

What are people telling us about delays to hospital care and treatment?

Key messages from our evidence

November 2021

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About

This briefing provides an update for national health and social care stakeholders about those who have been or are still waiting for NHS hospital care and treatment, including:

- How long people are waiting to receive treatment
- What type of treatment people are waiting to receive
- What communications people are receiving during their waiting time
- The quality of communication and support people are receiving
- How delays have impacted people's quality of life

This briefing is informed by:

- The views of 1441 people in national polling commissioned by us and carried out by YouGov between 19 – 23 August 2021. YouGov screened the total sample size of 6248 adults for those either waiting for treatment or with a family member waiting for treatment. Healthwatch England then filtered the sample again to capture data from England only. Of the resulting sample size of 1675 respondents, 1441 completed the survey. Throughout this briefing, we describe these views as from the [YouGov poll](#), with all figures referenced from YouGov Plc.
- The views of 1075 people either waiting for treatment or who have received treatment in the past 18 months in our national survey, which was live between 6 September and 11 October 2021. Throughout this briefing, we describe these views as from the [Healthwatch survey](#).

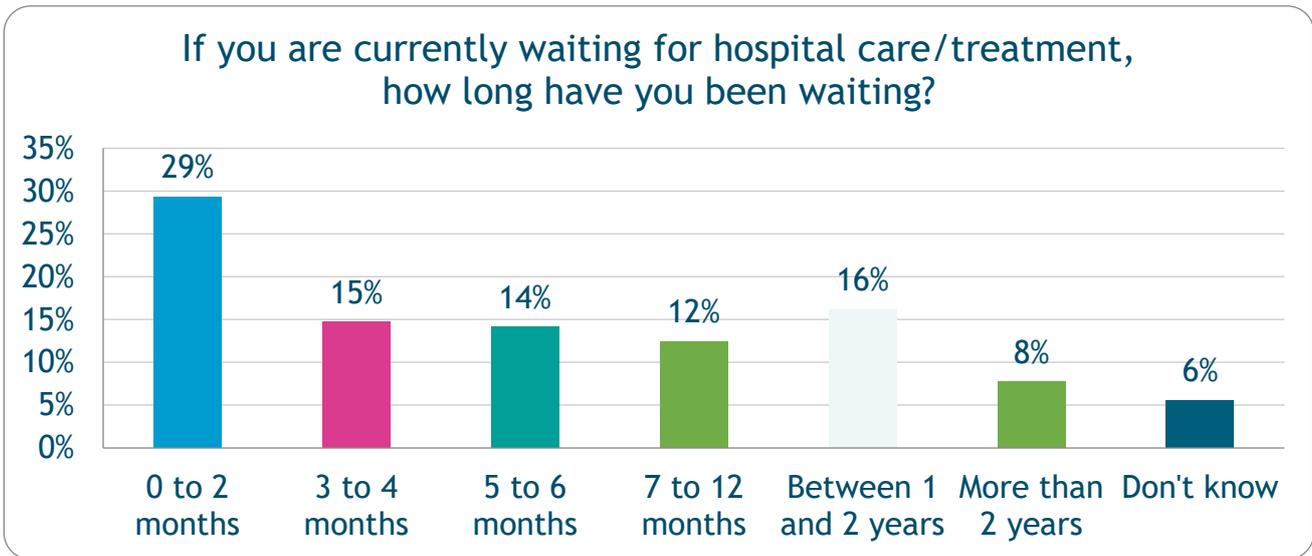
Key Messages

Length of wait

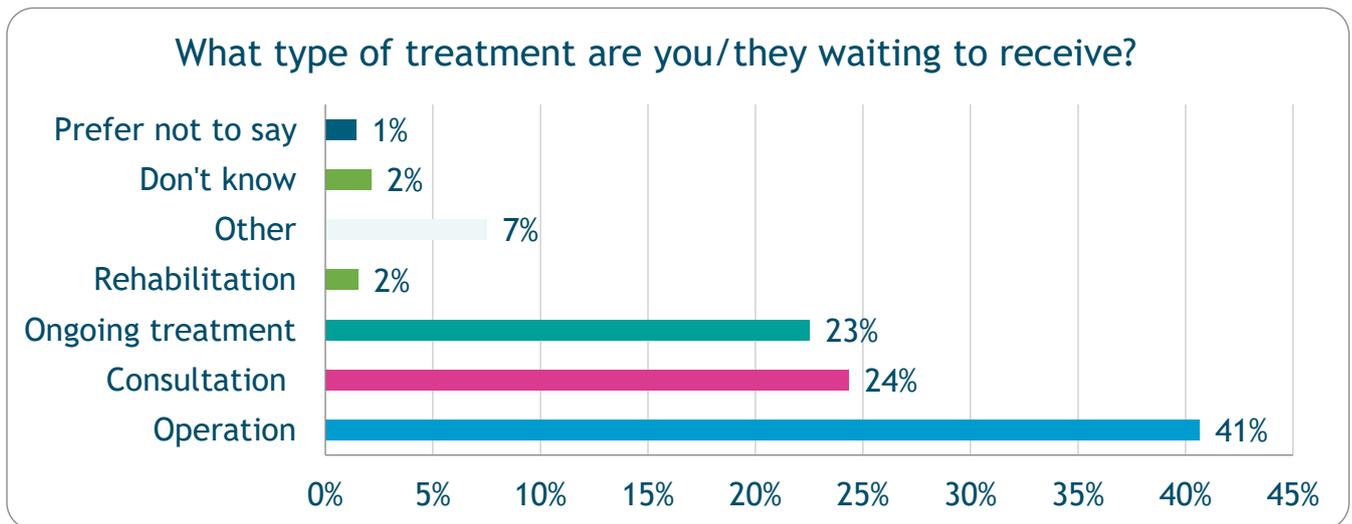
In both the poll we commissioned through YouGov and the online survey we conducted, we found:

