than 0.1%, than the number of attendances, which has grown at 5%. However, the number of people waiting more than 12 hours from decision to admit to admission has increased sizeably over pre-pandemic levels: in March 2024, nearly 43,000 people (over 10% of people admitted) were waiting more than 12 hours to be admitted to hospital, compared with around 330 (under 0.1%) people who waited this long in March 2019 (figure 13).

Figure 13: All emergency admissions to hospital from urgent and emergency services and time taken from decision to admit, January 2019 to June 2024



Source: NHS England, A&E Attendances and Emergency Admissions

More worryingly, the Royal College of Emergency Medicine (RCEM) has described the 12-hour decision to admit metric as the 'tip of the iceberg', which does not capture the true extent of delays for patients. The RCEM recommended looking at how many people wait longer than 12 hours from the time of arrival rather than the decision to admit.³⁷

Using the time of arrival as a measure shows that too many people are waiting too long in emergency departments to be seen, have a decision about their care, and then be admitted. In January 2024, over 174,000 people attending an emergency department waited over 12 hours from their time of arrival. This is over 3 times higher than the number of people waiting 12 hours from a decision to admit to actually being admitted.

The stark difference in numbers highlights that considerably more people are waiting a very long time from arriving in the emergency department before a decision is made about their care, which undoubtedly has a negative effect on their experiences and outcomes. Several people described the impact of long waits in an emergency department through our Give feedback on care service:

"I was taken to [the emergency department] by ambulance with a clostridium difficile infection and severe dehydration. I was extremely unwell. I was put in a cubicle where I stayed for 26 hours. I was on a trolley as I was not allowed a bed as I was not supposed to be there for that length of time."

"My 95-year-old Aunt was admitted by ambulance this morning after a fall at home... When we got there at 1pm she had not been seen by a doctor and was on a trolley. When we had to leave at 5pm she was in a corridor on a trolley and not once had she been given a drink or anything to eat or asked about her medication that she needs to take (it was left behind by the ambulance staff). She still had not seen a doctor. She desperately wanted to use the toilet, but despite us asking numerous nurses no-one came to her assistance."

"My [89-year-old] mum was admitted to A&E ... she was seen by the doctor and was informed that she needed to be admitted to a ward in the hospital. I was informed that there was not a bed within the hospital, she was moved into a corridor by the A&E. She was on a trolley in the corridor for 2 days with a nurse looking after 18 patients within the same area... my mum has now a grade 2 pressure ulcer."

These experiences are supported by findings from our inspections of urgent and emergency care services, which have found issues around delays and access frequently reported. An analysis of a sample of our inspection reports identified themes around crowded waiting areas. This led to delays in people being triaged, as well as long waiting times for referral to treatment and arrangements to admit. Delays in accessing services also meant that patients who exhibited signs of deterioration (such as sepsis) were not always seen quickly enough by qualified clinicians. Some inspection reports also described delays in discharge, where patients remained in emergency departments for long periods, due to issues around capacity.

We can also identify changes in the level of demand for services by looking at the proportion of emergency admissions to hospital. In 2023/24, we have seen a small increase in the percentage of attendances at type 1 services (emergency departments) that result in admissions. March 2024 saw the highest numbers of emergency admissions through this route in over 5 years. The increases in attendance and admission figures, while not huge at a national level and compared with the more level long-term trend, are signs of continued pressure on an already stretched part of the system.

Despite all these pressures, evidence from our urgent and emergency care inspections has highlighted how people who used the services, their relatives and carers, said staff had treated them with kindness, dignity and compassion, listening to them, considering their individual needs and offering emotional support when needed. Patients often recognised that staff worked hard to care for patients, despite being extremely busy and having to work in difficult environments.

Hospitals running at capacity

The long delays in urgent and emergency care services have many causes, with pressure on other parts of hospitals and the wider health and social care system contributing to this. This is often talked of in terms of 'flow'.

When hospital beds are available, patients who need to be admitted can be moved out of an emergency department to where they can receive the care they need. NHS England's data on bed occupancy shows that the number of overnight beds in general and acute hospital settings (where patients from the emergency department would often be admitted) has reduced over the long term, from an average of around 109,000 in 2010/11 to around 104,000 in 2023/24.

Compared with other nations, the UK has a very low total number of hospital beds relative to its population. In OECD (Organisation for Economic Cooperation and Development) EU nations, there is an average of 5 beds for every 1,000 people, but in the UK, this is just 2.4 beds.³⁸

The number of overnight beds and the level of occupancy is one of the factors affecting flow through a hospital. There are other factors, but in general, high levels of occupancy means that flow is more likely to be restricted. Many of these beds are taken up by people who do not need to be in hospital, but whose discharge has been delayed (see section on discharge delays). Since the beginning of 2022, more than 1 in 10 occupied beds are being used by someone whose discharge was delayed.

While bed occupancy reduced during the pandemic, it has since increased and has remained consistently very close to or above 90% for general and acute beds for the past 2 years. The bed occupancy rate in March 2024 was consistently high across all regions in England, with most integrated care systems (ICSs) reporting occupancy rates exceeding safe levels (above 90%). This varied across ICS areas from 89.9% to 98%.

Bed occupancy is closely related to the length of stay in hospital beds, with longer stays meaning fewer beds available for people. The number of patients staying for 7 or more days increased from around 34,000 (43%) in April 2021 to a peak of around 50,000 (53%) in January 2023. This has reduced slightly during 2023 and into 2024, but is still around 50% on average. The picture is very similar for patients with stays of 14 or more days and 21 or more days, which also saw an increase both in absolute numbers and as a percentage of occupied beds.

Delayed discharges

Delayed discharges are when a person has not been discharged from hospital despite being assessed as being medically fit to leave. While most people admitted to a hospital will be discharged home without any additional support, some may need support from homecare (domiciliary) services, a short-term bed, rehabilitation or a permanent bed in a care home.³⁹

As highlighted in our section 'Spotlight on intermediate care', when intermediate care works well, it can improve flow and discharge from acute and community hospitals, as well as free-up NHS hospital capacity for those who need it most.

However, discharges are often delayed because of internal processes, for example waiting for pharmacy, a diagnostic test or a therapy assessment or treatment, as well as a lack of capacity in adult social care.

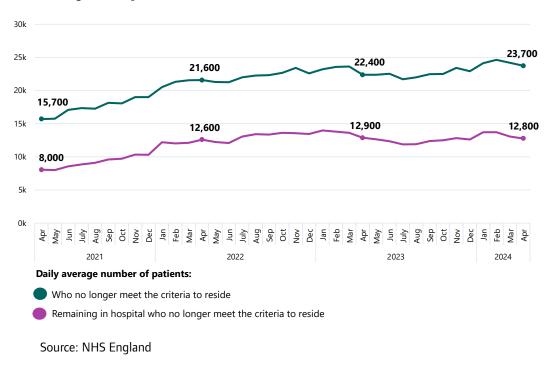
Respondents to the 2022 NHS Adult inpatient survey described challenges around being discharged, including having to wait a long time before all the relevant paperwork and processes were completed, which made the discharge seem poorly organised.

"...on the 2 occasions I was hospitalised I was told I was being discharged, but it took until the early evening before I received the drugs to take home and the discharge letter."

"Discharge was poorly handled. Discharge was confirmed at around 8am but paperwork including doctor's signature, physiotherapist comments and pharmacologist information was not completed until 6pm. This also happened for 2 other patients in my ward."

Figures from NHS England show the average number of people discharged from hospital each day increased by 43% between April 2021 and April 2024 from 15,700 to 23,700. However, the number of people ready to be discharged but whose discharge was delayed increased by 59% over the same period, rising from a daily average of 8,000 to 12,800 people (figure 14).

Figure 14: Average daily number of people ready for discharge and of those, the number whose discharge was delayed, April 2021 to 2024



Delayed discharges can have a significant impact on people. Longer stays (3 weeks or more) are associated with an increased risk of hospital-acquired infections. There is also an increased risk of people losing mobility and/or cognitive function, which makes it harder for them to regain their independence after leaving hospital and increases their need for care. ⁴⁰ A quick discharge when patients are medically fit and have an appropriate place to go not only improves flow, but also helps minimise how much people deteriorate, which can make it harder to return to their home or other previous setting.

In the section on 'Waiting for adult social care', we highlight how waits for care home beds and home-based care remain key reasons for delayed discharges. The proportion of delayed discharges attributed to these reasons, for patients who stayed in hospital for 14 days or longer, has increased since April 2021 (figure 4). Lack of community care provision, such as reablement facilities, has also contributed to delays in discharge from hospital (see section on 'Spotlight on intermediate care').

But, at the same time, many people described feeling that they had been discharged too early, which in some cases had led to them being readmitted to the same hospital, or seeking help from other care providers such as GPs and emergency departments. In some cases, we heard how pressure to free up beds had led people to be discharged without the right support in place. We raised the issue of the increasing pressure to discharge people from hospital and discharging people too early in last year's State of Care, but results from the 2022 NHS Adult inpatient survey show that people continue to report negative experiences of discharge:

"The discharge process was shocking. The nurses were desperate for the bed. They did not contact social worker to put care in place. They confirmed with family only. Council advised proper process not followed."

"I felt I was discharged too early after the major surgery. I was discharged the next day but was expecting to stay for 2 more days. I lived alone and did not have any help from social services."

Long waits for care

Waits for diagnostic tests

The pressure being felt in emergency departments as the 'front door' of hospitals can also be seen in other parts of the system. One such area is the long waits for people who need diagnostic tests in secondary care after being referred by their GP. As at March 2024, around 1.62 million people were waiting for a diagnostic test or procedure.

The NHS Constitution sets out that people should wait less than 6 weeks from the point at which the referral is made. However, data from NHS England shows that in March 2024, over 354,000 people (22%) in England waited

more than 6 weeks for a diagnostic test or procedure and around 118,000 people (7%) waited more than 13 weeks from the point of referral.

As this is often the first stage in a journey towards treatment, delays after a referral mean people can wait a long time before their concerns are addressed. A delay is not only stressful – it means that people do not get the diagnoses they need within the right timeframe, delaying their treatment and potentially leading to their condition becoming worse and risking poorer outcomes.⁴¹

This is supported by a recent survey by the <u>Patients Association</u>, which found that of the 1,000 people who responded, nearly 1 in 5 (17%) said their long-term recovery was set back significantly because of delays in diagnostic tests. Many more reported consequences for their mental and physical health, and their wider work and family life, as is illustrated by David's story.

David's story

David is 60 years old and had always been generally healthy and a keen runner. In September 2021, David visited his GP because he was getting back pain. Despite being prescribed painkillers, the pain kept getting worse, leaving him unable to run and keep fit. An X-ray in May 2022 showed multiple historic rib fractures, but to David's knowledge he had never fractured his ribs. As part of ongoing investigations, the doctor sent David for an MRI scan, but the waiting list was 52 weeks long.

By this point, David was taking time off work sick because the pain was getting so bad. He started ringing the MRI clinic daily to see if there were any cancellations and finally got an MRI scan booked in for October 2022. Before this, in August 2022 while waiting for the MRI scan, David requested a blood test from his doctor because he was concerned about the painkillers and the effect they were having on him. The blood tests revealed David had multiple myeloma (a type of bone marrow cancer), which had significantly affected his spine and ribs. David was admitted to hospital where a bone marrow test confirmed this diagnosis. Two days after being discharged from hospital, David went to A&E as the pain in his spine had become so unbearable. Eventually, he had an MRI scan in October 2022, which showed multiple fractures and a wedge collapse. David feels that a lot of the spinal issues would have been detected a lot earlier if the MRI had been done sooner.

(Interview with a member of the public)

Waiting lists for diagnostic tests are getting bigger. In total, the number of people on a waiting list for an NHS diagnostic test or procedure has increased by 52% between March 2019 to March 2024. But, as with other areas of care, the level of increase depends on where in the country people live. While all regions in England have seen an increase, some are larger than others and the size of waiting lists still varies across the country. As at March 2024, 30% of people on the diagnostic waiting list in the East of England region were waiting more than 6 weeks for a diagnostic test or procedure, while in the North East and Yorkshire region, only 17% of people on the list waited more than 6 weeks.

The size of waiting lists also varies depending on what type of diagnostic test is needed. Tests are split into 3 main categories:

- imaging (such as MRI and CT scans)
- physiological measures (such as audiology assessments)
- endoscopy (such as colonoscopy).

More than two thirds of people on the diagnostic waiting list are waiting for an imaging test, with around 190,000 people (17%) in England waiting more than 6 weeks, and around 48,000 people (4%) waiting more than 13 weeks. The waiting list for diagnostic imaging examinations increased by 42% between March 2019 and March 2024 (rising from 784,000 to 1.11 million), with waiting lists in March 2024 varying from around 92,000 to around 220,000 across the regions.

One potential reason for the long waits is the shortage of diagnostics staff, as the numbers of staff in the NHS workforce has not kept pace with rising demand for tests. There are significant vacancies across all specialities. For example, in 2020, the <u>Independent Review of Diagnostic Services for NHS England</u> estimated that 3,500 extra radiographers would be needed by 2025.

Delays in getting NHS diagnostic tests are leading people to seek help elsewhere. Use of private diagnostics services have continued to increase since 2020/21, in line with the increased demand and waiting times for NHS diagnostics. This has continued to rise and is now almost a third higher in 2023/24 (162,000), than 2019/20 (127,000) (figure 15).

175k 162,000 165k 155k 28% 145k 139,400 135k 126,900 125k 122,200 115k 105k 95k 85k 82,600 75k 2022/2023 2020/2021 2021/2022 2023/2024 2019/2020

Figure 15: **Use of private diagnostic procedures 2019 to 2024**

Source: PHIN, Volume and Length of Stay datasheets

Again, these figures are supported by the findings of the <u>Patients Association</u> survey. This found that 3 in 5 respondents (60%) would be willing to pay to get a test privately if they faced a long wait or if the test they needed was not available on the NHS. This included patients who did not consider themselves to be 'rich', highlighting how important it is for people to get a timely and accurate diagnosis.

Waits for elective care

Once people receive a diagnosis, they are continuing to face long waits to start treatment. In England, 92% of patients should wait no longer than 18 weeks from referral to treatment. However, as highlighted in last year's State of Care, too many people are still waiting too long for planned hospital care. In August 2023, a record 7.7 million people were waiting for care. While this fell to 7.5 million in March 2024, since then the number of people waiting has slowly started to increase again, with 7.6 million waiting in June 2024.

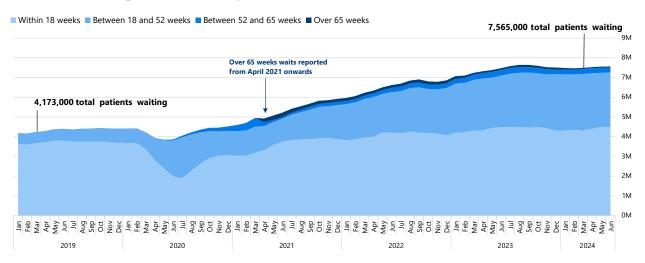
NHS England's <u>Elective Recovery Plan</u>, published in February 2022, set out standards to eliminate waits of:

- over 104 weeks by July 2022
- over 78 weeks by April 2023
- over 65 weeks by March 2024
- over 52 weeks by March 2025.

To support attempts to reduce waiting lists, the previous government made up to £14 billion available to tackle the backlog and speed up discharge.⁴³ But, despite these measures, performance continues to decline.

Between March 2019 and March 2024, the number of patients waiting for elective treatment increased by almost 80% (from almost 4.2 to just over 7.5 million) (figure 16). Comparing figures from March 2019 with March 2024, there were almost 6 times more patients on the waiting list for longer than 18 weeks, and over 250 times more patients waiting at least 52 weeks.

Figure 16: **Total number of patients on the elective care waiting list, January 2019 to June 2024**



Source: NHS England, Referral to Treatment (RTT) Waiting Times

The standard of 92% of patients waiting less than 18 weeks from referral to treatment has not been met since 2015/16, but this fell particularly sharply during the pandemic and has not recovered. In March 2024, the proportion of people seen within 18 weeks stood at 57% (figure 17). The Recovery Plan's standard of eliminating over 65 week waits by March 2024 was not met either, with nearly 50,000 people having waited over 65 weeks at that time.

Figure 17: Percentage of patients starting treatment within 18 weeks of referral January 2019 to June 2024

Source: NHS England, Referral to Treatment (RTT) Waiting Times

While waiting times for treatment vary significantly by specialty, in March 2024, no specialty achieved the target of treating 92% of patients in less than 18 weeks. The highest proportion of waits over 18 weeks were in the specialties of: ear nose and throat, oral surgery and plastic surgery.

Eleanor's story

We spoke with Eleanor, a 43-year-old mother of two, about her experience of waiting for surgery on her throat.

In October 2021, Eleanor was referred to the emergency department by her GP after presenting with a large bulge on her neck. She described feeling not quite right and finding it difficult to swallow. After urgent blood tests and a scan, Eleanor was told that the bulge in her neck would be removed in 2 to 3 weeks, at which point they would test to see if it was cancer.

By August 2022, Eleanor had not heard anything more, and by this point she could barely breathe, couldn't walk, was struggling to swallow, and found everyday things an effort due to tiredness. She contacted the GP to find out what was happening but was told she would have to speak to the hospital. Despite contacting the hospital on numerous occasions, Eleanor couldn't get through or was told they would ring back. She never received any phone calls back and wasn't given any information about where her case was up to.

Eventually, Eleanor secured an appointment with the Ear, Nose and Throat department at her local hospital after contacting the Patient Advice and Liaison Service (PALS). After this appointment, Eleanor was referred on to another specialist who made the same decision that was made a year earlier in the emergency department – that the growth in her throat would need to be removed. Further blood tests and scans showed the bulge in her throat had grown a further centimetre. This worried Eleanor, as cancer was known to grow, but she had still not been told if it was cancer or not.

Eleanor had the bulge removed in November 2022, a year and 1 month after she had first attended with symptoms. The doctors explained after it had been removed that it had grown so much they were surprised she could still breathe. Eleanor had lived for over a year with the worry it might be cancer, unable to enjoy walking, struggling to eat and swallow, and felt she just wasn't the person she was before.

(Interview with a member of the public)

When looking at how waits have changed over the past 2 years (comparing March 2022 with March 2024), we see the greatest percentage increase in the number of people waiting for:

- respiratory medicine (50%)
- 'other' medical services (37%)
- cardiology services (36%).

The number of people waiting over 18 weeks for these services has grown even more sharply, with all doubling or nearly doubling.

Often, services combine data on waits for children with those for adults. However, we can see some child-specific data under paediatric services. This shows that the number of children on the waiting list has increased by 7% in the past 2 years, with the number waiting more than 18 weeks increasing by 32% over the same period. As highlighted in our section on children and young people's health, delays to treatment for children can have significant consequences.

In last year's State of Care, we stressed how waiting a long time for treatment can have detrimental effects on patients, for example conditions worsening, the need for more complex surgery, increased medication and/or a slower recovery process. It may also lead to more people needing care from their GP or in an emergency.

This is supported by our analysis of free text responses to the 2022 NHS Adult inpatient survey. We analysed responses from a sample of people who reported that their health had become worse while they waited to be admitted to hospital. Some people described suffering physical and emotional pain and stress because of waits and delays. Others described social and economic consequences of waiting. For many, delays and cancellations are an additional trauma on top of their existing issues, as this experience shows:

"Now, once again, I am on a waiting list [for a gynaecology operation] and I have been on waiting list for 2 years. In the meantime, I continue working with pain. I am a nurse and have worked for the NHS for over 18 years and this is the treatment I get. Recently, due to the increased pain ..., I have not booked more shifts in the hospital. Like me, there are many staff in similar situations."

Cancer care

<u>Macmillan Cancer Care</u> estimates that there are currently more than 3 million people living with cancer in the UK, which it predicts will rise to:

- 3.5 million by 2025
- 4 million by 2030
- 5.3 million by 2040.44

With these estimated figures increasing, it is unsurprising that a recent survey of 2,000 people by the <u>University of Cambridge</u> found that cancer is the public's biggest health concern – higher than for any other medical condition, including having a heart attack. People were most worried about late detection of cancer.⁴⁵

In last year's State of Care report, we highlighted concerns about delays for people in getting a GP referral for cancer as well as delays in starting cancer treatment. Analysis of feedback received through our Give feedback on care service shows that access to care – long waits, delays and cancellations – remains the most pressing concern for people.

In October 2023, NHS England revised the standards that cancer waiting times are measured against. There are now 3 waiting time standards that measure performance:

- **1. 28-day faster diagnosis standard:** people have a diagnosis of cancer or it is ruled out within 28 days of referral (set at 75% and rising to 80% in 2025/26)⁴⁶
- **2. 31-day treatment standard:** people with cancer start their treatment within 31 days of a decision to treat their cancer (set at 96%)
- **3. 62-day treatment standard:** people with cancer start their treatment within 62 days of an urgent referral (set at 85%).⁴⁷

Many people who provided feedback through Give feedback on care reported positive experiences, with gratitude towards their GP for taking swift action in following the 2-week cancer pathway. However, delays in receiving a referral and cancer diagnosis were frequently cited, with many people discussing the detrimental effect of this on their health and wellbeing. For example, some people discussed having gone to their GP with symptoms or concerns for suspected cancer, but that their GP had dismissed their concerns across several consultations. In some instances, this dismissal had led to the person's cancer being diagnosed later and spreading.

"I ended up with stage 3 cancer at the age of 24 because of them ignoring my glaringly obvious symptoms for years and have been through hell because of them."

"This GP failed on diagnosing my wife's cancer despite her regularly raising her concerns. No tests or scans offered to her. Now it's too late she is stage 4 bowel liver and lung cancer."

As with delays in referral, cancer treatment following diagnosis was frequently found to be delayed. People told us that appointments with oncologists and/or secondary care specialists were often cancelled without explanation. People described how timeframes to start cancer treatment were pushed back without explanation, and how treatment cycles were delayed and rescheduled despite the potential risks.

People described how these delays could leave them feeling anxious, and that there was a lack of care, consideration, and support available to them in both managing their wellbeing regarding their cancer diagnosis and limited care or support for them with their cancer treatment.

