

Health Disparities: waiting for planned care

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Summary

Elective or 'planned' care often refers to treatments such as knee, hip or eye surgeries, or other 'non-urgent' operations, appointments, or diagnostic tests for which people are referred to hospitals.

The NHS faces rising waiting lists for these services, with COVID-19 having a huge impact on the number of postponed or cancelled appointments.

And though data shows a decline in the number of people waiting two -years, the [latest NHS figures](#) show that a record 6.4 million people were waiting to start treatment at the end of March 2022.

We wanted to understand the stories behind those waiting for care following [our research from November 2021](#).

While people understand the pressures the NHS is facing, we have consistently found that they are still struggling to access the information and support services that can be crucial to them when they have to wait an increasingly long time.

Our research highlights that these challenges are not always experienced equally across all patient groups. All too often, we can see that a poor experience of waiting is linked to wealth, disability, education, gender or ethnicity.

And when we combine identities, for example, by looking at responses from people from an **ethnic minority** background with **lower wealth** and comparing their experiences to people from a **white British** background with **higher wealth** - we can see stark and worrying differences across specific research questions.

We need to understand why this is and how we can support services to understand the people waiting for care and help them with dedicated and personalised support.

Because although it is important to look at data which shows how many people are waiting for care, the people waiting are not just numbers on a list. They're not packages to be delivered, they're not customers queueing for purchases, and they're not items waiting to be checked out. They're not 'a backlog', not 'bed blockers', and not KPIs or targets.

They're the full-time carer who hasn't taken a break in years and who always puts the needs of their loved one first. They're the person who doesn't own a mobile phone or computer or struggles with using the internet and who feels completely forgotten. They're the person whose mental health is deteriorating due to fears over their condition getting worse due to delays. They're the person with a physical disability whose mobility has worsened, leaving them feeling isolated. They're the person struggling to make ends meet in a cost of living crisis who can no longer work due to the pain they're feeling.

And they're everyone in between real people with their unique situations, challenges and barriers.

For all these people, the treatment and the support they receive while waiting isn't 'elective'. It is a lifeline to help them back to work, back to caring for loved ones who need them, and back to living the lives they want to live without preventable pain or stress.

The Impact of Waiting



The NHS faces enormous pressures to reduce a record elective care waiting list. But it's important to remember that behind every number is someone's story. The impact on those waiting for care is very real and, in some situations, can cause harm.

We need a greater understanding of people's individual experiences to focus support in the right places at the right time. We need to limit harm by enabling people to tell services when their symptoms are getting worse. And we need better communication and administration from hospital trusts to help ensure people don't feel forgotten or don't have treatment unavoidably cancelled.

People know the NHS is working hard to get to them as soon as possible, and the government has invested extra money, but it's how we manage the backlog that matters.

Louise Ansari

National Director, Healthwatch England



Background

In September 2021, we [joined forces](#) with the King's Fund to show that people who live in poorer areas are nearly twice as likely to experience a wait of over a year for hospital care than those in the most affluent areas.

Our further analysis found that people on low incomes are significantly more likely to report living in pain and struggling to manage work and household chores due to their wait.

In November 2021, [we published a briefing](#) for health and social care stakeholders highlighting what people had been telling Healthwatch about delays to hospital care and treatment.

That briefing was informed by the views of over 2,500 people and reported on the impact waiting for care was having, including on the pain they experienced, their inability to work, and their mental health. It was clear that people were unhappy with the communications they received too, and the lack of support they were given to help with things like pain relief or accessing physiotherapy.

Again, people did not experience these concerns equally, and findings were particularly stark among those with disabilities or long-term health conditions and the least financially secure respondents.

And though there was some indication that people from ethnic minority backgrounds were experiencing similar issues to those on low incomes, the number of people from these communities who responded to our research was not great enough to draw any statistically significant conclusions.

With this report, we wanted to understand health inequalities to address the barriers people face and best support the NHS in developing solutions to manage the elective care waiting list.

Fieldwork

This briefing is informed by the views of 1,000 people in a national survey commissioned by us with fieldwork carried out by [GuineaPig](#) in February 2022.

The sample completed 90% of responses via an online survey, with 10% telephone responses targeting those without internet access.