People's experience of delays is supported by figures from NHS England, which show that the 3 waiting standard measures are not being consistently met, with performance varying considerably between types of cancer and integrated care system (ICS) areas. We found that between July 2022 and June 2024:

- There were improvements in performance against the 28-day faster diagnosis standard, with the standard being met for the first time in February 2024 (78%). While the majority of ICSs have met the target at some point in the past 2 years, only 12 have met the standard for half or more of the time.
- The 31-day standard has not been met nationally in the period we reviewed. Only 10 out of the 42 ICSs met the 31-day standard at least once over the period, and only 4 of those met the standard more than twice.
- Performance against the 62-day standard is poorer than the others, with a national average of 65% since July 2022, 20% below the target. No ICS has met the standard during this period, and this standard has the widest range between the best and poorest performing ICSs, with the best performing at 79% on average, against the worst at 50%.

A picture of variation

As highlighted, the performance of cancer services varied greatly across the 3 waiting standards and depending where in the country people live. In this section, we explore this variation through measures relating to the 4 most common cancers – breast, lung, prostate and colorectal cancer – which make up over 50% of all cancers.

In England, there are 3 different routes of diagnosis for cancer: National Screening Programme, Urgent Suspected Cancer and/or 'Breast Symptomatic but Cancer Not Suspected'. Depending on the type of cancer, people may receive a referral through different routes. Looking at national figures, we can see that performance against the 28-day faster diagnosis standard varies across the 4 cancer types.

Data shows that between January and March 2024, 81% of people with suspected lung cancer and 89% of people with suspected breast cancer received a diagnosis or were given the all clear within the 28-day target.

However, during the same period, performance against the 28-day target was lower for people with other types of cancers – 62% of people with suspected colorectal cancer and 56% of people with suspected prostate cancer received a diagnosis or were given the all clear within the 28-day target.

Meeting the 28-day faster diagnosis standard also varied depending where in the country people lived. For example, for people with suspected lower gastrointestinal cancer referred through the National Screening Programme, 83% received a diagnosis outcome within 28 days in the best performing ICS area, while in the worst performing area, only 14% received a diagnosis outcome within 28 days.

The picture was worse for the 31-day standard. For January to March 2024, across all the most common cancer types, the target of 96% of people with cancer starting their treatment within 31 days of a decision to treat was not met nationally. This varied across the 4 most common cancer types, with rates for lung cancer closer to target than other cancers at 92% (against a target of 96%). However, between January and March 2024, the biggest variation in performance between ICSs was for breast cancer, with the top performing ICS achieving the target 98% of the time, and the lowest only 72%.

Following on from the 31-day standard, again we see that, nationally, none of the 4 most common types of cancer met the standard of 85% of people starting treatment within 62 days of being referred. Performance against this standard varies between the 4 types, with performance for colorectal cancer again the worst at 54%.

Performance between ICSs also varied for the 62-day standard, with prostate cancer having the largest variation between them (93% for the best compared to 24% for the worst).

The stage at which cancer is diagnosed can have a major impact on prognosis – people whose cancers are detected and treated in the early stages have a better 1-year survival than those diagnosed with late (stage 4) cancer. The previous government set an ambition for 75% of all cancers to be diagnosed early (stage 1 and 2) by 2028. As of 2021, 54% were being diagnosed early.

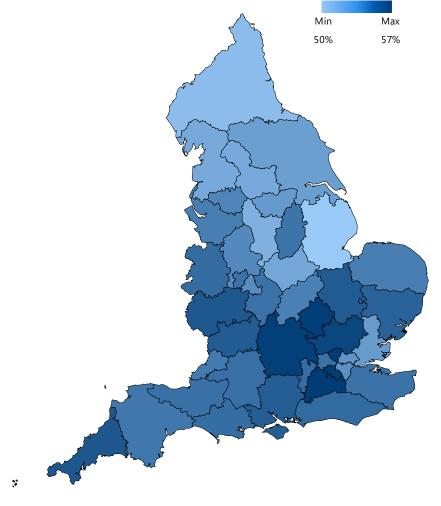
Patients in more deprived areas are more likely to be diagnosed at a later stage. A 2020 report by <u>Cancer Research UK</u> found that over 30,000 extra cases of cancer in the UK each year can be attributed to social and financial deprivation, with survival rates worse for people in the most deprived groups.⁴⁸

As we show in our section on access to GP practice appointments, difficulties in getting an appointment can have adverse impacts on care including cancer screening. Findings from our survey that asked 2,000 adults about their experiences of accessing health and adult social care services shows that access to GPs varies, as people receiving benefits and financial support were more likely to have difficulties with access.

This is supported by recent analysis from the <u>Nuffield Trust</u>, which shows that people living in the least deprived areas have had a consistently higher rate of early cancer diagnosis than those living in the most deprived areas.⁴⁹

Similarly to waiting time standards, the map shows that diagnosis of early stage cancer varies across the country (figure 18).

Figure 18: Percentage of cancer patients diagnosed early (stage 1 and 2) for all cancers, by integrated care system, 2021



Source: NHS England, National Disease Registration Service

Workforce inequalities

In last year's State of Care, we emphasised the importance of having an ethnically diverse workforce that reflects the population it serves – particularly at senior level. This helps to raise awareness of the reality of racism and discrimination, as well as supporting staff to:

- feel equal and represented
- have role models and advocates for progression
- feel able to speak up and raise concerns.

Data on the NHS <u>Workforce Race Equality Standard</u> also shows the vital contribution to the NHS made by staff from ethnic minority groups.

Between March 2018 and March 2023, the proportion of staff from ethnic minority groups increased from 19% to 26%. This upward trend is also reflected at a regional level. Last year, London had the highest proportion of staff from ethnic minority groups at 50%, which has increased to 52% this year. The South West continues to have the lowest proportion at 15%, which is an increase from 13% last year.

However, the 2023 NHS staff survey shows that staff from ethnic minority groups are still considerably more likely to experience discrimination, compared with staff in white ethnic groups. The survey found that they were:

- almost 4 times more likely to experience discrimination from people using services, their relatives or other members of the public in the past 12 months, compared with staff in white groups (19% compared with 4.8%).
- more than twice as likely to have experienced discrimination from a manager, team leader or other colleagues in the last 12 months than staff in white groups (15% compared with 6.7%).

Staff from ethnic minority groups were also noticeably more likely to experience harassment, bullying or abuse, compared with colleagues in white ethnic groups, as the survey found:

- a higher percentage of staff (21%) were harassed, bullied or abused by other colleagues in the last 12 months compared with staff in white groups (16%).
- a higher percentage (28%) were harassed, bullied, or abused by patients, family, or the public than staff in white groups (24%).

Workforce Disability Equality Standard (WDES)

The <u>Workforce Disability Equality Standard</u> (WDES) is a set of 10 specific measures for NHS organisations to compare the workplace and career experiences of disabled and non-disabled staff.

The 2023 NHS staff survey showed that NHS staff with long-term health conditions or illnesses continue to suffer discrimination and have much poorer experiences, compared with staff who do not have such conditions. For staff with a long-lasting health condition or illness:

• 27% said they had felt pressure from their manager to come to work compared with 18% of staff with no such conditions

- 15% said they had experienced harassment, bullying or abuse at work from managers, which was almost twice as high as the proportion of staff with no such conditions
- 24% said they had experienced harassment, bullying or abuse at work from other colleagues, compared with 15% of staff with no such conditions.

An improved and safer use of medicines

Sickle cell disease and access to pain relief

In last year's report, we included a focus on sickle cell disease, which is particularly common in people with African or Caribbean heritage. Knowing that people with sickle cell disease do not always receive high-quality care, we reported on how prepared NHS trusts were to make sure people who experience a sickle cell crisis can access timely and effective pain relief. We found that not all trusts had the right policies to do this, and that there were gaps in the level of knowledge among staff to support people.

This year, we followed up with NHS trusts to understand what progress was being made in this area of risk. We found many had taken actions to make improvements, including:

- reviewing and improving the availability of medicines, providing the most appropriate painkillers and developing a more holistic approach to prescribing
- focusing more on education and awareness, across medical and healthcare staff
- improving policies to support staff, with trusts involving people with experience of sickle cell disease to develop these
- improving collaborative working for example, one trust was piloting the deployment of community nursing teams to support patients with sickle cell disease in their area, to prevent admissions to hospital.

Although we heard about some excellent examples of improvement, some trusts had a more comprehensive approach to sickle cell pain relief than others. Some non-acute trusts and those in geographical areas with a low proportion of people with sickle cell disease viewed this clinical area as a low priority.

Supporting people who take insulin

Incidents involving insulin are one of the most reported errors in hospitals and can have a significant impact on people's health.

In 2023, we asked chief pharmacists in NHS trusts how their pharmacy teams were supporting patients who take insulin. They told us:

 Electronic prescribing and medicines administration systems have enabled trusts to pre-set safety measures, alert prescribers and nurses of high insulin doses, prioritise high-risk patients, and obtain an accurate list of people's medicines.

- Many trusts had developed bespoke in-house insulin training. One trust had developed a competency framework, which all nurses or staff administering insulin completed.
- Some trusts saw self-administration as an opportunity to support people
 to gain confidence and maintain independence, and had the potential to
 avoid incidents. One trust had developed specific self-administration roles
 who liaised with ward staff to identify patients who would benefit. This
 had released time for nurses and reduced the workload on district nurses
 when people were discharged back into the community.

Environmental sustainability

Medicines account for about 25% of emissions within the NHS in England. A small number of medicines account for a substantial proportion of these, particularly gases and nitrous oxide, and asthma inhalers.

We have carried out research through the <u>Regulators' Pioneer Fund</u> to improve our understanding of how health and social care services are improving the environmentally sustainable use of medicines, while improving people's care.

The NHS has committed to reaching <u>Net Zero by 2045</u>.⁵⁰ One way hospitals are tackling this is reducing the carbon impact of 2 gases – nitrous oxide and desflurane.

In maternity wards, new equipment is being used to convert nitrous oxide from exhaled air into harmless gases. This has ensured that patients continue to have access to long-established and safe pain-relief in labour, while reducing exposure for staff and protecting the environment by reducing greenhouse gas emissions.

NHS trusts have also reduced or eliminated the use of desflurane – one of the most environmentally harmful anesthetic gases – replacing it with an alternative equally effective anaesthesia. This provides effective patient care while offering large carbon savings.

In general practice, the <u>2022/23 Investment and Impact Fund</u> took important steps to improve people's respiratory care and, at the same time, reduce the carbon footprint by prescribing lower carbon asthma inhalers and optimising medicines treatment regimes.⁵¹

Other initiatives include specialist teams of pharmacists and pharmacy technicians working with people living in care homes, their families and care home staff to review people's medicines. This improved outcomes for people by reducing the risk of side-effects, as well as reducing wastage and ultimately reducing the carbon footprint.

State of Care



Areas of specific concern

Maternity care

Children and young people's health

Care for autistic people and people with a learning disability

Black men's mental health

People with dementia

Termination of pregnancy services

Deprivation of Liberty Safeguards (DoLS)

Areas of specific concern

Key findings

- Too many women are still not receiving the high-quality maternity care they deserve. Of the 131 locations we inspected in our national maternity inspection programme, almost half were rated as either requires improvement (36%) or inadequate (12%).
- We have concerns that children and young people are not always able to access services in a timely way – both planned and in an emergency. Anecdotal evidence suggests that parents and carers are well placed to recognise when their child is very unwell, but many feel they are not being listened to.
- The number of health visitors, who give individual support for young children and their parents, has declined by 45% over the last 9 years.
- Only around a quarter of people with a learning disability were recorded on the learning disability register, which means that many people are missing out on the proactive care and treatment they are entitled to.
- Despite fewer new referrals for autism diagnoses over 2023/24, the average waiting time to start an assessment reached a peak of nearly a year (328 days) in April 2024, rather than the recommended 3 months.
- People in Black or Black British ethnic groups are over 3 and a half times more likely to be detained under the Mental Health Act than people in white ethnic groups.
- Work on our cross-sector dementia strategy is highlighting the compassionate care and initiatives that are improving people's lives, but staff do not always understand the specific needs of people with dementia.
- The Deprivation of Liberty Safeguards (DoLS) system has needed reform for over 10 years, and we continue to see people in vulnerable circumstances without legal protection. Unless there is substantial intervention, we are concerned that the long-standing challenges will continue.

Maternity care

The quality and safety of maternity services have remained under scrutiny in recent years. While a series of high-profile investigations identified key failings at specific NHS trusts, our recent national maternity programme – an inspection of all hospital maternity locations that had not been inspected since before March 2021 – showed many of the issues raised are widespread across England.⁵²

We are concerned that too many women are still not receiving the high-quality maternity care they deserve. Of the 131 locations we inspected, almost half (47%) were rated as either requires improvement (36%) or inadequate (12%). At 12 locations, ratings for being well-led dropped by 2 ratings levels and at 11 locations, ratings for being safe dropped by 2 levels.

These findings highlight that work to help improve safety already underway needs to continue and that there are specific issues that must be tackled as part of NHS England's 3-year delivery plan for maternity.

The inspection programme identified unsuitable maternity estates as a key issue affecting the quality of care women received. We found several maternity units were not fit for purpose, lacking space, facilities, and in a small number of cases, appropriate levels of potentially life-saving equipment. Our national maternity report called for additional capital investment to ensure women receive safe, timely care in an environment that meets their needs.

Chronic issues around recruitment and retention of the maternity workforce were another barrier to high-quality care. While some services had good oversight of staffing levels, managers did not always have the resources to adjust staffing levels according to the needs of women.

It is vital that maternity services can recruit to maintain safe staffing levels. Staff should then be supported to carry out their roles with the appropriate levels of training. With high numbers of midwives being driven away from the profession by current workload pressures⁵³, it is important that leaders prioritise the wellbeing of staff to foster an open and supportive culture. There is also work to be done to future-proof the workforce and attract students to a career in midwifery, as data from UCAS shows midwifery applications for June 2024 were at their lowest for more than 6 years.⁵⁴

Inequalities in maternity care

In our <u>Safety, equity and engagement in maternity services report</u> and our last <u>State of Care report</u>, we highlighted that there are still unwarranted variations in clinical outcomes for women with protected characteristics under the Equality Act 2010. The most recent <u>MBRRACE-UK data</u> showed that, compared with women from white ethnic groups, Black women were 2.8 times more likely to die during or up to 6 weeks after pregnancy, and Asian women were 1.7 more times likely to die during the same period.

Our national maternity inspection programme found huge differences in the way trusts collect and use demographic data, particularly ethnicity data, to address health inequalities in their local populations. Without national guidelines, we are concerned that trusts have no way of effectively evaluating

if initiatives to make maternity care more equitable are driving much-needed change.

We also found that communication with women and their families is not always good enough, particularly for women whose first language is not English. This affects their ability to consent to treatment and can perpetuate levels of fear and anxiety. Through our Give feedback on care service, many women told us that a lack of communication negatively affected their birth experiences. A cultural shift is needed so that all women are given the information they need, in a way they understand it, to make informed decisions and consent to treatment.

Safety of maternity services

The safety of maternity services remains a key concern. When inspecting the safe key question in our national maternity inspection programme, almost half of services were rated as requires improvement (47%), while 35% were rated as good and 18% were rated as inadequate. No services inspected as part of our programme were rated as outstanding for being safe. We found significant variation in the way trusts operated in key areas such as triage and learning from patient safety events.

More work is needed to improve the way services report, learn and communicate with women when things go wrong. Although most services managed patient safety events well, we are concerned that a lack of reporting is leading to harm becoming normalised and opportunities for learning are being missed. While recognised complications such as postpartum haemorrhages may be common to staff and do not always constitute a patient safety incident, the impact on women can be significant. We are concerned that women do not always receive the information they need to process what has happened to them and make informed decisions about future pregnancies. Research shows that 4 to 5% of women develop post-traumatic stress disorder (PTSD) after giving birth.⁵⁵

Despite this, we found a significant number of patient safety events went unreported — either because staff were overstretched or because they did not trigger a patient safety incident and were not recorded locally. Not reporting patient safety events such as postpartum haemorrhages suggests a tendency to accept them as inevitable, but we know this is not the case. For example, monitoring levels of haemoglobin after birth can reduce the likelihood of a postpartum haemorrhage. Issues with recording and grading patient safety events could also result in a lack of oversight and missed opportunities to learn from them.

With no national targets or standards for maternity triage, we found significant variation. While a 'one size fits all approach' may not be appropriate across all services, we are concerned that not everyone received a safe and timely assessment. Maternity triage is a recognised high-risk clinical area, where women who have an emergency or concern about their pregnancy can contact a hospital for an urgent assessment. Staff will use this assessment to prioritise their care.

The first step is usually to call a telephone triage line. Although most services offered a telephone triage service, we saw variation in how effectively they were operated. We found instances where the triage phone went unanswered, which risked missing urgent calls or vital early warning signs. Similarly, when people arrived at hospital, issues with staffing and the triage environment meant some women were not assessed in a timely way. In some cases, delays in triage were so severe that women discharged themselves before being seen by a midwife or doctor.

These issues meant that unsafe practice in triage formed the bases of 81% of enforcement actions issued to providers. It was also recognised as a safety concern in around a third of all inspections.

Children and young people's health

Secondary care

We know that getting care the right care, at the right time in the right place is important for all patients. But not getting the care they need when they need it can be particularly damaging for children.⁵⁶

The Royal College of Paediatricians has previously flagged concerns about the numbers of children waiting for elective care treatment. In May 2023, it highlighted that there were over 400,000 children on the waiting list for consultant-led paediatric services. While this has subsequently reduced to 363,000 by June 2024, over 140,000 of these had already waited over 18 weeks.

Delays to treatment for children can have significant consequences. Many treatments and interventions must be administered within specific age or developmental stages. Treatments and interventions may be less effective if not administered within these stages, and the opportunity to intervene can be missed completely if the wait for diagnosis is too long.

Additional impacts include the loss of schooling, financial impact for families with carers missing work, and disruption to family life. These effects are often greatest for the most vulnerable children and families. For example, a child waiting to be seen in clinic for specialist asthma treatment may be missing school due to their symptoms, as well as being at increased risk of an episode of severe or life-threating exacerbation of asthma requiring an inpatient admission.

Between 1 April 2022 and 31 March 2023, 3,743 children aged 0 to 17 died in England. The causes of child mortality are numerous and complex. However, we are concerned that this represents an increase of 8% on the previous year and the highest number of deaths recorded since the National Child Mortality Database was launched in 2019.

We also have concerns that in an emergency, children and young people are not always able to access services promptly. An analysis of a sample of our inspection reports shows specific issues in urgent and emergency care services, including low numbers of qualified staff – specifically children's nurses – and gaps in staff training in subjects such as safeguarding and sepsis recognition. These issues meant that in some services, there was a risk that a deteriorating child might not be identified quickly, and patients at risk of sepsis not being assessed and treated promptly.

We found that crowded emergency departments meant waiting areas did not always assure the safety of children and young people. In one case, staff could not ensure appropriate visual supervision or carry out risk assessments and mitigate risks in waiting areas.

Anecdotal evidence suggests that parents and carers are well-placed to recognise when their child is very unwell.⁵⁷ Therefore, actively involving parents in their child's care decisions and addressing their concerns promptly is critical to safety.

In May 2024, we commissioned a survey of parents with children aged 0 to 18 years who had taken their child to see a healthcare professional in the

last year. Of the 1,000 respondents, 44% (439) stated they had raised a concern about the health of their child or children to a healthcare provider in the last year. Of these, 78% felt that the health provider took their concern seriously. However, in 22% of the cases they did not feel their concern was taken seriously. Where respondents had a negative experience, they described their experiences of staff with words such as 'dismissive', 'judgemental', 'not friendly', or 'not compassionate'.

Where people felt their concerns were not taken seriously (95 respondents), 86% felt there was a negative consequence, including:

- losing trust in the healthcare provider (49%)
- feeling like their child did not get the help they needed (41%)
- reporting their child's health deteriorated as a result (31%).

To support patients and families to get the care they need, in April 2024 NHS England introduced a pilot of 'Martha's Rule' in 143 hospitals across England. Martha's Rule will ensure that where patients are admitted to a hospital in England, information will be gathered daily from patients, families and carers. Martha's Rule also empowers patients, people who use services and their families and carers to seek a rapid critical care review if they feel their concerns are not being addressed by their current clinical team.

Martha's Rule reinforces the fundamental principles of listening to people who use health and care services and their families – and acting on what they say. It supports care that is person-centred, responsive, and aligned with high standards of professional practice.

We welcome the way that Martha's Rule emphasises effective teamwork, mutual respect, and open communication. The emphasis on professionals working together encourages active listening, promotes person-centred care and supports a culture of learning and improvement.

The introduction of Martha's Rule follows the rollout in November 2023 of the national paediatric early warning system (PEWS). The tool, developed in collaboration between NHS England and the Royal College of Paediatrics and Child Health and the Royal College of Nursing, attempts to standardise the recognition of, and response to, unwell children. It supports doctors and nurses treating children to quickly identify deterioration, escalate care, and act on parental concerns.

Children and young people's mental health care

In 2023, 1 in 5 children and young people between the ages of 8 and 25 were estimated to have a mental health disorder. Not getting the help they need when they need it can have a huge impact on children and young people. One young person described the consequences of what they felt to be inadequate support from community services, leading to long-term hospitalisation: "I didn't know what to do because I didn't have any GCSEs and I thought no one's gonna want to give me a job and I'm not gonna be able to go to college...I wasn't a normal person of my age because I was in hospital and I missed out on all the things".

We also heard about the positive impact of getting the right support early enough: "I do still think back on my time at CAMHS and I was like, if I didn't [get that support], I would be in such a different place today... I got very lucky."

Long waiting times could lead to children and young people feeling unsupported and as though they were not enough of a high risk to get help. People also spoke about how long waiting times could lead to a lack of trust in mental health services for children and young people.

Alex's story

Alex first started struggling with food at the end of 2020. Her dieting became gradually more extreme and then escalated in the summer of 2021 when she was rapidly losing weight.

Alex visited the GP in October 2021 who made a referral to children and young people's mental health services. She describes her visit to the GP as quite a negative experience:

"She (the GP) kept saying 'ohh Alex thinks she has this' and 'Alex feels she is bisexual' and I just immediately felt like [this service] was not gonna be very helpful to me because they just don't actually listen and they don't actually trust me because in their eyes, I'm a silly teenage girl instead of, like, an actual person who's going through actual things."

Anticipating a long wait for the service, Alex sought support from a private eating disorder therapist, which she found very helpful. However, Alex and her family still wanted to access family-based therapy and support from a nutritionist through children and young people's mental health services. Alex waited 7 months for initial contact from the service. Nutritionist support was put in place quickly after that, but the wait for therapy was another 6 months. Alex did not feel she was kept well informed while she was waiting for care and regularly had to call for updates, which were always very vague.

In November 2022, Alex started therapy with an eating disorder specialist from the children and young people's mental health service. However, she didn't develop a good relationship with the therapist and felt they patronised and misunderstood her. She found these sessions so frustrating that she would regress with her eating because of them, so she decided to discontinue the therapy.

"This was really upsetting because we've been on a wait list for a year to receive therapy and now that therapy was doing me more harm than good."

After 8 months of waiting, Alex was given an appointment with a psychiatrist to support with the underlying depression. By this point, Alex wasn't struggling with depression anymore, so it was decided no further support was required. However, the psychiatrist suspected that Alex had ADHD (attention deficit hyperactivity disorder). Assessments were then carried out quickly to get a diagnosis, which allowed Alex extra time and rest breaks when she sat her A-Level exams in the summer of 2023 – something that she is very grateful for.

Alex was still receiving support from her private therapist throughout this time, who she found she was making great progress with. When she reached her 18th birthday and was discharged from children and young people's mental health services, she decided she didn't want to be referred to adult mental health services.

(Interview with a member of the public)

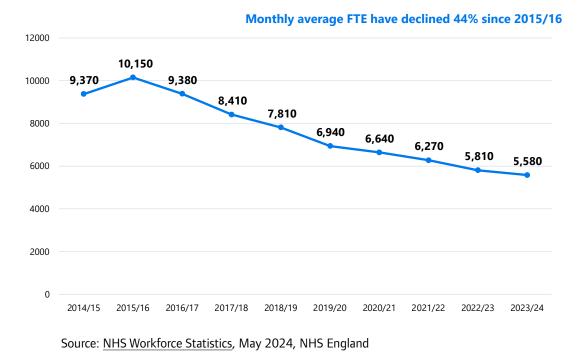
Community health care

Overall NHS nursing numbers have increased by 21% from 2015/16 through 2023/24, including a 10% increase in community health nursing. However, for several key roles in the community health care sector, there have been reductions in numbers. The largest reduction is in monthly average numbers of qualified health visitors, which we examine in more depth.

Health visitors are registered nurses or midwives who have undertaken additional training in community public health nursing to provide individual support and advice for families with a new baby, from late in the antenatal period up to 5 years of age.

The number of qualified health visitors has seen a sustained decline. Between 2015/16 and 2023/24, the monthly average number of FTE health visitors has decreased by 45% – the equivalent of over 4,500 FTEs (figure 19). (Note, these figures reflect the data published by NHS England, which excludes non-NHS providers such as community interest companies.)

Figure 19: Monthly average of health visitor full-time equivalents in England, April 2014 to March 2024



This decline could be partly explained through a greater percentage of health visitors giving 'retirement' as a reason to leave their jobs, compared with nursing staff overall. Health visitors are a comparatively older workforce – based on a snapshot of staff in post on 31 March 2024, 75% of qualified health visitors were over 40 years old, and 28% were over 55. Less than 5% were under 30. By contrast, in the overall nursing workforce, 50% were aged over 40, 15% over 55 and 16% were under 30 years.

Despite the sharp reduction in numbers, responses from health visitors to the 2023 NHS Staff Survey were better than comparable staff across many key areas. However, compared with registered nursing overall, the one major theme associated with lower scores from health visitors was for 'work pressure' – potentially pointing to the additional workload placed on this decreasing resource. Health visitors also reported they were significantly more likely to work unpaid hours and scored lower in reporting a manageable level of demands on their time.⁵⁸

The <u>analysis</u> by the <u>Institute</u> of <u>Health Visiting (IHV)</u> of its 2023 survey identifies that infants under 1 year have the highest proportional representation in emergency departments compared with other age groups. Attendance rates for infants aged 0 to 4 years increased by 42% between 2012/13 and 2022/23, from 1.8 million to 2.6 million. The IHV suggests that a large proportion of these attendances could have been avoided if better access to health visiting services had been available.

The IHV goes on to give an example that, in North West London, 59% of babies who attended an emergency department in 2022 did not need treatment and were sent home after reassurance, costing an estimated £1.8 million a year in this one area of London alone. While acknowledging that the emergency department is the right place for very sick babies and young children, the IHV says improving access to high-quality care in the community could help to reduce attendance in babies and young children, and reduce undue worrying for parents.

In an article on improving childhood vaccine uptake, the IHV points out that vaccination is one of the most effective public health interventions available, preventing illness and disability, and saving lives, and that health visitors have a role in raising awareness of its importance. There has been a 4% reduction in the uptake of the measles, mumps, and rubella vaccine, as well as other vaccines in the last decade. While other factors will have influenced this, the reduction correlates with the decline in the number of health visitors over a similar period.

Another result of declining numbers of health visitors is having insufficient time to build and maintain longer-term relationships with families, with a latest IHV survey finding that less than half (48%) feel able to do this.

The ambition of the <u>NHS Long Term Workforce Plan</u> is to expand the number of training places for health visitors by 74% to address preventable child illness and take the pressure off stretched emergency departments.⁵⁹ However, since the ambition is to reach this by 2031/32 and, considering the length of time it takes to train (2 years for a qualified nurse or midwife), this means it may be some time before an improved health visitor resource could have the desired effect. While this is the first focused effort on increasing health visitor numbers since 2015, it may not address the reductions mentioned above, as there is no minimum standard for provision.

Care for autistic people and people with a learning disability

Health inequalities for autistic people and people with a learning disability is still an unacceptable issue. The latest <u>Learning from Lives and Deaths – people with a learning disability and autistic people (LeDeR)</u> report, published in November 2023, highlighted that life expectancy for these groups of people remains lower than for the general population. The report again shows that people from all ethnic minority backgrounds are at an increased risk of premature death.

While the report shows evidence of an increase in life expectancy for women with a learning disability, they are still dying 23 years earlier than women in the general population. In addition, the number of deaths of people with a learning disability who live in the most deprived areas of the country are 3 times more than those living in the least deprived areas.⁶⁰

The LeDeR report goes on to say that 42% of deaths of people with a learning disability were rated as avoidable, compared with 22% for the general population. This is reflected in information we receive through our regulatory work, such as people dying of avoidable constipation and choking. For example, a person with a learning disability who was admitted to hospital with constipation died in hospital 48 hours later with an impacted bowel.

Annual health checks with a GP

Anyone aged 14 and over who is on their GP's register of people with a learning disability is entitled to an annual health check once a year so they can talk to a doctor or nurse about their health, and any problems can be found and treated early. This also enables people with a learning disability to receive reasonable adjustments, such as having longer appointments, bringing a carer with them, or having an appointment at the beginning or end of the day, if they find it hard to be in a busy waiting room.

<u>Data published by NHS England</u> suggests that in 2022/23, 80% of people aged 14 and over who were on the register of people with a learning disability received a health check.⁶¹ This was a significant increase compared with the previous year, and a huge improvement compared with 2018/19 when the data suggests just 59% of registered people received a health check.

However, these figures may only show a fraction of the picture, as not all GP surgeries maintain an up-to-date register. A <u>report by the Women and Equalities Committee</u> notes that, although an estimated 1.3 million people have a learning disability in England, only around a quarter of these were recorded on the register of people with a learning disability. This means that many people with a learning disability are missing out on the proactive care and treatment they are entitled to.⁶²

The report goes on to say that reducing the current waiting time for a diagnosis of autism is crucial to tackling health inequalities for autistic people (see below).

Through our regulatory work, we have seen examples where autistic people and people with a learning disability have not been supported to attend routine medical screening, such as breast screening, either by their social care service, or by their GP as part of their annual health check. We heard of an example where, following the identification of changes in a person's breast, a service didn't facilitate a visit to the GP in a timely way. The person was subsequently found to have breast cancer.

Our Expert Advisory Group has explored the challenges and barriers for people when accessing their GP, the inequalities related to primary care and the access to, availability and quality of annual health checks. The group includes people with lived experience and key stakeholders representing people with a learning disability and autistic people. They told us the key issues were related to:

- communication
- making reasonable adjustments for them
- lack of a person-centred approach
- the environment in waiting rooms
- lack of consideration of people's other protected characteristics.

They also spoke about the importance of continuity and choice, staff training and co-production to make sure people's individual needs were understood and met. The Expert Advisory Group then supported us to develop a set of questions they felt were important for CQC to ask during our assessments of primary care services.

These questions are feeding into our priority area of work to help tackle inequalities in health and to reduce early mortality. The project relates to the Learning from Lives and Deaths (LeDeR) programme, which was established in 2017 to investigate and reduce the unacceptably high levels of early mortality for autistic people and people with a learning disability.

To help inform our regulatory activity, we are exploring issues such as:

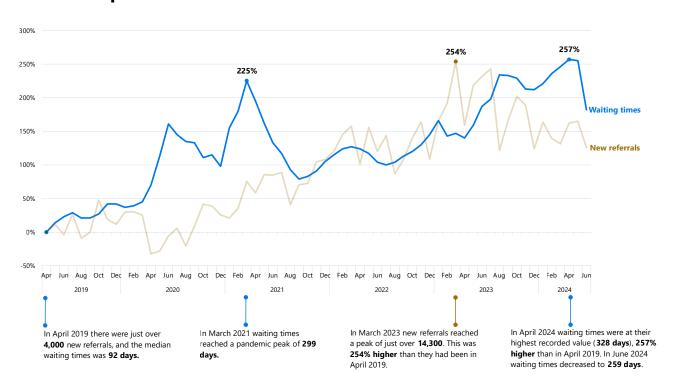
- the barriers and inequalities faced by autistic people and people with a learning disability in accessing primary care
- the quality and consistency of annual health checks and action plans with a GP for autistic people and people with a learning disability
- the provision of reasonable adjustments.

Health services are required to make reasonable adjustments to ensure that they can meet the health needs of people with a disability, including learning disabilities. This can include making information easier to read, using texts or making telephone calls to remind people to attend appointments, and allowing more time for consultations. In September 2023, the Reasonable Adjustment Digital Flag Information Standard was published. This aims to clearly identify everyone who may need reasonable adjustments during annual health checks and other contact and processes. We look forward to reviewing the impact of the digital flag on reducing health inequalities, which became mandatory from April 2024.

Diagnosing autism

NICE guidelines recommend that people who have been referred for a possible diagnosis of autism should have an assessment started within 3 months of their referral. NHS England data shows that average waiting times against this recommendation have been increasing over recent years, reaching their highest level at 328 days in April 2024. Increases in average waits up to April 2024 come despite a broad trend of decreasing numbers of new referrals over the past year. As at June 2024, there were over 9,000 new referrals a month, compared with just over 14,300 in March 2023 (figure 20). While the data for June 2024 also shows a reduction in median waiting times, more data is required to see whether this is sustained.⁶⁴

Figure 20: Average waiting time from referral for a diagnosis of suspected autism to first appointment and number of new referrals – percentage change relative to April 2019



Source: Mental Health Services Dataset (MHSDS)

Average waiting times are even longer for children and young people – at 356 days in April 2024 compared with 238 days for adults. This may be because the number of referrals for young people is considerably higher than for adults, at nearly 7,000 in April 2024 compared with just under 4,000.

Worryingly, since 2019, the proportion of open referrals without any appointment has been increasing, reaching 81% in June 2024, compared with 44% in April 2019. This means that many people are being referred and not being seen.

NHS Long Term Plan commitments

In last year's report, we described how our Mental Health Act reviews showed that autistic people and people with a learning disability continue to be placed in a mental health hospital inappropriately when they should be receiving care in the community. Inappropriate hospital placements can cause considerable harm, especially if a person is in long-term segregation. Mainstream psychiatric inpatient care environments are usually bright and noisy and unsuitable for neurodiverse people. Inappropriate inpatient environments can also pose a higher risk to upholding people's human rights.

The <u>2019 NHS Long Term Plan</u> included several commitments relating to autistic people or people with a learning disability when they are an inpatient.⁶⁵ To assess the progress on these commitments, we reviewed <u>NHS England's Learning Disability Services Monthly Statistics</u> from the Assuring Transformation dataset published in June 2024. We found the following from our review of the commitments and targets:

- 1. NHS Long Term Plan commitment: Reduce the number of autistic people and people with a learning disability in mental health inpatient facilities to less than half of 2015 levels by March 2023/24. In March 2015, there were 2,905 autistic people and/or people with a learning disability as inpatients. By March 2024, the target's deadline, there were 2,155 inpatients. This is only a 26% decrease on the March 2015 figure and as such, this commitment has not been met.
- 2. NHS Long Term Plan commitment: By March 2023/24, for every 1 million adults, there will be no more than 30 people with a learning disability and/or autism cared for in an inpatient unit. We found that, in March 2024, the rate of adult inpatients who are autistic or have a learning disability was around 43 per million. As such, this commitment has not been met. This rate also varies considerably by integrated care board area ranging from 75 inpatients per million adults to 21 inpatients.
- 3. NHS Long Term Plan commitment: Reduce the proportion of children and young people who are autistic or who have a learning disability in inpatient facilities to no more than 12 to 15 per million. As at March 2024, of the 2,155 inpatients who are autistic and/or have a learning disability, 245 were under the age of 18, meaning there were 21 children and young people who were autistic or had a learning disability in inpatient facilities for every 1 million children under the age of 18. As such, this commitment also has not been met.

People with a learning disability in mental health hospital settings

NHS England data for June 2024 shows that among autistic people and people with a learning disability who are inpatients in a mental health hospital:

 more than half (53%, 1,080 people) had a total length of stay in hospital of more than 2 years • nearly 1 in 6 (17%, 340 people) had a total length of stay in hospital of more than 10 years; the majority (71%) of these inpatients were subject to Part III of the Mental Health Act.

As at June 2024, less than a quarter (23%) of autistic people and people with a learning disability who were inpatients had a planned discharge date. Where a discharge had been planned, it was recorded that the relevant local authority was aware that an inpatient was to be transferred or discharged to their area in only 62% of cases. This lack of comprehensive joined-up planning and communication may inhibit the ability of services to arrange suitable care and support for people in the community.

At the end of March 2024 (last available data), there were 220 autistic people or people with a learning disability whose discharge from hospital was recorded as delayed. The following were the most commonly recorded reasons for these delays:

- more than half (56%) involved a lack of suitable housing
- a third (33%) involved delays while awaiting a place in a residential home
- a quarter (24%) involved a lack of social care support.

Our report Out of sight – who cares? and previous Independent Care (Education) and Treatment Reviews (IC(E)TR) looked at the care given to autistic people and people with a learning disability who were in long-term segregation. The report that followed from Baroness Hollins focused on autistic people and people with a learning disability who are detained in mental health and specialist learning disability hospitals. As a result of one of the report's recommendations, the previous government has asked us to take the lead on IC(E)TRs for the next 2 years, funded by the government's grant in aid initiative.

In the first year, we will be working alongside NHS England. We re-started the programme in May 2024 when there were 96 autistic people and people with a learning disability in long-term segregation. We are engaging with integrated care boards to prioritise those people for IC(E)TRs.

We want to highlight good practice that we can share with system partners to enable positive commissioning practice to shape the market. This will help ensure that the right support is available at the right time for people – especially support in the community. We will report on this activity throughout the 2-year programme, including its impact on people's quality of life and how each person has experienced the IC(E)TR process.

In all services, we expect care to be person-centred and providers to promote a culture that supports recovery, builds trust, and protects the safety and wellbeing of all people using services. Where we find this is not happening, we will continue to take action to make sure that people are safe.

Quality of mental health care for autistic people

Our analysis of comments received through Give feedback on care showed that many autistic people are struggling to get the mental health care they need. People described issues in feeling they were refused access to mental health care, including referrals not being made and feeling that they were referred to services that did not support all their needs.

Some autistic people who sought care for their mental health found it difficult to make appointments, particularly at their GP practices. Autistic people sometimes reported that GP practices did not make reasonable adjustments to support them in booking their appointments, which led to them not being able to access their GP for support. This could lead to their mental health getting worse:

"I asked if I could make appointments outside of this time and over the phone and they outright refused, so I now don't make appointments for things I need to."

"My wife is also experiencing psychological harm as she is unable to get the mental health treatment she requires. My wife is (undiagnosed) autistic and she finds the GP surgery very unaccessible [sic]."

Across all sectors, people perceived a lack of knowledge about autism among staff had implications for how they believed they were treated in relation to their mental health. A few people described positive experiences of staff taking account of their autism in the care they provided. For example, one person told us:

"Nurse practitioners are skilful, warming and understanding. I have had amazing experiences with [2 doctors] who have both been absolutely amazing with my mental health, autism and ADHD."

However, many autistic people reported a lack of understanding around autism and mental health, which could influence staff attitudes and create further barriers to access support. This included autistic traits being mistaken for symptoms of mental ill health, or staff not understanding that autism is not a mental health condition.

"During the assessment I exhibited autistic behaviours; these were mistaken for a mental health crisis and I was detained under a section 5(2)."

"The practice appears chaotic in its administration and there appears to be a total lack of knowledge on autism, it is not a mental health condition."

In particular, we heard that staff lacked knowledge around treating mental health issues in autistic young people, which people felt could be improved through better training:

"If professionals could have a little more knowledge on autism? I feel like this would be beneficial in delivering treatment that may help me more."

"I believe it would have made my mental health appointments a lot easier if I felt like people could understand or at least empathise with my struggles and the barriers around accessing support."

Autistic people said this lack of understanding could make their mental health worse, and reinforces the need for better knowledge among staff around both autism and mental health to ensure autistic people get effective mental health support:

"I said I needed to leave to get some space (I am an autistic individual and can have meltdowns and overwhelm) and I asked them to do what needs to be done. I was then told in that intense moment of upset that if I left, I would be discharged, and that is what happened, despite me explaining I felt worse and I felt like I was a danger to myself and feeling hopeless."

Restrictive practice in services for autistic people and people with a learning disability

Our <u>cross-sector policy position on restrictive practice</u> makes clear that in all services we expect care to be person-centred and that providers promote a culture that supports recovery, builds trust, and protects and promotes the safety, wellbeing and human rights of all people using services. Where we find this is not happening, we will take regulatory action to make sure that people are safe.

Through our inspections and the information we receive, we know that people with a learning disability and autistic people are too often subject to various forms of restrictive practice, including the inappropriate use of chemical restraint and extreme restraint in the form of intubation.

This can happen when there is a lack of suitable skilled and trained staff to support people who are distressed. It has led to multiple examples of abuse and inappropriate and illegal restrictive practices being used.

We have also seen examples of closed cultures forming because staff do not speak up – either because they are part of the culture, they don't recognise that what they are doing is restrictive, or because they are worried about repercussions.

Last year, during an inspection of a residential care home providing personal care and support to autistic people and people with a learning disability we found that staff used blanket restrictive practices without ensuring safeguards were in place to protect people's rights. For example, staff used verbal,

authoritative commands to instruct people what to do and what not to do. Staff did not recognise this as a restrictive intervention and the provider did not have a monitoring system to evaluate whether they met ethical and legal standards.

Where we have found disproportionate restrictive practice and unlawful deprivations of liberty, we have taken enforcement action and shared our concerns with local authority commissioners and safeguarding teams to make sure people are protected from harm. We continue to monitor these services to check that they have made improvements and complied with the requirements to enable them to meet the regulations.

Our concerns about excessive restrictive practices in services for autistic people and people with a learning disability are reinforced by our experimental analysis for this report of provider information returns submitted by care homes to CQC between April 2021 and April 2024. The analysis found that:

- On average, around 15% to 20% more residents had restraint or restriction in their care plan in care homes where over half of residents had been recorded as autistic or having a learning disability compared with care homes where no residents were recorded as being autistic or having a learning disability.
- In care homes where over half of residents were recorded as autistic or having a learning disability, the incidence of restraint was on average nearly 12 times higher than in care homes where nobody was recorded as being autistic or having a learning disability. This amounts to a yearly average of approximately 2 incidents of restraint for every 3 residents in care homes where over half of residents are recorded as autistic or having a learning disability.

Many services are working hard to ensure their staff are trained in line with regulatory requirements in supporting people with a learning disability and autistic people. However, there are still services providing care and support from staff who have not been trained.

Following a <u>consultation</u> last year, some services have been waiting for the Oliver McGowan Code of Practice to be published before securing training for staff.

The Code of Practice will greatly help to improve the understanding of the requirements on health and social care staff to support people with a learning disability and autistic people.

It is not acceptable that staff who have not received training, which is mandated in regulations, continue to provide services to people. Our focus is on how providers and leaders are assured that their staff have the skills they need to deliver care and support to people in a way that meets their needs. We know that where staff are trained to meet the needs of autistic people and people with a learning disability, quality of life and outcomes are improved.

Black men's mental health

In last year's Mental Health Act annual report, we highlighted that:

- Black or Black British people are over 3 and a half times more likely to be detained under the Mental Health Act than people in white ethnic groups.
- They are also 8 times more likely than people in white ethnic groups to be placed on a community treatment order (CTO), where supervised treatment is given in the local community.

This is a long-standing concern that needs to be addressed urgently – particularly for Black men.⁶⁶ For this year's State of Care report, we looked in detail at responses to the NHS Community mental health survey from Black men and men from a mixed Black ethnic background. While many men were happy with the care they received, some reported concerns around timely access to care, including a long wait for talking therapies, and a lack of follow-up care.

- Out of 106 respondents who had been in contact with NHS mental health services for the past 2 years, 13% reported waiting 3 to 6 months and 8% said they waited more than 6 months for their first appointment for treatment following assessment with the NHS mental health team.
- About a third felt the waiting time was too long and, of these, 56% said their mental health deteriorated while they were waiting.

We found that Black men had longer stays in hospital than white men:

• For every 100,000 men receiving care for their mental health in hospital, 100 Black men had stays in hospital longer than 60 days compared with 25 white men who had the lowest length of stay.