The following quotas split the sample:

- Waiting for NHS hospital treatment or care (>6million) in England
- Gender: male/female 50:50
- Age: natural fallout
- Geographic: natural fallout
- Ethnicity

Analysis Groups	Quota	n
White British	40%	400
White other/ white mixed	10%	100
Asian/ Asian mixed	25%	250
Black/ black mixed	20%	200
Other/ Mixed	5%	50

- Financial situation

Financial situation (survey question)	Quota	n
I have more than enough money for basic necessities, and a lot spare, that I can save or spend on extras or leisure	10%	100
I have more than enough money for basic necessities, and a little spare, that I can save or spend on extras or leisure	40%	400
I have just enough money for basic necessities and little else	40%	400
I don't have enough money for basic necessities and sometimes or often run out of money	10%	100

The following findings are based on our analysis of this survey. Though two points must be noted:

- Some variables have been aggregated to better understand the differences between groups with more statistical confidence. Significance was tested using z-score test of two proportions at 95% confidence.
- Recruiting for this survey to meet ethnic minority quotas meant geographic location played a larger role than anticipated. As such, ethnic minority recruitment was slightly more concentrated in city areas, whereas white British recruitment was more geographically dispersed.

Key Findings



Wealth is a factor in long waits and poor experiences

When we look at all populations combined, wealth is a crucial indicator for both long waits and poor experience of waiting. This was evident in our previous evidence briefing and remains significant.

We asked participants questions about the length of their wait, communication from the NHS, and the impact waiting was having on them:

- Those with **lower wealth (54%)** are more likely to have been waiting or have waited longer (over four months) for hospital care/treatment than those with **higher wealth (43%)**
- Those with **lower wealth (57%)** are more likely to have had their treatment delayed or cancelled than those with **higher wealth (46%)** combined.
- Those with **higher wealth (55%)** are more likely to have been given a clear point of contact with the NHS than those with **lower wealth (44%)**
- Those with lower wealth are more likely to have been negatively impacted by the wait than those with higher wealth.
 - My mental health and wellbeing - **52% lower wealth vs 36% higher wealth**
 - My physical fitness - **49% lower wealth vs 38% higher wealth**
 - Ability to care for others - **31% lower wealth vs 20% higher wealth**
 - Ability to work (voluntary or paid) - **39% lower wealth vs 29% higher wealth**

I have been negatively impacted by my wait



With many more people facing financial challenges due to increases in the cost of living, the government and NHS must ensure long waits, delays, and cancellations do not further exacerbate wealth inequalities and poor health outcomes. The communication of helpful information and access to support services must remain a priority.

Disparities between lower and higher education

Our results also highlight education as a significant indicator behind people's experience of waiting:

- Just **54%** of people with **lower education** felt well-informed about their treatment compared to those with higher education (63%).
- Just **53%** of people with **lower education** felt well-informed about their condition compared to higher education (63%).
- **63%** of **people with a lower level of education** felt the communications they received from the NHS were clear and easy to understand, compared to **73%** of those with **higher education**.
- Only **46%** of those with **lower education** were given a clear point of contact at the NHS compared to **55%** of those with **higher education**.
- **60%** of people with **lower education** and **67%** of people with **higher education** were happy with the amount of information the NHS gave them to manage their condition.

Those with a **lower level of education (54%)** were also more likely to have waited/are waiting longer than four months for treatment than those with **higher education (42%)**.

We all have a different relationship with the NHS, both in terms of the treatments we might require and how we access, communicate with, understand and use information about services to make decisions about our health.

A person's level of education or health literacy shouldn't be pre-requisites to a good experience of care. Feeling 'well informed' is subjective, so services must be supported to deliver easily understood information about people's treatment and condition in their preferred format.

Ethnic inequalities in hospital cancellations

In our previous elective care research, we compared responses from people with different characteristics against the total population and again against a comparable sample in terms of that characteristic. For example, the experiences of those with lower incomes were compared against the total sample and again against the experiences of those with higher incomes.

We could not run any comparisons by ethnicity in that research, due to the small sample size of people from ethnic minority backgrounds.

For this research, we had high enough quotas to compare the experiences of people from ethnic minority backgrounds against the experiences of people from a white British background. In this way, we hoped to understand whether services were working equally for all people.

More in-depth research is required to analyse the experiences of separate ethnic minority groups.

On cancellations, we asked participants: "Was your treatment delayed or cancelled at any point?"

In total, **51%** of **all** respondents answered yes. However, we can see a disparity in experience by ethnicity:

- **People from ethnic minority backgrounds (57%)** are more likely to have had their treatment delayed or cancelled than **all respondents (51%)** combined.
- At **42%**, **people from white British backgrounds** respondents are least likely to have had treatment delayed or cancelled.

People from **ethnic minority backgrounds (51%)** were also more likely to have been given a week or less notice before their care was delayed or cancelled than **people from white British backgrounds (37%)**.