Black male respondents to the NHS Community mental health survey also raised concerns about crisis teams, with 1 in 5 saying they would not know who to contact out of office hours within the NHS if they were in a mental health crisis. Other people reported issues with accessing crisis services, with 11% saying they did not get the help they needed and 12% said they had to wait too long to get through, or got little support from them when needed.

"Crisis team came out to check on me and to ask why I escaped - I told them why. They was here no longer than 5 minutes."

"The crisis team tried to refer me to the home treatment team, however after waiting about 5 hours for a call from the crisis team they told me to go to the emergency department to be assessed, in order for me for me to be referred to the home treatment team."

Although few in number, 2 people made specific reference to their ethnicity and how this had a negative impact on the care they received. One person reported they did not feel they received the same level of care that a white person would have, as they were not offered the most appropriate treatment for their diagnosis:

"I was diagnosed with EUPD (emotional unstable personality disorder) in 2017, I have a psychology degree and I know one of the main treatments for this condition is DBT (dialectal behaviour therapy) and CBT (cognitive behavioural therapy), so why have I never been referred to any of these for 6 years, and I vehemently believe that if I was a Caucasian person, my care would be taken more seriously, I have experienced much neglect."

Joseph's story

Joseph is a dual heritage man with a diagnosis of paranoid schizophrenia. As a young child, he knew something wasn't right. He went to his GP as a teenager to seek help, thinking it might be a physical health issue – it wasn't, but he was told to just be more active. Two stresses through his young life were his identity and racism. At university, he became interested in Black men's mental health on his course. On a placement abroad, his health deteriorated, as he became more and more paranoid and had to return home.

Back in the UK, he experienced his first voluntary admission into hospital and started treatment on anti-psychotic medication. This caused his weight to balloon, which has been a problem ever since. Thinking this was a one-off and that he would recover, he assumed the anti-psychotic medication would end but he is still on it.

After months in hospital, he recovered and went on to university to complete his masters degree – the best years of his life. When the university asked him about his mental health, he told them he had depression – but he was ashamed of his diagnosis and felt it would impede him from doing what he loved. Stigma was a real driver of stress for him alongside his experience of being dual heritage.

Joseph's medication was changed over the years due to side effects, which continue to this day, particularly around his weight. It was many years later when he was seeing his consultant that he saw his diagnosis on a report on the desk. This was the first time he knew that his diagnosis was paranoid schizophrenia, as he had never been told.

"I understand they didn't want to devastate me with such a diagnosis, but at the same time, you know, I needed to know the chronicity of what I was dealing with."

He got employment in statutory mental health services but found poor attitudes among staff, who had quite negative views about some people who use services. During this time, a change in his medication caused real stress, leading to a breakdown that led to him seeking support out of the area due to working locally. He described the consultant he saw as being open and honest with him, which made a big difference after experiencing years of what felt like being dismissed or misled.

He moved to a job in the care sector where he still works, and which he finds more supportive and understanding of him. He describes the mutual support and informal support structures from work, family, and friends as being more helpful to him in his whole life than anything statutory services have done.

"There are people who have known you for long enough to know your experiences, that makes such a difference."

Although Joseph gets annual health checks, his weight remains an issue and he has diabetes, but there is no plan to support this aspect of his health. He did have a free gym membership and he eats healthily, but this is more through support from friends than the service.

Looking back, he feels that he has had to make sense of both his dual heritage, his diagnosis and how to deal with stigma and discrimination himself.

(Interview with a member of the public)

People with dementia

Record numbers of people are being diagnosed with dementia in England. NHS England figures show that in July 2024, nearly half a million people in England (490,163) had a diagnosis.⁶⁷

We want our regulatory work to influence and drive improvement in the provision of services, models of care and the quality of health and care services for people living with dementia.

To achieve this, we will be developing a cross-sector dementia strategy shaped by the central question, 'How can CQC use its role to improve the experience of using health and social care services for people living with dementia and their carers?'

The first phase of our project has involved speaking with a range of stakeholders, including people with lived experience of dementia and their carers.

Alongside analysis of the significant information and data we collect through our regulatory work, these discussions have directed our work and illustrated some of the challenges faced by people with dementia and their families and carers in navigating primary, secondary and social care, as well as what good care looks like.

Summary findings from our first phase of analysis

From our analysis of NHS Urgent and emergency care and Adult inpatient surveys, we found some key issues:

- hospital staff do not always understand the specific needs of people living with dementia, which can have an impact on the quality of their care and treatment, as well as their experience of care
- the busy hospital environment can be distressing for people with dementia, especially if they are waiting a long time to be treated
- family members and other unpaid carers play an essential role in supporting people with dementia to access services and to receive appropriate care and treatment, but their own needs often appear neglected, or they feel poorly communicated with
- it is especially important that care is joined up and discharge is safe when caring for people with dementia
- positive experiences can help to highlight what is important to people with dementia and their carers.

These findings are illustrated through the mixed experiences of some respondents to our NHS Adult inpatient survey:

"The people treating him didn't know how to communicate and shouted at him about causing distress. I intervened on several occasions. We were left for long periods of time with no explanations." "Mum was moved ward and became very disorientated. She was very confused and frightened. She volunteered to be moved but don't think her dementia was taken into account."

"I was unable to leave her, even for the toilet, due to her wandering and ripping out her cannula. I didn't eat or drink anything for over 26 hours as I had to remain by her side. I had a stool (no proper chair) to prop on all night while she slept and was freezing cold."

"He was also given his medication to take back to the care home. He has dementia and is not capable of knowing that he had the medication. This was particularly dangerous as he could have taken the tablets without knowing what he was doing."

"[Person's name] was taken into a small back ward to be assessed and treated. Wow, well done everyone involved and thank you NHS for working hard to improve your services even when under such pressure. It made my time less stressful."

Through our Give feedback on care service, we found similar themes about adult social care services and dementia care:

- the levels of staff, their ability and behaviours did not always meet the additional and complex needs of people living with dementia, especially when their condition deteriorates
- stimulation, interaction with others and familiarity with surroundings are important components of good dementia care, but these were sometimes lacking in people's care
- examples of high-quality, compassionate care for people living with dementia helped to highlight what good care can look like.

People described the impact of these experiences:

"Clients do not have regular hygiene needs met. My father sleeps in his clothes and the family do all of his basic needs. Staff have a poor understanding of dementia and how to meet needs."

"Dad was left to his own devices in his room alone. No interaction. The staff either sat in the TV room on their phones, or in the dining room out of the way. In 2 and a half months I never saw any classes or therapy to help residents."

"In hospital, Mother was under 24-hour observation, but with very little human interaction witnessed from the staff. Last week I visited Mother in the home and she was sitting fully dressed in the lounge quietly singing Christmas carols while one of the carers was giving her a head massage – who wouldn't thrive in an environment such as this?"

Adult social care providers used the provider information return to tell us about some of the challenges they were facing in supporting people with dementia, including:

- access to external services, such as GPs, mental health services and dental care, with assessments generally subject to long delays
- the recruitment and retention of staff with the appropriate skills and experience to provide consistent care for people living with dementia
- more people being admitted with a higher level of care need, or a more advanced stage of dementia.

Despite these challenges, care providers told us about the approaches they were taking to improve people's experiences, such as:

- adapting living environments to be more 'dementia friendly', therefore supporting people to lead more independent lives, improve accessibility, and reduce the risk of falls
- supporting people to eat and drink, as people living with dementia lose their appetite, and may have difficulty swallowing
- using a variety of inclusion approaches that cater specifically for the care
 of people living with dementia, including dementia-friendly activities,
 accessible communication and equipment
- acknowledging the combined impact of dementia and protected equality characteristics, such as disability, ethnicity and LGBT+ although this was an area of limited awareness where we plan to do more work.

Acknowledging the combined impact of dementia and protected equality characteristics

A man kept leaving his care home. It became apparent that he was going outside to urinate. There were issues around him using the toilet and he was getting very distressed. Through [guided] life story work, the staff were able to see that this man believed that he was in 1940s/50s rural Punjab, where you went into the fields to go to the toilet.

So, there was a conversation within the care home about how the staff could create a safe space for him, rather than making him use a toilet or stopping him from getting fresh air.

(Example from commissioned research by RSM UK Consulting LLP)68

Sue was diagnosed with Alzheimer's Disease and moved to a residential care home. At the home, Sue started to refer to herself as Cliff. Sue would increasingly become distressed at her appearance and physicality. The care home managers had no contact with Sue's family or awareness of her medical history, so they were unaware she was a trans woman.

A worker at the care home asked a local charity for advice on how to remain sensitive to Sue's gender identity. A partnership was set up to support Sue's needs, which included care home staff, the GP service and local voluntary organisations. Awareness training on trans identities was also organised for care home staff.

As Sue's dementia progressed, staff were able to offer her appropriate support, knowing that their approach was tailored to her needs.

(Example from National Care Forum, <u>Dementia care and LGBT communities:</u> A good practice paper)⁶⁹

We plan to share our findings in more detail in 2025, as part of a strategy over several years that aims to improve the outcomes for people with dementia and their families and carers.

Termination of pregnancy services

The level of demand for termination of pregnancy services is increasing. In 2022, just over 251,000 abortion procedures were carried out, a 17% increase since 2021. While the reasons for this are complex, a study by the British Pregnancy Advisory Service (BPAS) found that for over half of women (57%), the decision was mainly or partly related to financial factors, with respondents citing the cost of living, childcare costs and housing considerations. In addition, over a third (33%) of women surveyed said they had been unable to access contraception or had to wait longer for it than they wanted.

Amid rising numbers of abortion procedures, we are concerned that not enough women can access termination of pregnancy services close to where they live, at a time when they need them. Integrated care boards (ICBs) commission the majority of these services, but the model is fragile, with 2 independent providers delivering the majority of abortions in England (approximately 80%) from the independent sector.

Independent termination of pregnancy services are not evenly distributed across the country, meaning some women face travelling significant distances to access them. This is particularly concerning given that women living in areas of high deprivation are twice as likely to use abortion services. In response to this, some charities cover the cost of travel to ensure women can exercise their choice.

In addition, independent services often do not provide overnight facilities and in some cases, we have seen issues when women need to be transferred back to NHS services to continue their care. Independent hospitals offering termination of pregnancy services also have criteria for admission, which women with multiple health conditions do not always meet. In these cases, access to services can be more problematic, with only 5 NHS trusts in England commissioned to provide late surgical abortions up to the legal limit for these women.

When women are able to access termination of pregnancy services, we are concerned about the quality of care they receive.

As part of our inspections, we are working to improve the quality and safety of services delivered.

Improvement through inspection

An inspection of one termination of pregnancy provider highlighted that although the organisation had a clear vision, there were issues with corporate and financial governance processes. As one of the main independent providers of termination of pregnancy services, these issues posed risks to the stability of the sector.

We issued a Warning Notice, working closely with NHS England to drive improvements at the provider, which would help to stabilise abortion services across the country. A follow-up inspection showed significant improvement, with a new executive board, better sharing of information and examples of succession planning.

Despite these improvements, we remain concerned about women's access to termination of pregnancy services. In March 2024, NHS England published a <u>letter</u> setting out its objectives and vision for abortion services. It outlines actions for ICBs, including agreeing and adopting appropriate local referral pathways and procedures to ensure smooth transfers of care between independent and NHS providers when required. It also highlights the importance of appropriately funded, financially sustainable services, concluding that there are "national and regional risks if the fragility we are seeing in services is not addressed."

Deprivation of Liberty Safeguards (DoLS)

Key findings

- Too many people are waiting too long for a Deprivation of Liberty Safeguards (DoLS) authorisation, despite multiple examples of local authorities trying their best to reduce backlogs and ensure sustainable improvement.
- We remain worried about the rights of people at the heart of the DoLS system. We continue to see people in vulnerable circumstances without legal protection, which not only affects them but also their families, carers, staff and local authorities.
- The system has needed reform for over 10 years. Unless there is substantial intervention, we are concerned that these challenges will continue.

The Deprivation of Liberty Safeguards (DoLS) were introduced under the Mental Capacity Act (MCA) 2005. The safeguards were designed to protect the <u>human rights</u> of people aged 18 or over if they do not have the mental capacity to consent to their care arrangements and they need to be deprived of their liberty. The safeguards apply in care homes and hospitals.

If a person is deprived of their liberty, they are not free to leave the premises on a permanent basis, for example to live where and with whom they choose to, and they are subject to continuous supervision and control. This means they are monitored or supervised for significant periods of the day and they are not allowed to make important decisions about their own life. The safeguards are vital in ensuring that such deprivation of liberty only happens when it is necessary, proportionate and in the person's best interests.

Concerns have been raised about the effectiveness of the DoLS system for over 10 years. In 2014, the House of Lords MCA post-legislative scrutiny report warned of the lack of understanding and poor implementation of the safeguards, which meant that, "thousands, if not tens of thousands, of individuals are being deprived of their liberty without the protection of the law."⁷⁰

In successive State of Care reports, we have raised strong concerns about the operation of DoLS, including delays in processing applications and the variable knowledge of staff about the safeguards. Across both health and social care services, we continue to find that many of the issues outlined in the House of Lords report are still relevant 10 years on and have been exacerbated by the stark increase in the volume of applications, bringing new challenges for the DoLS system.

DoLS were due to be replaced by the Liberty Protection Safeguards (LPS). These would have addressed the main limitations of the DoLS system, such as:

- streamlining processes
- extending the scheme to cover 16 and 17-year-olds

- giving families greater involvement
- applying the safeguards to additional settings, including people's homes and supported living services
- crucially, giving responsibility for issuing authorisations to NHS trusts and integrated care boards, along with local authorities, to reduce the strain on the system.

However, in April 2023, the government announced that the implementation of LPS would be delayed "beyond the life of this parliament". At present, it is unclear when or if the LPS reforms will be implemented. We are keen to establish a dialogue with the new government about this.

Within a system struggling to cope, in 2023/24 we continued to see people in vulnerable circumstances being left without legal protection with their rights affected. This not only affects people using services but also their families, carers, staff and local authorities.

The chronic backlogs

Ten years ago, a landmark Supreme Court judgement, known as 'Cheshire West', clarified and broadened the definition of what constitutes a deprivation of liberty. Since then, applications to deprive a person of their liberty have continued to increase far beyond the levels expected when the safeguards were designed.

This has culminated in local authorities facing unprecedented volumes of DoLS applications, and in many cases, continuing backlogs to process them, as we have reported in previous State of Care reports. In 2023/24, applications to deprive a person of their liberty increased to just over 330,000, an 11% increase compared with the previous year.

The delays in implementing LPS mean that local authorities are still the only organisations able to give a standard DoLS authorisation. To do this, local authorities have 21 days in which to assess whether the deprivation of liberty is appropriate. But in 2023/24, only 19% of standard applications were completed within the statutory timeframe. In recent years, backlogs for processing applications have remained high, with figures showing 123,790 people were waiting for an authorisation as at March 2024.

Applications to deprive a person of their liberty must be authorised by a 'supervisory body'. In England, the role of a 'supervisory body' is undertaken by local authorities, who are responsible for arranging assessments to make sure that a deprivation of liberty is only authorised if certain requirements are met. Standard authorisations can last for up to a year. If a person urgently needs to be deprived of their liberty before they have had a full assessment, providers can grant themselves an urgent DoLS authorisation. These can last up to 7 days and can be extended for a further 7 days if necessary.

We found a wide variation in how local authorities were managing applications in 2023/24. It was clear that some were struggling to process applications promptly enough, and yet one local authority had no backlogs. We continue to hear from our external stakeholders that the DoLS system is "not working" and there is "no movement once the application has been submitted."

Some local authorities had high numbers of applications waiting to be reviewed, which meant some people had been waiting for an assessment for over a year. We are particularly worried about people's human rights in these cases, as assessments may highlight that their care is more restrictive than it needs to be. When local authorities can carry out assessments, we have seen how this can identify unnecessary restrictions so that DoLS conditions can be used to mandate that care arrangements are the least restrictive possible.

Variation in backlogs between different local authorities means people in similar situations may have different experiences of the DoLS system because of where they live. Many factors contribute to this variation, including budget allocation, the make-up of local populations, and the number of hospitals and care homes in an area.

Local authority backlogs also have a knock-on impact on hospital and care home staff: while waiting for DoLS applications to be reviewed, they have to balance keeping people safe with protecting their rights. Our inspectors told us about staff feeling stressed and confused trying to navigate the DoLS system when waiting for an authorisation. Worryingly, our inspections and assessments have also highlighted instances where backlogs in processing existing applications mean some care providers have stopped submitting new applications. This means people have restrictions placed on them without an application or any legal safeguards.

Providers must formally notify CQC without delay when they know the outcome of an application for a deprivation of liberty, whether it was made to the <u>Court of Protection</u> or under DoLS. This includes both when an authorisation has not been granted or the application has been withdrawn.

In 2023/24, we received around 161,000 DoLS notifications, a 23% increase from the previous year. Recent changes in data reporting have highlighted some discrepancies between the data collected by local authorities and data we hold on notifications from providers, and we are taking steps to understand the reasons for this.

Behind the backlogs

To better understand the pressure on local authorities, this year we surveyed representatives from the National DoLS Leads Network and heard the views of over 50 respondents from supervisory bodies across England. We heard widespread concern from the local authorities that they are often significantly under-resourced to process increasing volumes of DoLS applications, as their funding has not increased in line with the number of people requiring assessments. One local authority told us:

"DoLS is a broken system. It was designed for a pre-Cheshire West time with relatively few applications. It is impossible to make it work with the resources we have, leading to a big backlog...The situation is so bad that, if we just stopped getting any applications and just assessed people from the backlog, we would be doing this for around 18 months just to clear it."

Insufficient staffing levels were also identified as a primary barrier to performance. Many supervisory bodies are struggling to recruit enough assessors, with some local authorities relying significantly on independent assessors to manage the volume of applications. Some respondents noted high staff turnover within DoLS teams, describing working in this area as a "marmite experience" where members of staff either thrive, or more often, leave the service.

Amid these challenging circumstances, a member of our external stakeholder group described local authorities going "above and beyond to create systems that are as safe as possible." NHS England data shows that the number of applications completed by local authorities has increased over the last 5 years by an average of 9% each year. But while DoLS backlogs decreased by 2% in 2023/24, the number of people waiting for an authorisation remains significant. In our assessments of local authorities, we have seen multiple examples of supervisory bodies trying their best to reduce backlogs and ensure sustainable improvement. For example, many local authorities adopt risk-based approaches and tools to prioritise applications. We also saw local authorities recruiting and training more best interests assessors.

Respondents to our National DoLS Leads Network survey frequently cited the ADASS screening tool as a way of helping local authorities to prioritise applications, by categorising them as either high, medium or low priority. However, this method relies on detailed, accurate DoLS applications. We heard that many local authorities are not always confident that the information services provide on DoLS applications is correct. This increases the risk that people who urgently require an assessment are not being appropriately prioritised. Although tools can help local authorities to identify those in need of urgent attention, the statutory 21-day timeframe applies to all standard DoLS applications and the need to prioritise may be another symptom of a broken DoLS system.

We are also concerned that the use of prioritisation tools may result in some groups of people, such as people with a learning disability or living with dementia, being disproportionately affected by delays in processing DoLS applications. A respondent from the National DoLS Leads Network noted that while these people usually meet the requirements for DoLS, they often do not meet the prioritisation criteria and may be "overlooked". We also heard from a member of our external stakeholder group about some assessments being carried out virtually. While this may offer greater flexibility, virtual assessments are not always suitable for the people who are being assessed. A member of our external stakeholder group reflected that differences in the way local authorities approach DoLS makes it difficult to support managers of care homes spread across different counties.

Local authorities told us that ongoing issues with the level of understanding of the safeguards among health and social care staff can exacerbate the backlogs. We heard that applications from care homes and acute hospitals are not always appropriate, and we have also seen evidence of this, with some staff unclear on the circumstances that require a DoLS authorisation. This risks people who need the safeguards getting lost in the high volume of referrals, or not having an application made when they need one. Local authorities found that the

quality of mental capacity assessments made by providers before they submit an application was sometimes poor, which can also result in unnecessary applications. It also means that they may need to contact providers to get information that should have been included in the application, thereby delaying the process and requiring additional resources from all parties.

Another factor that has a negative impact on the backlogs is a lack of communication between providers and local authorities. When providers apply promptly for DoLS renewals, it can help reduce workloads for supervisory bodies. Yet, we heard this does not always happen in practice. In addition, local authorities are not always informed of important changes following submissions, such as a person dying, being discharged, admitted to hospital or their condition changing. These people therefore remain on the waiting list for DoLS when they may no longer need to be. In other circumstances, providers may also not communicate important changes such as objections or increased restrictions, preventing local authorities from giving priority to some assessments that need it.

Limited understanding of the Mental Capacity Act and DoLS

The Mental Capacity Act 2005 (MCA) directly affects the lives of millions of people. Everyone providing care to people over the age of 16 must be familiar with this vital piece of legislation, which introduced rights and protections for people who may lack mental capacity. A decade after the House of Lords report, we continue to find a lack of understanding of the MCA among providers.

Any action taken as part of the DoLS process must be in line with the principles of the Act. While providers often demonstrate an awareness of the MCA and its principles, many managers and staff still lack confidence in applying them in their work. This is reflected in care records, mental capacity assessments and best interests decisions. We found that some care records did not show how best interests decisions were made and how the appropriate people were involved.

A key principle of the MCA is that people should be cared for in a way that least restricts their rights and freedoms. This principle shines through every aspect of the Act, including DoLS. For example, we saw services routinely reviewing restrictions to check if they remain the least restrictive option, rather than assuming the restrictions continue to be necessary simply because a DoLS authorisation was granted. However, providers continue to have a mixed understanding of DoLS. Some struggle to understand when the safeguards apply and we also saw examples of DoLS applications from providers that:

- did not include capacity assessments
- did not specify what and why specific restrictions were needed
- failed to acknowledge less obvious restrictions that were already being implemented, such as sensor movement trackers or bed rails.

Worryingly, we also heard of a misconception among some providers that a DoLS application equated to an authorisation being in place.

We saw how, in a few services, a lack of person-centred planning and staffing issues meant there were blanket restrictions – depriving all residents of their liberty despite not being necessary for everyone. One local authority also mentioned that some services are still influenced by a "protection imperative" when caring for older people. In their experience, older adults are more likely to have more restrictive care plans in place, as some providers feel a need to reduce risks to the person regardless of their capacity to make specific decisions.

If people lack capacity to make one decision, it is vital that staff do not assume they lack capacity to make all decisions. Yet, we have seen examples of this happening in some services, which could lead to unnecessary restrictions and is not in line with the Act.

Care plans, mental capacity assessments and DoLS authorisations should be reviewed regularly to ensure they remain appropriate. In our last State of Care report, we highlighted that restrictions were not always reviewed often enough, meaning providers may have missed opportunities to reduce them. This may also be a warning sign of a <u>closed culture</u>. When services stop recognising and reviewing restrictions, they risk becoming part of the culture, passed on and accepted by new employees.

Application of the safeguards

In some services for autistic people and people with a learning disability, we have seen DoLS assessments and authorisations that do not consistently show that the least restrictive option has been considered. DoLS authorisations in these services can also lack information on how people's emotional and physical wellbeing is protected when they are subjected to restrictive practices such as seclusion and restraint. We have previously raised concerns that poor understanding of the MCA and issues with the management of DoLS are contributing to the overuse of restrictive practices and our <u>policy position</u> is clear that the restrictive practices are only appropriate in limited, legally justified, and ethically sound circumstances in line with people's human rights.⁷¹

Our assessments highlighted some differences between hospitals and care homes in the way DoLS are applied. Because the length of stay in an acute hospital tends to be shorter than in a care home, DoLS backlogs mean often patients are not assessed before they are discharged or moved elsewhere. This means that people at the heart of the process may not practically benefit from the protection afforded by the safeguards for most of their hospital stay, despite the work and resources used by providers and local authorities to follow the process in line with the law.

Where a person has a DoLS authorisation in place during a hospital stay, we have seen the positive effects of this on their care. For example, in one case the authorisation meant staff were more aware of the patient's needs, which was evident in care records. By better understanding the patient and tailoring their care, staff were able to prevent escalations.

However, we also identified a lack of communication about DoLS at some acute hospitals, which affected numerous patients on the ward. For example, we found that people sharing a ward with someone subject to a DoLS

authorisation did not always know that certain restrictions, like not being able to open locked doors, only applied to one person. In mental health inpatient settings, we continue to see different interpretations of the interface between the Mental Health Act and the Mental Capacity Act, with the safeguards being used more frequently in wards for older adults.

Although staff should be familiar with the conditions for a DoLS authorisation, this is not always the case. We identified limited oversight of DoLS at some services and we are concerned that the safeguards are viewed as a 'management issue' rather than something every team member needs to engage with to protect people's human rights. A local authority also told us that frequent staff and management changes in care homes represents a challenge, as local authorities do not have the resources to regularly undertake in-depth work with providers to improve their understanding and application of DoLS.

While there is a clear need for further training, we found examples of a lack of training on DoLS in anticipation of the introduction of the Liberty Protection Safeguards. A member of our external stakeholder group explained that providers had invested energy preparing for LPS and some were finding it difficult to adjust to uncertainty around its implementation at such a late stage. However, it is vitally important that services ensure staff have adequate knowledge of DoLS to protect people's human rights – both now and in the future.

New registrations and the Mental Capacity Act

Concerns around providers' knowledge of DoLS and the MCA are mirrored in an analysis of our regulatory enforcement data on Notices of Proposal. At the point of registration, we expect all providers to demonstrate a clear understanding of the MCA and, when applicable, DoLS. As the regulator, we will serve a Notice of Proposal to impose conditions on a new provider or refuse registration if they cannot demonstrate this. We analysed a sample of 139 Notices of Proposal issued in 2023/24 to new adult social care providers and managers applying to register with CQC. This found that almost half the Notices (66) were based on a lack of compliance with standards outlined in the Mental Capacity Act (MCA). In many cases, applicants also failed to demonstrate compliance with other regulations.

Of the Notices of Proposal relating to the MCA, nearly all were refused applications because the applicant lacked vital knowledge in this area. For example, one applicant could not demonstrate that they understood how and when to use restraint. We were concerned that another applicant had a poor understanding of mental capacity, which presented a risk that consent may be gained from a person who is not legally able to give it.

Some Notices of Proposal were issued because applicants could not provide evidence that they would implement the principles of the MCA effectively. One applicant was aware that a representative with appropriate power of attorney was able to provide legal consent, but for people without a power of attorney, there was nothing else in place to ensure that people would benefit from the rights and safeguards afforded by the MCA. It is key that services and managers applying to register with CQC, and their staff, are aware of their responsibilities under the Act, to respect people's rights in line with both the MCA and Health and Social Care Act regulations.

People's experience and involvement

DoLS are essential human rights safeguards that were designed to protect people in vulnerable circumstances. Multiple members of our external stakeholder group told us about waiting years for responses to some DoLS applications. This leaves people without legal protection, and some do not have accessible routes to challenge their deprivation of liberty. In some cases, people are receiving overly restrictive care that is not aligned with their needs and does not respect their autonomy. Our <u>updated human rights approach</u> makes clear that care that does not respect and promote human rights is neither safe nor high quality.⁷²

Our last <u>State of Care report</u> highlighted how a lack of communication around DoLS authorisations can affect people and their friends and families.⁷³ It is important that people subject to a DoLS authorisation, their families, and carers have the information they need to understand the process and allow them to advocate effectively. One member of our external stakeholder group felt care settings are getting better at explaining the safeguards and people's rights, which they linked to the presence of best interests assessors being a "valuable education component".

However, we remain concerned about issues with communication. Many respondents to the National DoLS Leads Network survey noted confusion and upset among family members who are often unaware that a DoLS application has been made until being contacted by an assessor. Our external stakeholder group echoed this, with many sharing experiences of people and families who felt excluded or unheard. One care home provider explained that relatives of residents who had been determined to lack capacity by a hospital have often not been informed about DoLS, and are surprised when care home staff explain the Mental Capacity Act and DoLS process to them. Another member of the group highlighted that the DoLS process can be very confusing for patients and families, stressing the need for time, patience and a point of call for any questions.

We are particularly concerned about communication around DoLS for people who do not speak English as a first language or who use alternative ways of communicating. For example, we found that some acute hospitals were limited in being able to communicate with patients with a DoLS authorisation in any way other than verbally. Whereas using an alternative form of communication such as Makaton may have helped some patients to understand what was happening to them. Our external stakeholder group spoke of concerns around language barriers and inadequate interpretation services, which caused distress to people using services and their family members. One stakeholder felt these issues can be compounded by poor cultural competency among staff, which can lead to poorer care, less effective interventions, and reduced engagement with services.

Several local authorities felt that more challenges to DoLS authorisations have been brought to the Court of Protection in recent years. When a DoLS authorisation is in place, people have a right to have these arrangements reviewed by a court. It is positive that people are aware of their rights to challenge a deprivation of liberty and are supported to do so. However, a local

authority also told us that this can be a time-consuming process, which has a further impact on their resources.

Earlier in this report, we raised concerns about older teenagers who may fall through the gaps when accessing mental health services. Similar concerns about the quality of transitions from children to adult services have emerged through our DoLS survey, with one local authority noting that a 'start again syndrome' may happen when a young person enters adult services. They said the information provided by children's services is often insufficient for planning a DoLS application, which can lead to delays in the DoLS process when the person turns 18. At present, the Court of Protection is also responsible for authorising a deprivation of liberty for young people aged 16 and 17 who lack mental capacity, as DoLS only applies to adults. We heard some frustration from local authorities about delays in LPS implementation, as the new scheme would have helped to speed up authorisations for these young people. Like the DoLS process for adults, we have heard that there continue to be delays associated with the Court of Protection authorisation process.

Protecting people in the future

The DoLS system has needed reform for over 10 years. Unless there is substantial intervention, we are concerned that these challenges will continue, leaving people at the heart of this process without the key human rights safeguards that the DoLS system was intended to offer.

In 2023/24, approximately half of the total number of DoLS applications completed were closed without any assessments happening. This means that, in many cases, the DoLS application process may not bring increased safeguards for people's human rights, despite the efforts and resources used by care homes and hospitals to submit applications, and local authorities' work to process and triage these.

With the volume of applications continuing to increase, the current system means that local authorities remain the only organisations able to process them, and many have told us they do not have sufficient resources to cope with the demand. Supervisory bodies told us that increased funding, an updated Code of Practice, better training and regulatory oversight are all factors which could help to improve outcomes for people while we wait for the LPS to be implemented.

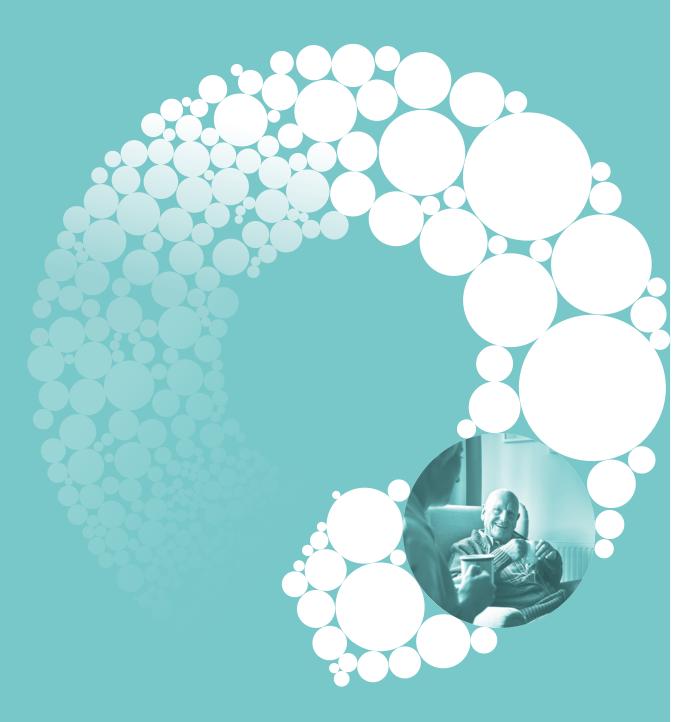
While we heard that DoLS remains an "overly bureaucratic system", local authorities across England have also implemented some improvements to help existing processes run more smoothly. These include:

- making assessments proportionate and using equivalent assessments when appropriate
- streamlining administrative processes, using IT systems and updating forms
- developing strong working relationships between local authorities and providers to improve communication, especially when circumstances change or when a renewal is due
- workshops and training for providers to reduce the number of inappropriate applications they receive and improve the accuracy of applications.

Despite these efforts, we remain concerned that the number of people requiring the legal protection afforded by DoLS continues to increase and the system is unable to cope with this demand. Ongoing issues with the DoLS system will disproportionally affect certain groups, such as disabled people and older people, who are more likely to need the safeguards. A recent report by Age UK highlighted that in 2022/23, 84% of DoLS applications were made for people aged 65 or over, and almost 50,000 people died while waiting for their application to be processed.⁷⁴ Reflecting on the operation of DoLS, the charity said, "The reality therefore is that the rights of some of the most vulnerable older people in our society have been and continue to be routinely denied."

Too many people are waiting too long for a DoLS authorisation, while variation in the level of knowledge of staff means that others may not have a DoLS authorisation in place when they need one. For many, the current DoLS system is not providing the vital safeguards they need. After a decade of chronic and widely documented issues, urgent action is required to ensure the system does not continue to fail people in the future.





Local system response

Integrated care systems
Local authority assessments

Local system response

Key findings

- Finance, joint forward planning and workforce depletion are among the main challenges for integrated care boards as people struggle to access the care they need.
- Urgent and emergency care services in crisis are a symptom of complex system problems that need resolving, by providing more services for people away from hospitals.
- Systems are focused on tackling health and care inequalities. They need to understand their populations to address issues that affect everyone, from children who need dental care to older people with dementia, but they face financial pressures and competing priorities.
- There are mixed views among integrated care systems (ICSs) about their capability to address local health inequalities. There are challenges and barriers around data and analysis skills, governance and accountability, and capacity and capability in the system.
- At all the local authorities we have assessed so far, there is work needed to identify carers and raise awareness that carers are entitled to an assessment and services to support them in their role – this was needed more for people in ethnic minority groups.
- Local authorities have taken steps to address known inequalities and understand the demographics of local populations. But there is a need for better engagement with the voluntary sector and community groups, which have seen some success in identifying groups that are seldom heard and at greater risk of inequality.
- Local authorities have a focus on safety through collaboration. Shared
 data and information is helping this, as it is made available across services
 and care pathways, improving safety for people moving between hospitals
 and the community.

Integrated care systems

The poor care that some people receive – and the problems that many people face in getting access to care – is often influenced or caused by services not being joined up, or not working well together. But we do know that people get better care when local services work together.

Integrated care systems (ICSs) have a responsibility to make sure services work together to meet people's health and care needs. In 2022/23, CQC was tasked with a new responsibility to provide meaningful and independent assessments of the provision of health and adult social care services within each ICS area. This work has begun with pilot assessments, and we are working with government and local systems to refine the way we will report on what we see locally.

Part of our new role is to find out how different parts of local care systems are working together to meet the needs of their local populations. This includes understanding how local authorities fulfil some aspects of their Care Act duties and inspecting to find out how well ICSs are functioning to meet the needs of local populations – this includes understanding what matters to people in local communities.

• In September 2024, we published an update on plans for <u>developing an</u> engagement and health inequalities improvement framework for ICSs.

Challenges and planning

In 2023/24, we piloted our new methodology framework for integrated care system assessments and learned from 2 completed pilot assessments. Following on from this, we have focused on the following 3 things to help us understand at what level systems have a shared vision:

- published integrated care system strategies
- joint forward plans (JFPs)
- local health and wellbeing strategies.

This focused work is in advance of our formal assessments of ICSs, which were planned to start over 2024/25. Our ICS assessment methodology will be updated for the Secretary of State for Health and Social Care to approve the final approach for our assessments, as required by the Health and Care Act 2022.

We set out to review ICSs' visions for their services – how they align at system and place levels, and if joint plans demonstrate how improvements will be delivered and implemented over the next 5 years.

Systems must update their joint forward plans annually. We wanted to understand any synergies among England's 42 ICS strategies, joint forward plans, and in health and wellbeing plans for specific system delivery areas where we previously identified that people often experienced poor quality of care.

NHS South, Central and West Commissioning Support Unit carried out an audit of the 42 system strategies in 2024, which was focused on actions taken to tackle health and healthcare inequalities. This work was a 'baseline audit' and identified that vision statements were focused on ensuring that populations and communities experience longer, healthier lives, using life expectancy and healthy life as the key metrics to track impact.

All systems used a 'life course' approach, ensuring that people have a 'best start in life, can live well and age well'. They all used the <u>Core20PLUS</u> approach.⁷⁵ The audit also supported themes in research by CQC and NHS Confederation conducted in 2023 into exploring health inequalities funding across systems.⁷⁶

We can see 3 main challenges:

- finance
- joint forward planning
- workforce.

Finance: This is identified as the main challenge. Our baseline audit supported research by CQC and NHS Confederation into exploring health inequalities funding across systems, indicating finances as the main challenge to tackling health inequalities. This report in 2023 highlighted that leaders ranked tackling inequalities as the primary ambition they would like to have achieved in 5 years. In our latest review, 1 in 5 ICSs were 'not' confident in their ability to tackle inequalities and none were 'very' confident in doing so.

Our review shows that several ICSs were planning significant investment for improved urgent and emergency care, better system flow, and tackling 18-week waits. ICSs that are looking at capital investment to improve waiting times are considering new surgical theatre suites, surgical hubs, and improved information technology systems. Some systems have identified digital transformation as a key factor in allowing health and care organisations to make the most of the information they hold and to work together.

As a minimum, plans of integrated care boards (ICBs) should set out how they, and partner trusts, will provide NHS services to meet local needs.

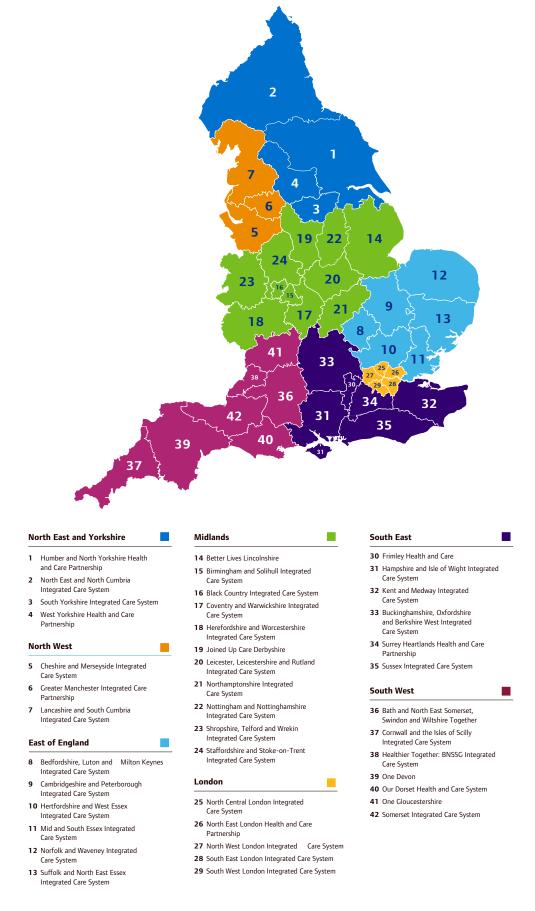
Joint forward plans: As well as finance, a key challenge demonstrated by the review – and in line with the audit – is that the joint forward plans lacked synergy across health and wellbeing board strategies, and ICS and integrated care strategies.

Only a minority of ICSs have developed detailed strategies with measurable key performance indicators (KPIs) for urgent and emergency care and system flow, dental care, children and young people, and dementia care. The KPIs rarely showed a localised approach to match inequalities and needs – without these indicators, people will not be able to assess annual progress.

Workforce: The third key challenge is workforce. ICSs provide the opportunity to take a 'whole system' view of the longstanding workforce challenges – and the strategies and plans recognise that the right workforce is key to achieving objectives. We found that most ICSs saw the importance of reducing their spend on temporary staff, and they have clear plans for improving recruitment, as well as staff retention.

However, along with upskilling a highly skilled and complementary skilled workforce to deliver new models of care, systems are still experiencing challenges related to <u>culturally competent workforces</u>. Culture, equality, diversity and inclusion and the <u>workforce race equality standard</u> are a key focus in ICS plans for the workforce.⁷⁷

Figure 21: Integrated care systems in England



Source: Map shared with the permission of NHS England.

Urgent and emergency care and system flow

Most systems had identified significant challenges with a high demand for services and shortages in the workforce, and there was a need to improve urgent and emergency care and system flow. Productive patient flows are those that support a patient's journey through the department so that they receive appropriate care in a timely way and are kept well informed during this process. However, not all system plans identified the improvements as a priority and the details in plans varied.

In our <u>2022/23 State of Care</u> report, we described plans from government and the NHS to boost capacity and speed up hospital discharges. This points to the importance of system-wide co-ordination for changes and improvements to keep people safe and improve care.

Joint forward plans now show a broad understanding of the importance of supporting emergency departments through improved access to GP services, hospital at home or virtual ward services, mental health services, and improved hospital discharge pathways. Several plans identified targets for tackling inequalities and improving patient outcomes, and many identified ways to improve system flow, citing working with local ambulance services or identifying the key stakeholders to help, including local authorities and people who use services.

Some ICSs have ambitious plans, including developing <u>system-wide step-up</u> models, which could play a key role in managing the level of demand for urgent care and building capability in the community to safely support people outside of a hospital setting.⁷⁸

However, many plans lacked a clear ambition to improve services. Mostly, there was a lack of cohesiveness between some joint forward plans and the integrated care strategies. And most local authority health and wellbeing strategies did not reference improving access to urgent and emergency services or improving patient flow.

ICS improvement strategies must be inclusive of local authorities to ensure there are pathways enabling patient flow through the system.

Plans from the Department of Health and Social Care and NHS England also referred to scaling up <u>intermediate care</u> to relieve pressure on hospitals and move people somewhere that is better for their needs.⁷⁹ Looking at 2023 data, the <u>Health Foundation</u> estimated that 125,000 people are entering intermediate care each month. And as described earlier in our spotlight on intermediate care, 1 in 5 people who have been in hospital for more than 14 days are delayed because of waits for a rehabilitation bed in a bedded setting, such as a care home or community hospital.⁸⁰

All 42 systems referred to intermediate care – their plans vary in content and description of how this care should be provided. Some plans also referenced neighbourhood-level integration in line with the <u>Fuller Report</u> and national targets.⁸¹

There is a combined effort to strengthen intermediate care services with a strong emphasis on collaboration across integrated community and social care networks. Plans include the expansion of virtual wards to manage patients

effectively as their care transitions – and to reduce unnecessary hospital admissions. It is anticipated that staff and stakeholders will learn more about the benefits of prompt discharge and community-based care solutions.

Most ICSs recognise the need for a sustainable integrated care model – they include plans to help people recover and increase their independence after a hospital stay, illness or operation, to help reduce repeat visits to urgent and emergency care services as well as taking pressure off GPs.

Good intermediate care relies on enhanced stakeholder engagement and partnership working with social care. There is evidence of this in some systems where discussions are focused on providing intermediate care.

For others, there are challenges in scaling up services and addressing strategic gaps effectively. However, ICSs are actively pursuing integrated approaches to intermediate care, focusing on collaboration, reducing hospital stays, promoting preventative care, and engaging stakeholders.

In one example, there was clear indication from South Yorkshire ICS about its intention to improve the flow of hospitals through intermediate care — working with integrated community services, including social care, to ensure sufficient capacity and maximising the use of virtual wards. The Rochdale Borough Locality Plan 2020-24 shares how working with partners has enabled them to commission a successful intermediate care service whose design moves away from a previous focus on activity/numbers and key performance indicators in care settings, to delivery of care in local care organisations.

18-week waits

Systems are demonstrating a commitment to reducing waiting times for people who need different kinds of care. But there is variation in descriptions of how ICSs are planning to tackle waiting lists.