People with disabilities need more support while they wait

We asked respondents if they considered themselves to have a disability, with 171 answering yes. When we compare the experiences of these people to those who do not consider themselves to have a disability, we can see disparities across multiple questions:

- People with a disability were more likely to:
 - Have waited more than four months for treatment (66% vs 44%)
 - Have felt waiting or a delay to treatment had an impact on:
 - Their ability to work (53% vs 29%)
 - Their ability to carry out household tasks (51% vs 33%)
 - Their ability to care for others (36% vs 22%)
 - Their ability to socialise (49% vs 31%)
 - Their physical fitness (60% vs 40%)
 - Their mental health and wellbeing (51% vs 41%)
 - Their relationship with their partner (40% vs 23%)
- People with a disability were less likely to:
 - Have felt informed about treatment timelines (39% vs 48%) or delays (34% vs 46%)
 - Have felt that communications from the NHS about their care or treatment were clear and easy to understand (57% vs 70%)
 - Have found the amount of information given to them to manage their condition excellent or good (50% vs 67%)

Women are more likely to be impacted than men

Our results also highlight several gender inequalities when waiting for care.

- Women were more likely than men to:
 - Have waited more than four months for treatment (54% vs 42%)
 - Have had their treatment delayed or cancelled (56% vs 46%)
 - Have felt waiting or a delay to treatment had an impact on:
 - Their ability to work (38% vs 29%)
 - Their ability to carry out household tasks (40% vs 33%)
 - Their ability to care for others (28% vs 21%)

- Their ability to socialise (41% vs 28%)
- Their physical fitness (49% vs 38%)
- Their mental health and wellbeing (48% vs 38%)
- Their relationship with their partner (29% vs 23%)
- Women were less likely to:
 - Have felt informed about:
 - Their treatment (54% vs 63%)
 - Their condition (53% vs 63%)
 - Treatment timelines (41% vs 51%)
 - Delays (39% vs 48%)
 - Have felt that communications from the NHS about their care or treatment were clear and easy to understand (64% vs 73%)
 - Have found the amount of information given to them to manage their condition excellent or good (58% vs 70%)

The importance of intersectionality

There are many inequalities in the health and care system, and work is underway to understand and address disparities where they exist. For example, through [the government's independent review into ethnic inequalities](#) or [NHS England's approach to reducing health inequalities](#).

But taken independently, ethnicity, disability, wealth, education or gender won't explain all the barriers someone might face 100% of the time. Needs and barriers to care can change depending on the issue or the service. And often, factors can combine to show a worse experience for people with multiple protected characteristics.

For example, we've looked at the ethnic and wealth disparities in the experience of hospital delays or cancellations. When we combine those indicators and look at **ethnicity** and **wealth** together, the differences are even more pronounced.

- **People from ethnic minority backgrounds** respondents with **lower wealth (63%)** are more likely to have had their treatment delayed or cancelled than **people from white British backgrounds with higher wealth (38%)**.

My treatment was cancelled or delayed



Similarly, when we looked at education as a factor in people feeling well-informed about their treatment and condition, people with higher levels of education were around 10% more likely to feel well-informed.

But when we combine **education** with **ethnicity**, these results are far starker, with differences climbing to **17%** (treatment) and **25%** (condition).

- Just **50%** of **people from ethnic minority backgrounds** with **lower education** felt well-informed about their treatment compared to **67%** of **people from white British backgrounds** with **higher education**.
- Just **44%** of **people from ethnic minority backgrounds** with **lower education** felt well-informed about their condition compared to **69%** of **people from white British backgrounds** with **higher education**.

I felt well-informed about my condition

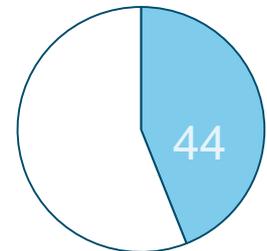
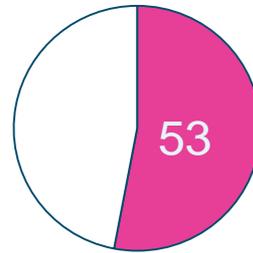
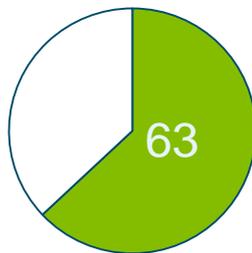
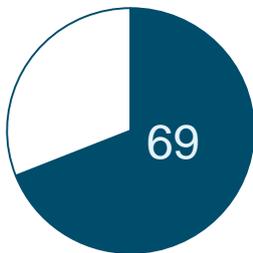
I felt well-informed about my condition (%)