Most ICSs have objectives to reduce waiting times and increase capacity to meet demand, but some are lacking in detail or direction on how the system will achieve those objectives. And few have a short-term plan to achieve the NHS Constitution statement that: patients should wait no longer than 18 weeks from GP referral to treatment.⁸²

In the ICSs with detailed plans, there was a focus on reducing significant backlogs and eliminating 52, 65, and 104-week waits for treatment. A small number identified a target date to achieve no waits longer than 18 weeks. And those systems that did share initiatives to reduce waiting times set out plans for improved access to diagnostic services in the community, working with cardiac networks, improving waiting list management and service productivity.

Most forward plans did not show how ICSs sought views from the public or input from voluntary, community and social enterprise organisations (VCSEs). But there were examples where VCSEs and other partners gathered local people's voices on which initiatives would work best in their communities – and with measurable outcomes. One initiative was to work with the VCSE to reduce drivers of ill health.

Dental services

In October 2023, we <u>reported</u> on the problems that people faced when trying to access NHS dental care. People told us how they resorted to spending thousands of pounds on private dental treatment because they were in pain but could not see an NHS dentist. And the <u>Health and Social Care Committee's report on NHS dentistry</u> in 2023 was clear that NHS dentistry needs 'urgent and fundamental reform' to ensure people get the care they need.⁸³

The NHS Confederation's <u>early adopters report</u> points to challenges including the national contract, access to data, workforce, and governance.⁸⁴

NHS England has delegated its responsibility for commissioning dental services to integrated care boards (along with pharmacy and optometry). We reviewed plans across all 42 ICS areas and found there were differing approaches to dental services. Some had clear strategies and acknowledged challenges with access to dental services, but others were not as explicit and did not provide details about their work.

There is recognition across ICSs of a need for increased investment in dental services – resources to tackle treatment delays and improve access. Several highlighted a strain on primary care, and we can see how some communities are actively involved in identifying access issues and influencing the focus of dental strategies. A few ICSs had published plans to expand dental services for their communities, including some innovative service delivery models.

We can see that health services for children are a significant priority and are focused on preventative measures, particularly for children under 5 years. One county in the North East and North Cumbria ICS (NENC ICS) has a comprehensive oral health strategy with proactive measures towards better outcomes for people. These strategies should include clear recommendations and objectives within a set timeframe.

Feedback from stakeholders and NHS guidance will play pivotal roles in shaping annual updates and refining commissioning arrangements within ICSs for dental services – and partners such as <u>Healthwatch</u> have shared observations. Collaborations with local authorities and public health leaders are underway in some systems to evaluate and enhance oral health provision, demonstrating a combined effort to address inequalities through targeted interventions and strategic partnerships.

Dementia health inequalities

There is significant variability in the way ICSs plan to address health inequalities relating to dementia, particularly in terms of early diagnosis, access to care, and treatment strategies. Many ICSs acknowledge the prevalence of dementia and propose various initiatives.

Health and care services for people with dementia is one of our regulatory priorities – we want to influence and drive improvement in the provision of services, models of care and the quality of services for people living with dementia. We are looking at how we can use our role to achieve this – for people with dementia and for their carers.

The establishment of formal dementia strategies with clear timelines and performance metrics is still in progress for many systems. In their first year while ICSs have been establishing demographic data, one common ambition is to create dementia-friendly communities.

Plans emphasise community engagement initiatives to encourage support networks, and health and wellbeing boards are collaborating to prioritise dementia care. Dementia initiatives reviewed in these plans include:

- implementing proactive dementia models
- developing anticipatory care models that focus on independence and quality of life
- actions identified in local care partnerships to enhance service provision with a focus on community wellbeing.

Emphasising the benefits of community interaction, these plans manage dementia through local engagement and support.

The intention is to reduce waiting times for memory assessment services with community-based initiatives to upskill local teams for early-stage support. This would free specialist resources for more complex cases. The strategies involve partnerships with stakeholders, engaging dementia advocacy groups and care providers to ensure support and feedback.

Systems acknowledge that in areas of high deprivation, ensuring equitable access to dementia services for rural and marginalised communities remains a significant challenge. There is also limited involvement from a broad range of stakeholders, such as community organisations, educational institutions, and businesses, which weakens the implementation of dementia-friendly initiatives.

Local authorities have a crucial role in systems for raising awareness of place-based partnerships and local neighbourhood models to support improved dementia care with better care pathways. Our review of published plans showed the need for more consistent and comprehensive approaches across all ICSs to ensure equitable and effective dementia care. Three ICSs showed clear alignment to health and wellbeing boards, tailoring models of engagement to enable genuine co-production and personalised care tailored to local needs and preferences of individual people, along with a strong reliance on social research and insight to inform decision-making. Examples included establishing dementia-friendly communities, improving access to early diagnosis, integrated care hubs and community engagement in managing dementia.

Children and young people

There are some transformation plans in place for children and young people's services, where systems are looking to improve outcomes for people who use the services. In those systems, the plans are linked to the integrated care strategies and joint forward plans. Some ICSs also have children and young people scrutiny boards to provide governance and monitor the planned implementation.

Among positive signs, the <u>Coventry and Warwickshire ICS Health and Social</u> <u>Care Delivery Plan</u> identifies an integrated approach to the transformation of services for children and young people. There was similar focus in both South Yorkshire and Gloucestershire.

The first year for many ICSs was about understanding how and where health inequalities were affecting children locally and acting to reduce any barriers to care. There is evidence of assessments to understand demographics and strategic needs to inform their planning – we saw how at least one system, Nottingham and Nottinghamshire, was making digital improvements to collect outcomes and using the THRIVE model.

In last year's State of Care, we reported on long waiting times for mental health and community therapy services. Demand was growing exponentially during and after the Covid pandemic, and ICSs continue to report these challenges in their plans. In Northamptonshire, we are aware of the ICB's work with local partners and residents to develop a 2023/24 transformation plan for children and young people's mental health services.

Some ICSs are struggling to deliver both initial health assessments and the review health assessments for children in care within a statutory timeframe. Waiting times for services remain a problem and the main challenge is demand versus supply – a significant increase in requests at the same time as workforce shortages. For example, it was clear in one locality that waits for children and young people's community services were largely driven by an increased demand for speech and language therapy – but this is also a national problem.

Only a minority of published joint forward plans gave information on COVID-19 impact assessments – these were done to assess the impact on children and young people and helped to shape priorities, such as the prevalence of diabetes in young children or children's mental health and wellbeing.

Planned priorities emphasised the importance of children's early years – the first 1,001 days is commonly cited.⁸⁵ Priorities included increasing universal antenatal and postnatal support, establishing new parents' groups, and reducing stillbirths. National priorities were articulated in published plans about asthma, diabetes, epilepsy, and mental health. Very few published plans reflected the priorities for oral health for children – and where they did, it was for children under 5 years.

Examples of priorities published included reducing the proportion of children who are overweight or obese, increasing support for children with diabetes who are transitioning to adult services and, in particular, priorities relating to children and young people's mental health.

There was some variation or lack of clarity in published plans about intended outcomes. But some had examples of action already taken; one Midlands ICS described its virtual wards for children, which had supported more than 1,150 children.

There were some good examples of systems with high aspirations. <u>Gloucestershire</u> Integrated Care Board's leadership includes an executive lead for children and young people, and for special educational needs and disabilities. There are 2 system-wide transformation programmes that are particularly focused on the needs of children, covering physical and mental health and clearly identifying collaborative system partners. Our review of plans found evidence that ICSs had engaged with young people and their carers, as well as with Healthwatch and the voluntary sector to inform strategies and make plans. We also saw an example in Northamptonshire of engagement with VCSEs where people had their say on new ways of delivering activities and respite, such as short breaks, for disabled children. The Humber and North Yorkshire system had evidence of a strong commitment to partnership working between the NHS and VCSEs, which focused on childrencentred approaches and maximising community engagement. There were similar examples in South West and South East London.

From our inspections of providers, we saw examples where specialist services for children and families with complex needs were often pivotal in leading multi-agency working and sharing learning. For example, in <u>West Yorkshire</u> the local authority developed several programmes with neighbouring local authorities and the VCSE sector to encourage healthy childhoods.

Communication between parents, carers and the local area partnerships, and between agencies, often needed to be strengthened. Poor communication had affected parents, as they were unable to access the right support or having to repeat their story. Between agencies, this meant that services were not always kept informed of actions and support for children. But consistent good multi-agency attendance and information-sharing was supporting and protecting children.

In some areas, leaders across the local authority and the ICB have worked together to identify, support and plan to meet needs. This meant there was oversight of the issues affecting families, and they were better placed to begin to address these issues.

Addressing inequalities at a system level

One of our core strategic ambitions is tackling inequalities in people's access, experiences and outcomes when using health and social care services.

This year, before we have begun formally reporting ICS assessments as part of our new role, we carried out a survey with the Nuffield Trust to begin to understand a baseline context from which ICSs are operating – the challenges they face and the opportunities ahead.

In 2023, we could see that most ICSs demonstrated a commitment to engaging with people living in their area; most systems publicly recognised the importance of equality, diversity, and inclusion, and addressing health inequalities and equity in access to care services.

In 2024, we reached out to ICSs, which have responsibility for planning health services for local populations. Again, we have focused on the theme of inequalities. We commissioned the Nuffield Trust to conduct an independent survey of progress on health inequalities across systems. The survey was targeted at individuals working on health inequalities in all 42 ICSs in England and more than half (29) took part, to whom we are grateful.

This year, our approach was to understand what ICSs perceive as the main challenges or barriers to addressing healthcare inequality, recognising various stakeholder views, including the <u>NHS Providers</u> point that "national leaders will rely upon [ICSs] to bring different parts of the system together to address [health inequalities]".⁸⁶

This work with the Nuffield Trust in 2024 was shaped by the importance of understanding a viewpoint from the ICSs themselves about their progress and challenges. This is before we start our formal assessment work with systems.

Central to our survey is a focus on the 5 priority clinical areas, nationally defined as the <u>CORE20PLUS5</u>. Our findings are presented in 3 parts, describing the key viewpoints about systems and inequalities:

- 1. Progress on health inequalities
- 2. Barriers and challenges
- 3. Key themes from free text responses

Progress on health inequalities

The Nuffield Trust survey asked about progress on health inequalities in 3 parts:

- addressing social determinants of poor health (for example, unfit housing or poor diet)
- addressing unequal burden of disease
- addressing people's access, experience and outcomes

On these areas of health inequalities, respondents to the survey perceived that the least progress had been made around addressing the social determinants of poor health: 15% of respondents said no progress had been made.

A further 41% said very little progress was made, while more positively, 45% also answered that moderate or significant progress had been made.

Respondents were more positive about the progress made in addressing inequalities in access to health care: 66% felt there was moderate or significant progress.

In addressing the unequal burden of disease, 65% felt moderate or significant progress was made.

Population groups targeted

The survey asked which population groups, or segments, systems were targeting to address these 3 key areas of health inequalities. The pattern of answers was broadly similar across all 3 areas.

Of the 5 options presented, respondents most frequently said they were targeting socio-economically deprived groups or small geographic areas, as defined in the national <u>Index of Multiple Deprivation</u>, to address inequalities in healthcare access or outcome (93% of respondents), the unequal burden of disease (90% of respondents), or the social determinants of poor health (86% of respondents).

This was closely followed by targeting actions among people in ethnic minority groups to address inequalities in healthcare access or outcome (83%)

of respondents), the unequal burden of disease (83% of respondents), or the social determinants of poor health (69% of respondents).

Respondents also targeted actions among locally defined 'inclusion' groups, such as homeless people, ex-offenders, or sex workers. This was to address inequalities in healthcare access or outcome (69% of respondents), the unequal burden of disease (69% of respondents), or the social determinants of poor health (79% of respondents).

Approximately half of the survey respondents said they had prioritised other groups with protected equality characteristics across inequalities in access, burden of disease and social determinants. A small number of respondents highlighted other communities they were targeting, such as people with a learning disability.

A very small number of respondents answered that they were not targeting any of these groups.

Progress on national priorities and inequalities

There are 5 priority clinical areas, nationally defined as the <u>CORE20PLUS5</u>. The survey asked about the extent to which survey respondents thought that their ICS had made progress towards addressing inequalities in these clinical priorities and in smoking cessation.

Most respondents tended to 'agree' or 'strongly agree' that their ICS had made progress across all priority categories. Slightly more respondents strongly agreed to having made progress in addressing inequalities in maternity (18%) and cancer (18%).

No respondents strongly disagreed or disagreed that their ICS has made progress on smoking cessation, although 21% of respondents were neutral.

Around a third of respondents were neutral about whether their ICS had made progress on chronic respiratory disease (37%) and cancer (32%).

Respondents most strongly disagreed that progress had been made around chronic respiratory disease (7%) and mental illness (7%). It is important to note that due to the very small numbers of this survey, any additional responses could change this weighting significantly and so this must be interpreted with caution.

Challenges, barriers and opportunities

We wanted to identify where respondents felt their ICS faced the most significant barriers or challenge to progress in health inequalities, and where they saw opportunities for progress.

Respondents were presented with a series of statements about their ICS's data infrastructure, governance, and capacity and capability. They were asked to state the extent to which they agreed with the statement.

Comments were allowed in free text boxes, but the survey grouped statements into 3 broad areas:

- Data and analysis skills
- Governance and accountability
- System capacity and capability

Data and skills

Overall, responses suggest that access to analytical capability is a significant challenge shared across many ICSs, alongside accessing the right types of data to support analysis of population needs.

Respondents answered more positively to these statements:

"My ICS has access to the expertise needed to understand key drivers of inequalities" (45% agreed, 28% strongly agreed)

"My ICS is actively using data to understand population needs" (45% agreed, 14% strongly agreed)

Answers were positive overall for this statement, with some negativity for:

"My ICS has access to the right data to understand population needs" (41% agreed, 14% strongly agreed, 17% disagreed, 3% strongly disagreed)

There was a clear difference in the pattern of response to this statement:

"My ICS has the right analytical capability to analyse complex data and make decisions"

A relative majority of respondents answered more negatively (24% disagreed, 21% strongly disagreed) and a smaller proportion was positive (24% agreed, 10% strongly agreed).

All respondents chose an answer for this question, none chose 'unsure/not applicable'.

Governance, leadership and strategy

Most respondents said they agreed with statements related to governance, leadership and strategy.

Statements on leadership and accountability were especially positive: 45% of respondents agreed and 34% strongly agreed that their ICS has a dedicated leadership to drive progress on health inequalities, and only a small number disagreed with this statement (none strongly disagreed).

Furthermore, 39% of respondents agreed while 43% strongly agreed that it was clear who is accountable for leading work on health inequalities in their ICS, with a small percentage of disagreement (15% disagreed or strongly disagreed). It is possible that some responses may be biased towards the roles of people who responded to the survey, many of whom are in leadership positions and accountable for health inequalities themselves.

There was more moderate agreement on statements related to having a shared understanding of priorities across local partners, the ability to balance competing national and local priorities, and having a clear and achievable plan to reduce inequalities in access, experience, and outcomes.

Around a third of respondents (34%) were neutral about the statements: "My ICS is able to balance competing national and local priorities to make progress on health inequalities," and, "My ICS has a clear and achievable plan to reduce inequalities in access, experience and outcomes across pathways of care." However, there was stronger disagreement with the latter statement, with 24% disagreeing or strongly disagreeing.

Respondents had a much more negative perception on the degree to which local partners within their ICSs agreed over how best to shift resources to prioritise reducing health inequalities. Over half (51%) either disagreed or strongly disagreed with the statement.

It was important to note that some responses may have been biased towards the roles of people who responded to the survey, many of whom are in leadership positions and accountable for health inequalities work programmes themselves.

System capability and capacity

There was less positivity around system capability and capacity.

The proportion of people who selected 'agree' or 'strongly agree' was not more than 50% in reply to any of the statements.

There was particular disagreement about ICSs having sufficient resources (time and money) to prioritise health inequalities, as 42% disagreed and 19% strongly disagreed.

A smaller proportion of respondents disagreed that their ICS has sufficient operational capacity to deliver on plans to reduce health inequalities (28% disagreed, 10% strongly disagreed), or buy-in to deliver plans and ensure they meet the needs of underserved communities (24% disagreed, 7% strongly disagreed).

The proportion who responded neutrally to the statements on capability and capacity is relatively large across all the questions, ranging from 23% for "My ICS has sufficient resource (time and money) to prioritise health inequalities,", to 45% for "My ICS has the cultural competence and understanding of underserved communities necessary to address health inequalities".

There was more agreement for statements about influencing social determinants of health and cultural competence around underserved communities.

Just under half (46%) of respondents agreed or strongly agreed that their ICS was able to influence wider socioeconomic determinants that drive health inequalities. Only 18% disagreed and no respondents strongly disagreed.

Barriers and enablers

Several themes have emerged from the Nuffield Trust survey that point to some of the main things that might make a difference for systems as they look to tackle local health inequalities.

Respondents were asked to provide additional comments on what they judged to be the biggest barrier in challenge areas, including data and skills, governance, leadership and strategy, and system capability and capacity. Fourteen respondents provided comments, their answers are perceptions rather than a representative indication.

- Financial pressures and competing priorities
- Relationships
- Challenges in getting the most out of existing data
- Power dynamics and influence

Respondents expressed concerns that financial pressures were adversely affecting ICSs' ability to make progress on inequalities: 11 out of 14 pointed to this, while 3 of the 11 pointed to the challenges of managing competing national and local priorities.

A further 5 of these 11 respondents expressed a frustration that, despite often having a strategy that commits to community or 'upstream investment' (addressing the root causes of poor health), in reality the system pressures meant that acute services continued to be prioritised.

"Despite verbal commitment to reducing inequalities, the ICB leadership have no practical commitment to this aim, choosing instead to prioritise acute secondary care in a traditional manner, which serves only to increase existing inequalities..."

"...our senior leaders are driven by financial priorities and [the] front door of A&E. They use wonderful rhetoric, but they are not creating the fundamental conditions to create a generational difference."

Three respondents specifically highlighted the importance of positive working relationships between partners in the ICS when making progress on health inequalities. One of them highlighted the importance of good joint working with voluntary, community and social enterprises (VCSEs).

When it comes to getting the best from existing data, limited capacity or capability for data analysis or interpretation emerged as themes in survey comments. Five respondents said their ICS either lacked the data to fully understand their under-served populations or had insufficient analytical capacity to make use of data.

However, 2 respondents mentioned positive efforts to better understand or use data, such as by establishing a specific population health intelligence unit. One respondent mentioned the challenges of attempting to procure a new data platform.

Power dynamics also appear to be an issue in these early years for ICSs. Two respondents expressed concern that ICSs and the local structures lack 'powers, resource and influence' to make a tangible difference. They suggested that financial inequalities needed to be addressed across sectors.

"...whilst local structures such as the integrated care partnership or health and wellbeing boards have good strategies, everyone knows they lack power, resources and influence. We have deep inequity here reflected in major disparities in life expectancy and health lives. We need a major step change and not tinkering around the edges."

Prioritisation

The survey also asked respondents to select which of these 3 main areas – data and skills; governance, leadership and strategy; or system capability and capacity – posed the biggest challenge to progress. The aim was to get more clarity on where systems need most support. When asked which of the 3 broad areas posed the biggest challenge to progress:

- 59% of respondents selected system capability and capacity
- 17% of respondents chose data and skills in their ICS
- 7% chose governance, leadership and strategy
- 17% opted for 'other'.

Respondents who chose 'other' could provide their own answers. These included themes such as the lack of prioritisation of prevention, insufficient place/locality-level working, and insufficient national levers, for example legislation and target-setting, as the biggest barriers preventing progress on health inequalities.

Those who answered 'system capability and capacity' as their greatest challenge area selected insufficient resource (time or money) to deliver on plans as the most significant barrier. Other answers highlighted challenges around operational capacity or buy-in, and a combination of operational capacity and financial resource.

Of the 17% who identified data and skills as the biggest challenge, most said their ICS did not have access to the right data to understand population needs. One respondent said their ICS did not have the right analytical capability to analyse complex data and make decisions, and one said their ICS was not actively using data to understand population needs.

This contrasts with 45% of respondents who disagreed or strongly disagreed that they had the analytical capability to analyse complex data and make decisions. It might suggest that while analytical capability is perceived to be insufficient, other barriers pose a greater hindrance to progress.

All the respondents who chose governance, leadership and strategy as the biggest challenge specifically identified the biggest issue as local partners in their ICS not agreeing on how best to shift resources to prioritise reducing health inequalities.

Only a small number of respondents said what they thought was the biggest barrier in each challenge area, so the answers should be seen as individual perceptions of the biggest barrier to addressing health inequalities, rather than a representative indication.

Final thoughts on challenges

Survey respondents had the opportunity to elaborate and comment freely about their chosen most significant challenges in addressing health inequalities. The 2 main themes here were financial pressures and the scope of power and influence of systems.

Of 19 responses, 13 mentioned a difficult financial context – issues around prioritisation of acute services, too little resource, time or energy for enabling change in inequalities. Some said there was genuine commitment for

change, but an inability to 'shift funding flows' and make a difference. Two respondents cited concerns about short-term funding and risks for small VCSE organisations because of unstable funding:

"If we are serious about shifting resources and focus, this entails changing funding flows and making difficult decisions about where we prioritise spending. This requires join up from acute players who may see this as a lose/lose choice, and for finance colleagues who are pressurised to focus on year end – the wider system does not support longer term strategic decision-making."

Some ICSs say they doubt their ability to 'move the dial' on the root causes of health inequalities. Three respondents flagged this as a major challenge, saying that local organisations have little ability to resolve this. They mention issues around housing and financial stress. One of the 3 also highlighted the complexity of accountability:

"The reality of the current working environment doesn't create much time/energy or leave much resource available to focus on reducing inequality. In addition, some of the areas covered in your survey [such as poor housing] are not really within the remit of NHS partners in the ICS to lead on, and as a 'two-tier' local government area this sits with 13 districts/boroughs, for example."

Local authority assessments

Local authorities are a central component of care systems – their work affects the way people experience health and care services by ensuring that people are able to live their best lives as independently as possible while ensuring that their equality and human rights are respected and preserved.

As well as inspecting health and social care services, we have a role in assessing how local authorities meet their duties under Part 1 of the Care Act (2014). This is a newer responsibility, which we began in 2022.

In 2023, we reported on the under-provision in some types of specialist care, such as services for autistic people, specialist dementia care, and in the availability of beds in care homes with nursing. Last year's report also focused on issues around people's flow through the local health and care system – and what system partners could do together to improve flow.

From the early stages of our work with local authorities, the information in this report is largely based on <u>5 pilot assessments</u> and the first 9 of our <u>formal published reports</u>.

We carried out our first 3 formal site visits in February and March 2024 – these first reports were published in May 2024. By October 2024, there were 58 assessments underway and 9 published.

Access to care

Local authorities have different ways to enable people to find information and access services and support, and there were varying degrees of success in making services accessible.

There are phone and internet services, but waiting to get through on the phone is a common issue and for some people digital access is a barrier.

We found that carers often struggled to access support. All the local authorities we have assessed had work to do in identifying carers and raising awareness that they are entitled to an assessment and services to support them in their caring role. We found that this was more acute for people in ethnic minority groups who would not see themselves as carers.

Access issues in general included:

- people who self-fund their care struggling to access support
- gaps in language or cultural needs to get information
- specific barriers for people in rural areas, such as poor infrastructure and lack of digital access.

Care pathways for autistic people and pathways for young people transitioning to adult services were not always clear – this made it harder to access support and we found this at several local authorities.

Nevertheless, we have seen some solutions to access issues, including:

- local authority-run 'conversation cafes' in the community <u>in Harrow</u>, where people, including unpaid carers, can access services
- voluntary organisation champions who reach diverse communities⁸⁸
- providing information in the community at GP surgeries and in libraries, and ensuring it is available in a range of accessible formats and languages.

A small number of local authorities had waiting lists for all areas of their work, including assessments and reviews, and some had waiting lists for a limited number of their services. For example, one had waiting lists for reviews in relation to the Care Act assessments for people with mental health needs, while another had a list that showed a review of placements to enable people to leave a care home and return to their own home – these were people who were temporarily placed in care homes for a recovery period. Nearly all local authorities identified waits for occupational therapy services.

All the local authorities we assessed have more work to do to understand and identify groups whose voices are seldom heard, especially beyond the demographic data available in a census. Some local teams had knowledge of these groups, or the local authorities were working with voluntary organisations to develop this work. There is also a challenge for local authorities to see where there is intersectionality, for example where there may be groups within groups, such as autistic people or people with disabilities within a larger ethnic minority group – and to understand how this intersectionality may affect someone's ability to access services and experience positive outcomes.

Where support is not available under the Care Act, local authorities are providing information about non-eligible support needs. One local authority had a roaming roadshow to share information.

There are gaps in care for people with more complex needs, including some working-age adults, people with a learning disability and autistic people, people with mental health issues, and older people with needs associated with dementia.

Local authority websites are generally a good source of information about accessing services, but some people have accessibility issues. Accessibility of websites and a lack of clear information about care or support pathways was found to be a barrier for some people. In several assessments, digital exclusion was cited as a barrier, especially for people with a learning disability, autistic people and people who do not speak English as their first language.

In <u>West Berkshire</u> there was a digital infrastructure group supporting some communities, including older people, refugees, and the Gypsy, Roma and Traveller community, but in general we found that greater flexibility and a variety of approaches was needed to engage people from all communities.

Carers

Unpaid carers continue to struggle to access the support they need, and this was more pronounced in local authority areas where there were staff vacancies or difficulties with recruitment. Carers also say information is not always presented in accessible ways. We have found:

- Access to services was affected by awareness some carers did not identify as carers, which affected their ability to access services or even understand that they could access services.
- A lack of flexible and responsive respite is affecting carers, especially their ability to work, rest and have choice and control in their lives.
- Access to services was poorer in rural areas.
- All local authorities were working to better identify carers but problems are more pronounced in some seldom heard groups – in some Black and ethnic minority cultures the caring role is more embedded and some people do not see themselves as carers, running greater risks of crises if the carer becomes unwell or unable to continue their role.
- Lack of digital access affected access to services, especially if this was supposed to be a solution to rural isolation.

Poor communication and hospital readmission

One full-time carer explained the variety of problems he experienced around communication after his wife was discharged from hospital – and how she ended up back in hospital with a urine infection. This man is a full-time carer for his wife, who has multiple sclerosis. He organises all his wife's appointments and care needs, with support from care workers twice a day.

After a successful operation in hospital, it was the hospital handover and aftercare that was disappointing. He said the "communication is very, very poor on discharge". There was no hospital handover that detailed the care his wife had received, or information shared about new medications she was given, or what catheter bags were needed. He said he had explained to the hospital that he needed to understand what had been done, especially because his wife was unable to tell him. He added that he often had to retell his wife's story to healthcare professionals, explaining about his wife's capabilities and incapabilities.

A problem, he added, is that "communications between departments is poor and information is not passed on".

The carer noticed things were not right with his wife's urine when she got home after the operation. In a call to a GP, he says he wasn't listened to and he felt "dismissed". Two days later, his wife was taken by ambulance to hospital for a urine infection, where she had to stay for a fortnight.

(Interview with a member of the public)

One local authority was in the early stages of working with partners in the ICS through the <u>Accelerating Reform Fund</u> to improve how unpaid carers are identified. It wanted to develop digital self-assessment and address waiting times for a carer's assessment. The <u>Better Care Fund</u> had been used to set up preventative services, including a social prescribing project and an urgent community response service to reduce admissions to hospital.

Waiting for services

Most local authorities said they had gaps in services for people whose needs are more complex to meet, particularly nursing needs or complex mental health needs, as well services for autistic people and people with a learning disability.

The gaps resulted in widespread examples of people being placed out of their local area – some in a nearby area, but others a long way from home. A common finding was that people with more complex needs, including autistic people and people with complex mental health needs, were more likely to be placed out of area. Some local authorities acknowledged that long-term work was needed to shape the market and resolve this problem. Among the ways this is affecting people, we found:

- Some people were on waiting lists for occupational therapy for so long that cases were closed because their needs had changed so much.
- Younger people with complex needs were admitted to adult services.
- People with sensory problems, for example with hearing or vision, were placed out of their area or in inappropriate care settings.
- The lack of services for working-age adults with complex needs affected young people who needed to transition to adult services; extra appropriate provision for working-age adults was needed to promote independence, such as supported living.

Where solutions have been found to some access problems, they often involve collaboration – for example, with housing organisations and the voluntary sector, and particularly for those groups experiencing most inequality. Local knowledge was used to identify gaps in provision and work with those at most risk of being unheard.

There are some examples of pooled budgets leading to better support for people with a learning disability and mental health needs, but this has not always worked. We also saw that where there was good joined-up working, people were less likely to need to repeat their story, which helped to build good relationships with the support staff.

Where there was a strong focus on preventative services, this helped people to lead more independent lives. These worked well in partnership with public health initiatives, focused on obesity and smoking cessation, as well as improving mobility and physical and mental health. They also worked well where people could access advice and guidance at the relevant facilities, such as libraries or leisure centres.

Addressing inequalities

Local authorities are taking steps to address known inequalities and understand the demographics of their local populations. Some had identified groups that were at risk of, or who were experiencing inequality. This looked different for each local authority and there were different groups of people identified who might experience inequality. Examples included people in ethnic minority groups, neurodiverse people, Gypsy, Roma and Traveller communities, as well as displaced people including refugees and asylum seekers.

The actions local authorities took to understand or address inequalities were not always clear, particularly where there were small minority groups within the wider population.

At one local authority, equality and diversity leads worked in partnership with voluntary organisations to get a shared understanding of the inequalities facing groups whose voices are seldom heard. There were mixed views about the effectiveness of these relationships.

For too many local authorities, the main focus in tackling inequality was around race, culture and ethnicity as single issues, rather than considering how different protected characteristics might affect people in combination – also called 'intersectionality'. Or, in predominantly affluent areas with a mostly white ethnic population, the focus was on urban/rural inequalities and deprivation. There was limited intersectionality analysis.

We did not see many examples of local authorities engaging with the LGBTQ+ community, particularly where it intersects with other protected equality characteristics, for example the needs of older LGBTQ+ people in the community, or LGBTQ+ people who have a learning disability. Some local authorities were aware there were potential barriers to engaging, and they were trying to connect with relevant groups to address these.

One local authority did have a dedicated senior manager to co-ordinate equality, diversity, and inclusion work. It used data and intelligence to consider people's different protected equality characteristics and to inform its approach. Commissioning was delegated to community groups to develop community assets for under-represented groups, and neighbourhood networking schemes were tasked to identify gaps in services, working with local groups to submit bids to fill these gaps.

Autistic people said they found it difficult to use the usual channels, such as websites, to engage with local authorities – services could be inaccessible, and it was hard for them to engage in co-production. This is a challenge for multiple local authorities. Among others potentially excluded were older people and people with sensory needs.

There were also shortfalls in other aspects of some local authorities' understanding of the intersection of protected equality characteristics – for example, some faith groups raised this in relation to gender and their access to services.

In areas with a higher proportion of people from ethnic minority backgrounds, there was evidence of more culturally-specific service provision. In <u>Harrow</u> and in <u>Birmingham</u> there was considerable work around meeting cultural needs.^{89,90}

However, feedback shows that the market is generally not well developed to meet culturally-specific provision, particularly in residential or nursing care. In Harrow, the local authority's market sustainability and improvement plan demonstrated that it was aware of capacity gaps in the market. There were also challenges in brokering culturally-specific provision at an affordable price. Providers had told the local authority they had issues providing services that meet the ethnic, cultural, and greater needs of people living with dementia. There were plans to use co-production with faith and voluntary groups to address gaps in provision.

Engagement with the voluntary sector was mixed and constraint on resources could be a factor. Where engagement with the voluntary sector was linked to strong governance processes, including co-production and participation in partnership boards, this was more effective and supported the local authority in understanding local communities – this resulted in targeted commissioning to meet needs.

However, even where these relationships were effective, local authorities did not always have sufficient resources to commission the necessary services. Also, a lack of strong links with the voluntary sector led to patchy coverage because local authorities did not have the knowledge or intelligence about local community needs.

The cultural competency of staff – including social workers and commissioners – was vital to ensure service commissioning that also supported people from ethnic minority groups. And access to interpreters was important to help provide equal access to care.

Inequality affects carers too – often they do not identify as carers at all and so they do not access support or get assessed for support. This was particularly the case for unpaid carers from ethnic minority groups.

There was recognition that some people in rural communities might experience inequality. One local authority revised its commissioning to address delays for homecare in rural areas. It worked with a small number of providers who were able to subcontract with other providers and there was a joined-up approach between public health, local authorities and health partners in looking at housing, and understanding the effect of poor housing on people's wellbeing.

Local authorities are trying to improve their understanding of local inequalities. There was good partnership working with public health in one local authority that was trying to predict future demographic changes and how its strategies might need to adapt. Frontline staff had a good understanding of their communities and the groups at risk of inequality. There was learning from reviews and a focus on involving people with lived experience in coproduction work, which provided extra opportunity to identify groups who may be at risk of inequalities.

In 2024, we published a report on <u>tackling inequalities through the regulation</u> <u>of services and organisations</u>, which considered the enablers and challenges to tackling inequalities.⁹¹

Improving safety by working collaboratively

Across our local authority assessments, we have heard how safety can be improved where local systems work collaboratively, bringing together health services, housing and probation services, and voluntary, community and social enterprise.

Shared data and information improved safety because it was made available across services and care pathways. For example, some local authorities were working in partnership with mental health trusts, and the IT helped to improve safety for people moving between hospitals and the community. This also helped young people moving from child to adult services, and it was part of improvement in safety for younger people building skills to support their independence.

These local authorities also described good joined-up working that resulted in better outcomes and more trusting relationships with people who need services, and that this supported their safety. We also saw examples where several local authorities were working well with statutory and other partners for better safety. This work was most effective where there was a strong safeguarding adults board, working closely with partners and where there were clearly-defined roles, governance and audit processes.

Safety was also bolstered through other collaborative work. Several local authorities are using information portals for different professionals, which helps to speed up people's triage by providing prompts for the right information.

One had implemented a <u>trusted assessor</u> system with some regulated providers carrying out assessments for people waiting to be discharged from hospital. It also had a community connectors scheme with partner organisations, leading to improved pathways for hospital discharge.

Most local authorities have integrated hospital discharge teams and there is sometimes integration in other areas, such as in mental health. In Hertfordshire, there was a jointly-funded director of health integration in the local authority leadership team — this was helping to develop partnership working.

We have also seen evidence of joint commissioning of services and partnership arrangements, including information sharing protocols and contingency planning to ensure safe pathways for people moving between hospital and home.

Other positive safety activities noted from our assessments included:

- Planning to safely manage people receiving self-funded care when their savings are diminished, if their housing/support is unaffordable through local authority funding.
- Ensuring people are safe to return home from hospital with a reablement package, which worked best with integrated teams involving hospital staff and adult social care services.
- Closer working across local authority teams, ensuring there are no communication barriers that can stop people getting the care they need.
- Collaboration across agencies, including the police and the fire service, to identify any risks or concerns for people's safety.

Improving quality

Where there are concerns about quality, local authorities have cited pressures on staffing as a concern and the cause of complaints. They say staffing issues are also a contributing factor where they have waiting lists.

Although they have quality monitoring teams, they say the resources available in teams affects how proactively they monitor quality in providers. Some local authorities said they relied more on CQC data and inspections to tell them about quality, rather than gathering their own intelligence.

However, they said they did share intelligence with health sector partners to identify where there may be quality issues. Looking to improve on quality, some said that the voluntary sector could help in terms of monitoring the quality of services and supporting them to understand people's experience within services — as well as supporting them to better understand people's needs.

A concern among some local authorities is for people who are placed 'out of county', or away from their home area. Most had gaps in relation to provision for people with complex needs — and these were people more likely to be out of their own county. When this happened, they usually relied on another local authority to monitor quality and inform them of any concerns.

Local authorities knew that good care was more likely where there were positive relationships, with partners taking a joint approach to quality assurance. Where resources were depleted, a reactive approach was more likely. But we saw quality monitoring processes that included a proactive approach to independent audits and annual reviews. Quality monitoring, including care package reviews, was usually integrated with the commissioning team.

We have found an awareness among local authorities of the areas that need to be developed and improved, as well as embedded cultures of continuous improvement. Similarly, we found positive and supportive relationships with providers, and they celebrated successes.

We also see strong relationships between some providers and the local authorities – often through forums, including co-production with providers and collaboration in market shaping and developing new models of care such as <u>supported living and extra care</u>. For example, one extra care service currently being developed is intended to reduce out-of-area placements; it involves 2 neighbouring local authorities that had worked on a supported living accreditation scheme, which should promote a consistent level of service quality.

Where local authorities were aware of good care, there were strong internal relationships between commissioners and social workers, and clear guidance and processes to manage risk when people were placed out of county.

Culture and leadership

Local authorities recognised the importance of good culture and leadership. This was borne out by some examples where there were clear cultures of openness, and the people felt 'listened to' and involved in co-producing strategies.

We have seen some clear leadership structures and cultures with an increasing focus on performance – and there was self-awareness where some senior leaders acknowledged that they were not as effective as they wanted to be.

In one local authority, we saw a culture of working openly with partners; there was an awareness of risk from senior leaders and councillors, with systems in place to monitor and manage this.

We have found leadership in local authorities to be open and transparent and, generally, staff were positive about their leaders, telling us about opportunities for professional development and training.

Many local authorities are going through a process of transformation to increase the focus on preventing, reducing and delaying the need for care and support. This includes cultural change, structural change and changes in approach to balance allocation of resources against increasing needs and demand for support. There is a common theme of increasing numbers of people with complex needs (learning disabilities, mental health illness in working age, as well as complex dementia, mental health, or frailty among older people).

Some local authorities were clearly focused on addressing the future needs of their populations and the associated delivery risks. Others were more focused on delivering support to respond to current needs. The local authorities that performed best had:

- a clear strategic vision alongside a clear delivery plan to meet current and future needs
- embedded processes to gather people's experience to inform strategy and support delivery, particularly where there was a recognition in governance that flexible or creative approaches were needed to provide personcentred support, especially for those population groups whose voices were seldom heard.

Local authorities are moving towards a more performance and data-driven culture and they are at different stages in developing their approach to achieving this. This shift requires establishing a combination of appropriate and robust systems to support performance measurement and monitoring, quality assurance and learning from when things have gone wrong, and embedding collective problem solving. There is a correlation between strong governance and authorities that have a multi-disciplinary leadership team.

The nature of relationships and the development of governance with voluntary, charity and faith (VCF) sector organisations was varied. Some authorities had a relationship based on grant giving to enable VCF organisations to focus on delivering specific outcomes for people. Others had more strongly developed and mature relationships with the VCF sector, including formal involvement in partnership boards and in the commissioning of services, such as carers support services, social prescribing activity, hospital discharge pathways, and helping to shape the local market to meet people's needs.

Workforce collaboration

Workforce recruitment and retention is a major issue for local authorities, as well as in the NHS, as described earlier in this report. This can have an impact on people's access to services across local care systems and the quality of the services.

Some local authorities were working with providers to support the adult social care workforce and using this approach to develop skills in the local workforce to address gaps in provision, particularly for the needs of older people and those with advanced dementia, or working-age adults with a learning disability, autistic people, and people with mental health needs. Local authorities were aware that they needed to be proactive and forward-looking to develop their workforce and the market.

We have seen how some are also working in partnership with regulated providers to address some workforce challenges – including processes for staff training through apprenticeships.

In one area, the local authority had increased capacity in its homecare market to ensure there were no delays for homecare or hospital discharges – this was attributed to effective work between the local authority and the care market to increase the homecare workforce, supported by sponsorship and training. There was also a local authority that held service provider forums to help develop a better understanding of the social care workforce and joint working across sectors – as well as discussions with an ICB about a 'one workforce' approach.

In North Lincolnshire, the local authority has been developing a campaign to address workforce challenges through their <u>Proud to Care</u> initiative. This was set up to raise the profile of care sector roles and highlight career progression opportunities within the sector, as well as support recruitment and retention of the social care workforce by developing various initiatives, such as funded childcare, providing electric bikes and scooters under their 'wheels to work scheme' and a subsidised gym membership. They also used this initiative to develop skills in the workforce to meet people's more complex needs. This work was just starting to have an impact and staff gave examples of people enabled to stay in their own homes with care at home support.

During our assessments we found some common recruitment issues:

- Competition across sectors meant adult social care providers often found it difficult to recruit, especially those near major local employers.
- Smaller local authorities found staff might leave and commute to neighbouring authorities, sometimes for better pay or development opportunities.
- Use of agency or locum staff was common as local authorities tried to maintain stable workforces, but it was hard to recruit to occupational therapy positions, which was affecting waiting lists and people's ability to maintain independence.

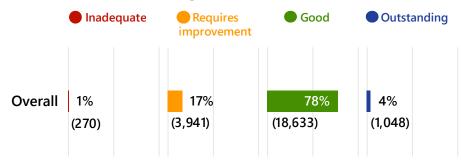
It was acknowledged that recruitment in rural areas was always a challenge, and this continued to affect the ability to provide services. Some local authorities were working with providers and visa schemes to support recruitment from overseas, while others reported a significant amount of recruitment through an immigration sponsor scheme.

Appendix: CQC ratings charts

Source: CQC ratings data, the latest ratings for all services active or registered as at 1 August 2024. Ratings for adult social care and primary medical services are at location-level only as we do not rate the provider organisation. NHS organisations received provider ratings, which is changing under the new assessment approach. See details about levels of ratings on our website.

Percentages may not add to 100 due to rounding. Percentages between 0.01% and 1% have been rounded up to 1%.

Figure A1: Adult social care, overall ratings, 2024

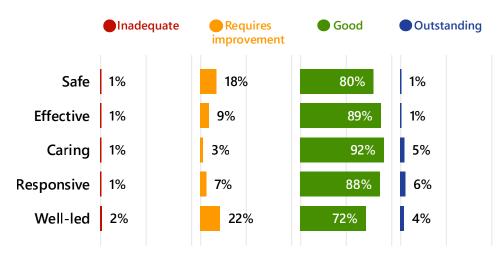


Source: CQC ratings data, 1 August 2024

Note: 2024 overall ratings include 20 'insufficient evidence to rate', representing 0.08% of the total ratings.

Percentages may not add to 100 due to rounding. Percentages between 0.01% and 1% have been rounded up to 1%.

Figure A2: Adult social care, ratings by key question, 2024

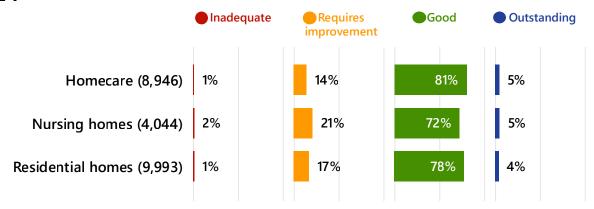


Source: CQC ratings data, 1 August 2024

Note: 2024 ratings at key question level include 'insufficient evidence to rate' represented in the following proportions:

Homecare (domiciliary care) agencies: 0.12% for caring, 0.18% for safe and well-led, 0.16% for responsive, and 0.17% for effective. **Residential homes:** 0.01% for well-led and safe, 0.02% for responsive, caring and effective. **Nursing homes:** 0.05% for responsive and caring.

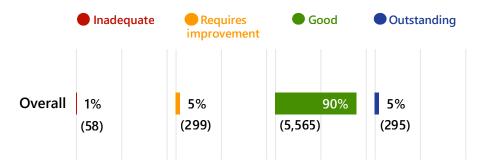
Figure A3: Adult social care, overall ratings by service type, 2024



Note: 2024 ratings include 'insufficient evidence to rate' for 19 homecare (domiciliary care) agencies (0.21% of total ratings) and 1 residential home (0.01% of total ratings).

Percentages may not add to 100 due to rounding. Percentages between 0.01% and 1% have been rounded up to 1%.

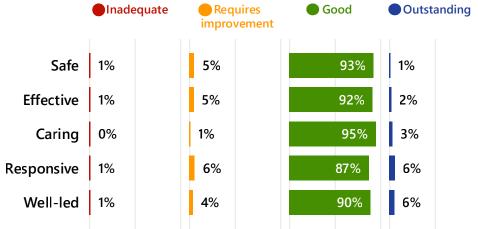
Figure A4: Primary medical services, overall ratings, 2024



Source: CQC ratings data, 1 August 2024

Note: Percentages may not add to 100 due to rounding. Percentages between 0.01% and 1% have been rounded up to 1%.