White British with higher education

Higher education

Lower education

Ethnic minority with lower education



And when looking specifically at the accessibility of communications, we can see a big difference in experience in the white British with higher education group:

- **83%** of **people from white British backgrounds** with a **higher education** found information from the NHS accessible to them, compared to:
 - **People from ethnic minority backgrounds with lower education** - 59%
 - **People from ethnic minority backgrounds with higher education** - 60%
 - **People from white British backgrounds with lower education** - 55%

Combining factors highlighted worse experiences for some groups and flagged otherwise unknown disparities. For example, we asked all participants if they felt waiting for care had impacted their ability to care for others or their relationships with their loved ones.

We have already flagged inequalities in experience by gender and disability for these questions, but there were no statistically significant disparities by ethnicity or wealth alone.

However, when combining wealth and ethnicity:

- **People from ethnic minority backgrounds with low wealth (39%)** reported a more negative impact on their relationships than **people from white British backgrounds with higher wealth (19%)**.

- **People from ethnic minority backgrounds with low wealth (31%)** reported a more negative impact on their ability to care than people from **white British backgrounds with higher wealth (15%)**.

Recommendations

What have we found?

Our research last year highlighted that long delays for treatment, last-minute cancellations, and a lack of personalised information and support were huge concerns for people.

And this latest research has highlighted that these issues disproportionately affect certain groups.

Disabled people, those with lower levels of wealth, women, and people from ethnic minority backgrounds are the most likely groups to have been waiting over four months for treatment and to have experienced a delay or cancellation.

Women and disabled people are also most likely to have been negatively impacted by their long wait for care, with relationships, socialising, ability to provide care for a loved one, and mental health and wellbeing suffering as a result.

People with lower levels of education are more likely than people with higher education to be happy with the information the NHS has provided them.

And though some disparities are clear to see, others require a more nuanced look at identities and characteristics for us to understand the barriers different people face.

What needs improving?

Last year we set out [recommendations](#) to NHS England on improving the experience of people waiting for treatment ahead of the publication of their [plan to tackle the NHS backlog](#).

Thanks to public feedback, we highlighted that many people and their loved ones were not getting the help and information they needed while waiting for care, making them feel anxious, ignored and alone.

We were pleased to see that NHS England listened to many of these concerns and that our asks were vital to the plan's recommendations.

And while some recommendations will still take some time for NHS teams to implement, our latest research shows the health inequalities some people continue to face, with cancellations, communications, and accessing personalised support all causing concern.

Everyone on the waiting list has an individual story behind their condition. Many people will also have additional communication needs or compelling life pressures like work or caring responsibilities, which affect when they can undergo treatment. And that is why we're recommending the NHS does more to understand and improve personalised support for the millions of people waiting who have reported feeling forgotten over the past few years.

This does not mean providing every patient with complicated clinical details on their treatment. But it should mean a greater focus on the barriers people may

experience and the help they might need. This could be with their mental health, the pain their condition has them in, the financial benefits they may be eligible for, the transport support the NHS can help with, or the information communicated to them.

But NHS teams will require specific support themselves to help more people in a personalised way.

It will be immensely challenging for increasingly burned-out staff to do this alone while continuing with their workloads in managing record waiting lists, dealing with other immediate pressures their departments face, and implementing wider NHS reforms.

Unfortunately, until NHS capacity can be increased to meet demand, long waits for elective care treatments are here to stay for some time. So, we must find solutions that improve the experience of waiting while supporting our NHS teams to carry out their clinical, administrative, and communication work in a safe and sustainable way.

Our recommendations

Recommendation	How will this help?	Who is the recommendation for?
<p>Publish a plan to recruit more administrative staff.</p>	<p>The NHS is under immense strain trying to manage a record waiting list, alongside other issues facing busy GP practices, A&E departments, and ambulance teams.</p> <p>But until a formal clinical workforce plan is announced, teams will continue to face challenges in meeting formal targets.</p> <p>In the meantime, people will continue to wait longer for treatment, some in increasing pain or feeling forgotten and left without personalised support.</p> <p>Feeling forgotten is subjective, and as we can see in our research, it is often based on things like education and language.</p> <p>We want to see a greater focus on recruiting skilled administrative staff who can dedicate their time to understanding the needs of those currently waiting and working to</p>	<p>NHS England, Health Education England, and the Department of Health and Social Care</p>