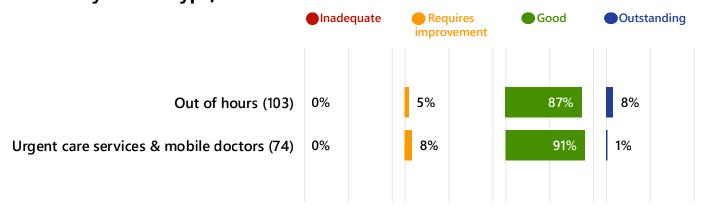
Figure A5: **Primary medical services, ratings by key question, 2024**



Source: CQC ratings data, 1 August 2024

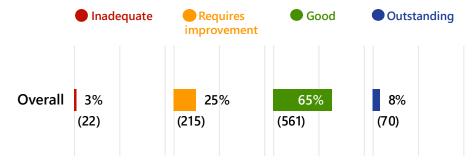
Note: 2024 ratings at key question level include 'insufficient evidence to rate' represented in the following proportions of the total: 0.02% for the safe, effective, and caring key questions.

Figure A6: Other primary medical services, overall ratings by service type, 2024



Note: Percentages may not add to 100 due to rounding. Percentages between 0.01% and 1% have been rounded up to 1%.

Figure A7: **NHS and independent mental health services, overall ratings, 2024**



Source: CQC ratings data, 1 August 2024

Note: 2024 overall ratings include 4 'insufficient evidence to rate', representing 0.46% of the total ratings.

Percentages may not add to 100 due to rounding.

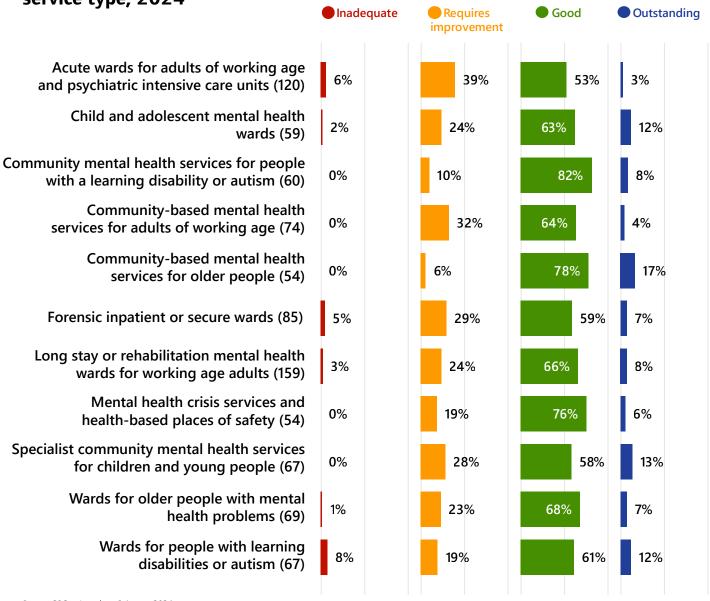
Figure A8: **NHS and independent mental health services,** ratings by key question, 2024



Source: CQC ratings data, 1 August 2024

Note: 2024 ratings at key question level include 'insufficient evidence to rate' represented in the following proportions of the total: 0.11% for safe and caring, 0.57% for effective and responsive, and 0.34% for well-led key questions.

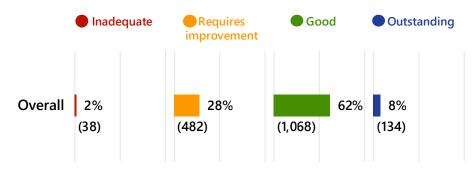
Figure A9: NHS and independent mental health services, overall ratings by service type, 2024



Note: 2024 ratings at service type level include 'insufficient evidence to rate' represented in the following proportions of the total: 0.83% for acute wards for adults of working age and psychiatric intensive care units, 1.64% for community mental health services for people with a learning disability or autism, 0.63% for long stay or rehabilitation mental health wards for working age adults, and 1.43% for wards for older people with mental health problems.

 $Percentages \ may \ not \ add \ to \ 100 \ due \ to \ rounding. \ Percentages \ between \ 0.01\% \ and \ 1\% \ have \ been \ rounded \ up \ to \ 1\%.$

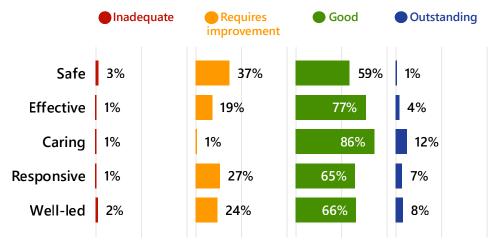
Figure A10: NHS acute hospitals, overall ratings, 2024



Source: CQC ratings data, 1 August 2024

Note: 2024 ratings include 3 'insufficient evidence to rate', representing 0.17% of the total ratings.

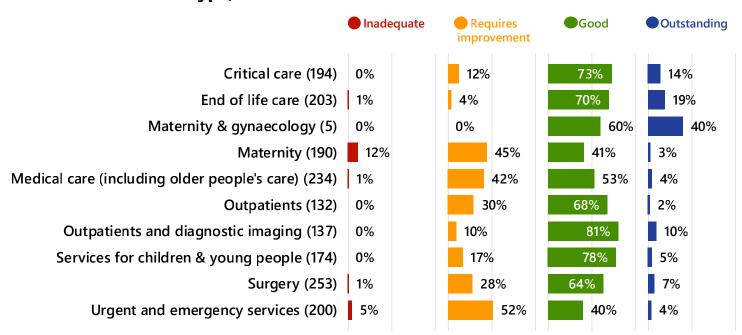
Figure A11: **NHS acute hospitals, ratings by key question, 2024**



Note: 2024 ratings at key question level include 'insufficient evidence to rate' represented in the following proportions of the total: 0.17% for safe, 0.30% for responsive and caring, 10.06% for effective, and 0.12% for well-led key questions.

Percentages may not add to 100 due to rounding. Percentages between 0.01% and 1% have been rounded up to 1%.

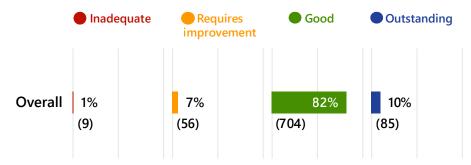
Figure A12: **NHS acute hospitals, overall ratings by service type, 2024**



Source: CQC ratings data, 1 August 2024

Note: 2024 ratings at service type level include 'insufficient evidence to rate' represented in the following proportions of the total: 0.49% for end of life care, 0.50% for urgent and emergency services, and 0.72% of outpatients and diagnostic services.

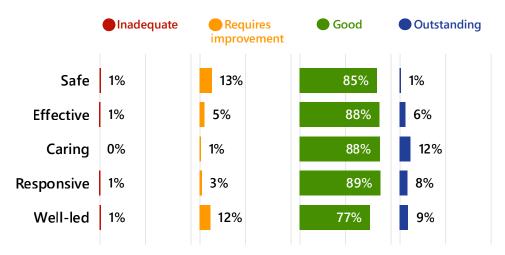
Figure A13: Independent acute hospitals, overall ratings, **2024**



Note: 2024 ratings include 11 'insufficient evidence to rate', representing 1.27% of the total ratings.

Percentages may not add to 100 due to rounding. Percentages between 0.01% and 1% have been rounded up to 1%.

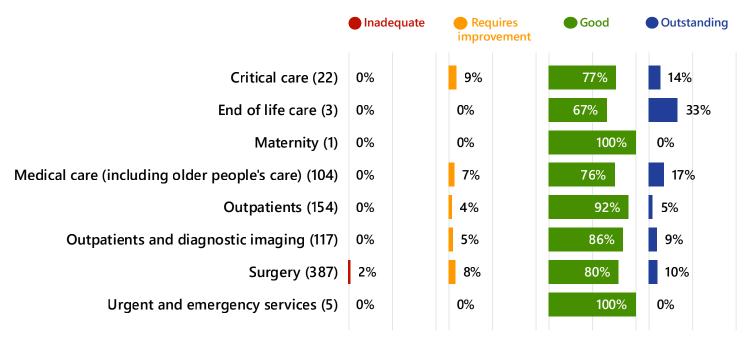
Figure A14: Independent acute hospitals, ratings by key question, 2024



Source: CQC ratings data, 1 August 2024

Note: 2024 ratings at key question level include 'insufficient evidence to rate' represented in the following proportions of the total: 1.16% for safe and well-led, 1.51% for responsive, 4.26% for caring, and 17.33% for effective key questions.

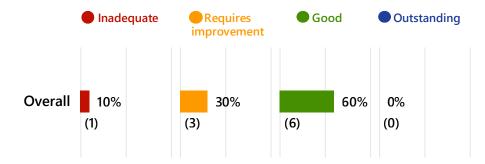
Figure A15: Independent acute hospitals, overall ratings by service type, 2024



Note: 2024 ratings at service type level include 'insufficient evidence to rate' represented in the following proportions of the total: 4.35% for critical care, 5.45% for medical care (including older people's care), and 6.15% of services for children & young people.

Percentages may not add to 100 due to rounding. Percentages between 0.01% and 1% have been rounded up to 1%.

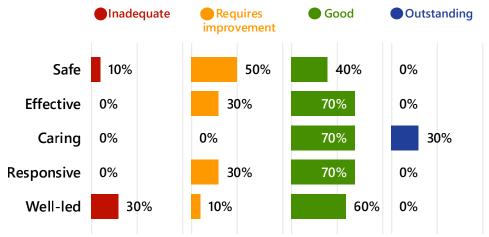
Figure A16: NHS ambulance services, overall ratings, 2024



Source: CQC ratings data, 1 August 2024

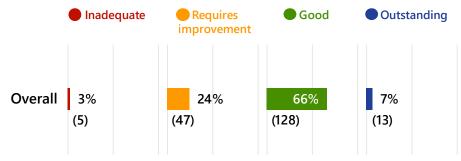
Note: Percentages may not add to 100 due to rounding.

Figure A17: **NHS ambulance services, ratings by key question, 2024**



Note: Percentages may not add to 100 due to rounding.

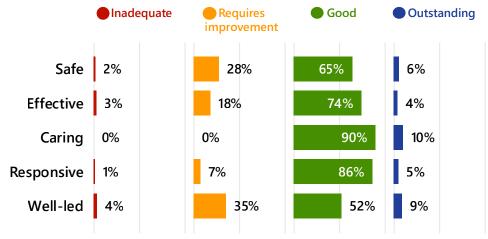
Figure A18: **Independent ambulance services, overall ratings, 2024**



Source: CQC ratings data, 1 August 2024

Note: Percentages may not add to 100 due to rounding.

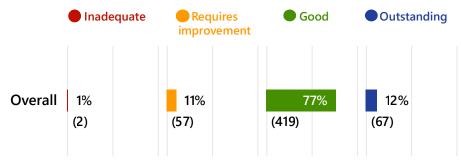
Figure A19: Independent ambulance services, ratings by key question, 2024



Source: CQC ratings data, 1 August 2024

Note: 2024 ratings at key question level include 'insufficient evidence to rate' represented in the following proportions of the total: 1.58% for effective, 1.04% for responsive, and 32.37% for the caring key questions.

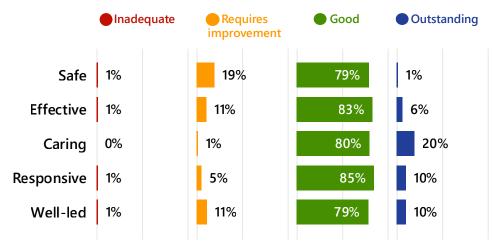
Figure A20: Community healthcare services, overall ratings, 2024



Note: 2024 overall ratings include 1 'insufficient evidence to rate', representing 0.18% of the total ratings.

Percentages may not add to 100 due to rounding. Percentages between 0.01% and 1% have been rounded up to 1%.

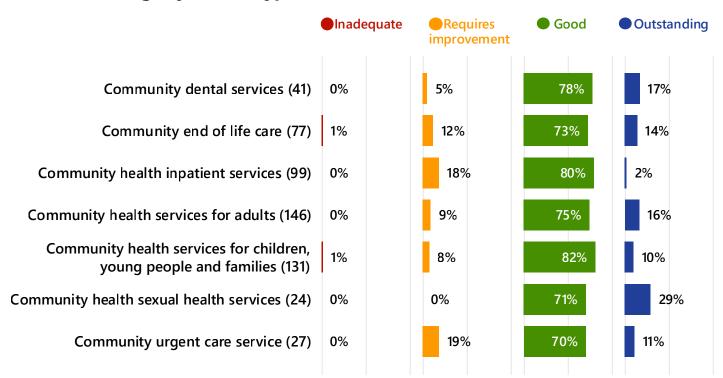
Figure A21: Community healthcare services, ratings by key question, 2024



Source: CQC ratings data, 1 August 2024

Note: 2024 ratings at key question level include 'insufficient evidence to rate' represented in the following proportions of the total: 0.18% for safe, effective, responsive and well-led key questions, and 0.37% for the caring key question.

Figure A22: Community healthcare services, overall ratings by service type, 2024



Note: 2024 overall ratings at service type level include 'insufficient evidence to rate' represented in the following proportions of the total: 1% for community health inpatient services.

References

- 1 NHS England, General Practice Workforce, May 2024.
- 2 NHS England, Appointments in General Practice, April 2024
- 3 NHS England, General Practice Workforce, May 2024
- 4 NHS England, <u>Dentists' Working Patterns</u>, <u>Motivation and Morale 2022/23</u>, April 2024
- 5 Canada Life, <u>Filling the gap: 9.4 million brits have performed a dental</u> procedure on themselves, April 2024
- British Dental Association,8 in 10 dentists seeing cases of 'DIY' dentistry, February 2024
- 7 Healthwatch England, Our position on NHS dentistry, July 2024
- 8 NHS England, Pharmacy First, January 2024
- 9 UK Parliament, <u>Health and Social Care Committee report on Pharmacy</u>, May 2024
- 10 NHS England, Requests for Support, December 2023
- 11 Local Government and Social Care Ombudsman, Review of Adult Social Care Complaints 2022/23, September 2023
- 12 NHS England, Discharge delays (Acute), May 2024
- NHS England, <u>Intermediate care framework for rehabilitation</u>, <u>reablement</u> and recovery following hospital discharge, September 2023
- 14 NHS England, <u>Adult Social Care Activity and Finance Report</u>, December 2023
- 15 NHS England, Discharge delays (Acute), July 2024
- 16 Skills for Care, <u>The size and structure of the adult social care sector and</u> workforce in England, July 2024
- 17 Office for National Statistics, <u>EMP17: People in employment on zero</u> hours contracts, May 2024
- 18 GMB Union, <u>70 per cent of carers say work negatively affecting mental</u> <u>health</u>, June 2024
- 19 Home Office, Monthly monitoring of entry clearance visa applications, August 2024
- 20 NHS England, <u>Personal Social Services Survey of Adult Carers in England</u>, June 2024
- 21 Association of Directors of Adult Social Services, <u>ADASS Spring Survey</u> 2024, July 2024
- 22 ARC England, Fee Rates for Learning Disability and Autism Services by Local Authority 2023-24, 2023
- 23 NHS England, Mental Health <u>Adult Crisis and Acute Care GIRFT</u>
 Programme National Specialty Report, April 2021
- 24 Care Quality Commission, <u>Special review of mental health services at</u>
 Nottinghamshire Healthcare NHS Foundation Trust, March 2024
- 25 Children's Commissioner, <u>Children's mental health services 2022-23</u>, March 2024

- 26 Care Quality Commission, <u>Monitoring the Mental Health Act in 2022/23</u>, March 2024
- 27 NHS England, <u>Acute inpatient mental health care for adults and older adults</u>, July 2023
- 28 NHS England, Long Term Plan Adult Mental Health Services, January 2019.
- 29 Mental Welfare Commission for Scotland, <u>Good Practice Guide: Human</u> Rights in Mental Health Services, May 2017
- Department of Health and Social Care, <u>Mental Health Act 1983: Code of Practice</u>, January 2015, para 8.25
- 31 NHS England <u>Integrated urgent care: key performance indicators</u> 2023/24, May 2023
- 32 NHS England, <u>Delivery plan for recovering urgent and emergency care</u> services, January 2023
- NHS England, <u>Delivery plan for recovering urgent and emergency care:</u>
 Progress update and next steps, May 2024
- 34 King's Fund, What's going on with A&E waiting times?, July 2024
- Jones S et al, <u>Association between delays to patient admission from the emergency department and all-cause 30-day mortality</u>, Emerg Med J, January 2022
- 36 Department of Health and Social Care, <u>Handbook to the NHS</u> <u>Constitution for England</u>, October 2023
- 37 Royal College of Emergency Medicine, <u>Tip of the iceberg: 12-hour stays</u> in the emergency department, June 2022
- 38 British Medical Association, <u>NHS hospital beds data analysis</u>, December 2022
- 39 Nuffield Trust, Delayed discharges from hospital, August 2024
- 40 The Health Foundation, Why are delayed discharges from hospital increasing? Seeing the bigger picture, March 2023.
- 41 Healthwatch, <u>The impact of waiting: the stories behind the numbers</u>, October 2023
- 42 Office for National Statistics, <u>NHS planned care waiting times across the UK</u>, June 2024
- 43 Department of Health and Social Care Media Centre, <u>Elective recovery</u> media fact sheet, December 2022
- 44 Macmillan Cancer Support, Cancer statistics in the UK, August 2024.
- 45 Cambridge University Hospitals NHS Foundation Trust, <u>Cancer is the</u> public's biggest health concern, poll reveals, July 2024
- 46 NHS England, <u>Changes to cancer waiting times standards from 1 October</u> 2023, August 2023
- 47 Cancer Research UK, Cancer waiting times, August 2023.
- 48 Cancer Research UK, <u>Health inequalities: "We have a moral duty to</u> reduce them", February 2022
- 49 Nuffield Trust, Cancer survival rates, July 2024
- 50 NHS England, Delivering a net zero NHS, July 2022

- 51 NHS England, <u>Investment and Impact Fund 2022/23</u>: <u>updated guidance</u>, September 2022
- 52 National review of maternity services in England 2022 to 2024 Care Quality Commission (cqc.org.uk)
- 53 <u>Stem the tide of midwives leaving the profession, RCM tells Downing</u> Street
- 54 <u>University nursing applications fall again to lowest in five years | Nursing Times</u>
- The All-Party Parliamentary Group on Birth Trauma, <u>Listen to Mums:</u> Ending the Postcode Lottery on Perinatal Care, May 2024
- Royal College of Paediatrics and Child Health, <u>Record high: Over</u> 400,000 children waiting for treatment amidst child health crisis, May 2023.
- Albutt A, Roland D, Lawton R, Conner M and O'Hara J, Capturing Parents' Perspectives of Child Wellness to Support Identification of Acutely Unwell Children in the Emergency Department, J Patient Saf, 2021, 18(5):410–414
- 58 NHS England, NHS Staff Survey National Results, May 2024
- 59 NHS England, NHS Long Term Workforce Plan, June 2023
- Kings College London, <u>Learning from Lives and Deaths people with a learning disability and autistic people (LeDeR)</u>, November 2023
- NHS England, <u>Health and Care of People with Learning Disabilities</u>, Experimental Statistics 2022 to 2023, December 2023
- House of Commons, Women and Equalities Committee, Inequalities in healthcare and employment for people with a learning disability and autistic people, Sixth Report of Session 2023–24, May 2024
- 63 NHS England, <u>DAPB4019</u>: Reasonable Adjustment Digital Flag, September 2023
- 64 NHS England, Autism Statistics, April 2023 to March 2024, May 2024
- 65 NHS, NHS Long Term Plan, January 2019
- Rethink Mental Illness, <u>Partnership to raise awareness of mental health in</u> the Black community launched, July 2024
- 67 NHS England, Primary Care Dementia Data, July 2024, August 2024
- 68 RSM UK Consulting LLP / Care Quality Commission, <u>Rapid Literature</u> Review: Inequalities in Dementia, September 2023
- 69 RSM UK Consulting LLP / Care Quality Commission, Rapid Literature Review: Inequalities in Dementia, September 2023
- 70 House of Lords, MCA post-legislative scrutiny report, March 2014
- 71 Care Quality Commission, <u>Restrictive practice</u> a failure of personcentred care planning?, August 2023
- 72 Care Quality Commission, <u>Our updated human rights approach</u>, December 2023
- 73 Care Quality Commission, State of Care 2022/23, October 2023
- 74 Age UK, A Hidden Crisis, March 2024

- 75 NHS England, <u>Core20PLUS5</u> (adults) an approach to reducing healthcare inequalities
- 76 NHS Confederation, Putting money where our mouth is?, March 2024
- 77 NHS England, NHS Workforce Race Equality Standard
- 78 NHS England, <u>Working together to deliver a resilient winter system</u> roles and responsibilities, July 2023
- 79 NHS England, <u>Intermediate care framework for rehabilitation</u>, <u>reablement</u> and recovery following hospital discharge, September 2023
- 80 The Health Foundation, <u>The challenges and potential of intermediate</u> care, March 2024
- 81 Dr Claire Fuller, <u>Next steps for integrating primary care: Fuller Stocktake</u> report, May 2022
- 82 NHS, Guide to NHS waiting times in England
- 83 UK Parliament, NHS dentistry report summary, July 2023
- 84 NHS Confederation, <u>From delegation to integration: lessons from early delegation of primary pharmacy, optometry and dentistry commissioning to integrated care boards, April 2023</u>
- Department of Health and Social Care, Policy Paper: <u>The best start for</u> life: a vision for the 1,001 critical days, March 2021
- 86 NHS Providers, System working as a vehicle to address health inequalities
- 87 NHS England, Principle 5: Encourage a supported 'Home First' approach
- 88 Care Quality Commission, <u>London Borough of Harrow: local authority</u> <u>assessment</u>, August 2024
- 89 London Borough of Harrow, <u>Harrow's Market Sustainability Plan (annex C)</u>, March 2023
- 90 Care Quality Commission, <u>Report on Birmingham City Council's care act</u> responsibilities, November 2023
- 91 Care Quality Commission, <u>Rapid evidence review</u>: <u>Tackling inequalities</u> through the regulation of services and organisations, May 2024

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