	<p>make their experience as bearable as possible.</p> <p>This would also help people develop better, more productive relationships with the NHS.</p>	
<p>Commission a national helpline to improve access to health and care benefits.</p>	<p>With more and more people telling us of the impact waiting is having on their ability to work, travel, care for others and move around their homes, raising awareness of the safety nets the government has in place could lead to more people accessing the financial support they need.</p> <p>For example, Statutory Sick Pay (SSP), Universal Credit, Employment and Support Allowance (ESA), Healthcare travel costs scheme (HTCS), Carer's Allowance, and Personal Independence Payments (PIP).</p> <p>This signposting could occur following a telephone, online or in-person check-up when for example, someone might mention they need help with transport, that mobility has become more challenging, or that they are concerned about being able to care for a loved one.</p> <p>It could be done proactively, with NHS teams using data from across integrated systems to target, i.e. people with caring responsibilities.</p> <p>And it could also be provided through a national helpline which supports people impacted by delays with signposting, information and advice.</p>	<p>The Department of Health and Social Care, the Department for Work and Pensions, NHS England</p>
<p>Extend the amount of time statutory sick pay can be paid to people who can't work because of NHS delays.</p>	<p>People pay into our health system, which in turn commits to hitting targets for providing that care.</p> <p>These targets are being missed. And for some, that means time out of work due to increased pain,</p>	<p>The Department of Health and Social Care, the Department for Work and Pensions, NHS England</p>

	<p>decreased mobility, or worsening mental health.</p> <p>Currently, you can get SSP for up to 28 weeks if you're too ill to work.</p> <p>And though NHS data at the time of publication shows median wait times of 12 weeks, 37.6% of people waiting for care are not being seen within 18 weeks, and 4.8% are still waiting over a year.</p> <p>Some of these people will have paid money into the NHS through taxation and will be forced to lose out on their wages or benefits due to further delays.</p> <p>An extension would prevent these people from effectively paying twice for their delayed care.</p>	
<p>Announce funding to boost the voluntary sector.</p>	<p>Many local organisations already provide expert signposting and information and advice to communities.</p> <p>Others provide services to help people with things like getting in touch with their hospital, carers breaks, physiotherapy, or with wellbeing groups.</p> <p>Where good work is already happening to give people the help they need, organisations should be formally resourced and supported to enable them to continue and, where possible, scale up their work.</p>	<p>The Department of Health and Social Care - in particular, the team writing the Health Disparities White Paper, and NHS England</p>
<p>Work with patient organisations to improve My Planned Care and implement the Good Communication with Patients guidance.</p>	<p>My Planned Care is currently limited in the type of advice it provides people, with the level of personalisation only going as far as someone's clinical condition.</p> <p>When working to improve this platform and the broader information and advice provided by trusts, the NHS needs to</p>	<p>NHS England and organisations including Healthwatch England</p>

	<p>understand people's experiences better. This might include asking:</p> <ul style="list-style-type: none"> • Why a patient might have rejected a new appointment date following a cancellation. • Why they might have turned down the offer for transport to an alternative hospital for care. • Why they haven't heard from the patient following recent contact. <p>The result might be that NHS staff send very similar information to large groups of patients. Still, given the results of our latest polling, the NHS must have the processes and data to understand an individual's pathway. This includes what barriers they may have faced, how they may be able to manage their condition, whether their situation has changed, or what their personal choices for care may be.</p>	
<p>Publish data on disparities in waiting times between different patient groups.</p>	<p>As our research has found, by looking at a combination of factors which might define someone's identity, we can better understand where people are experiencing barriers to support - and how these need to be addressed locally.</p> <p>Just as each patient may have their own personalised needs while they wait for care, each region and each NHS trust will face its own challenges due to local factors.</p> <p>Systems must measure the collection of this data as a first step to understanding the scale of any local issues.</p> <p>Local Healthwatch teams can often be well placed to support trusts</p>	<p>NHS Hospital Trusts and local Healthwatch</p>

	with their own evidence to enable a holistic look at local experiences.	
Take steps to understand who is waiting for care.	<p>If the system is to stand any chance of reducing health inequalities, it must do more to understand the people waiting for care.</p> <p>The NHS needs to improve data collection and sharing across integrated health and care systems to implement our previous recommendations.</p> <p>Better data sharing can crucially flag where patients may be particularly vulnerable to health inequalities or the wider determinants of poor health.</p> <p>This will be vital to services understanding patients as individuals and providing genuinely personalised support.</p>	<p>The Department of Health and Social Care - in particular, the team writing the Health Disparities White Paper, and NHS England</p>



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