- There is variation in how long individuals are waiting to receive care/treatment
- The greatest proportion of patients are waiting for operations
- Nearly a third of patients have received an appointment cancellation
- Of those who have had an appointment cancelled, many received very short notice

The YouGov poll clarified that, of the 1,441 respondents, 60% of people waited a year or less for care or treatment, with 8% waiting more than two years. Nearly three-quarters of people waited a year or less in the Healthwatch survey, with 4% waiting over two years.

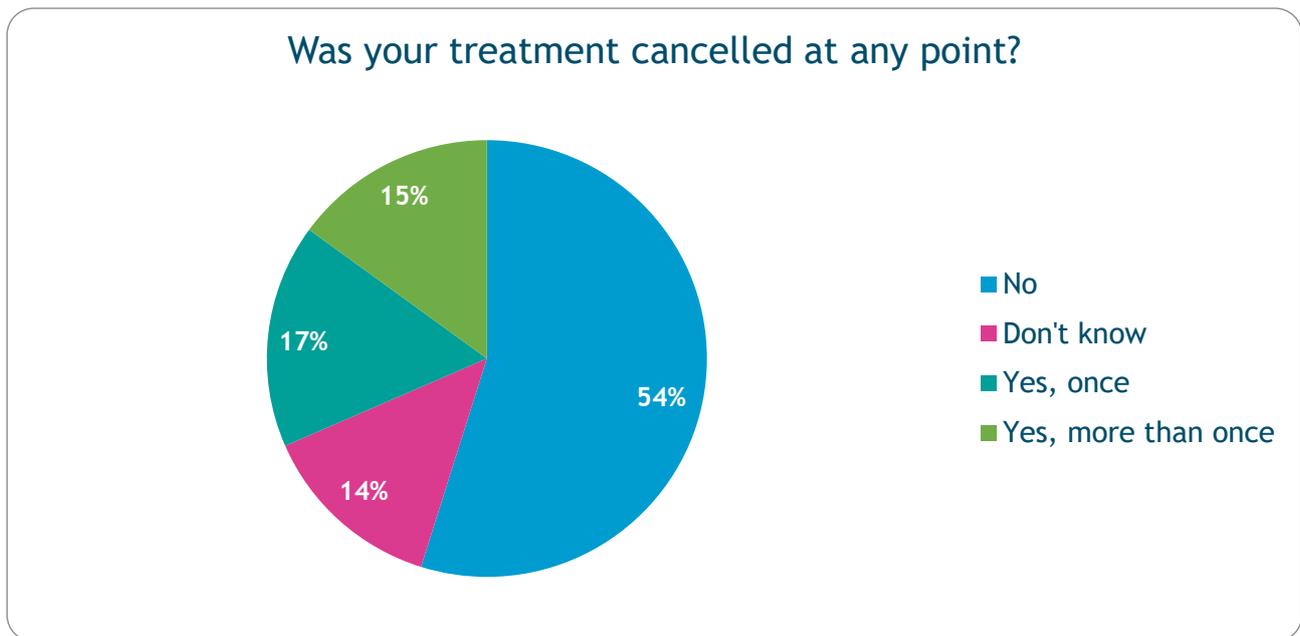


The YouGov Poll also showed the types of treatment people were most commonly waiting to have. Of the 1,421 people who responded on this topic, 41% said they are waiting for an operation (for example, surgery, biopsy or other procedure). Nearly a quarter said they are waiting for a consultation (for example, an outpatients appointment without an intervention or procedure). Finally, 23% said they are waiting for ongoing treatment (for instance, a pre-planned review of a long-term condition.)

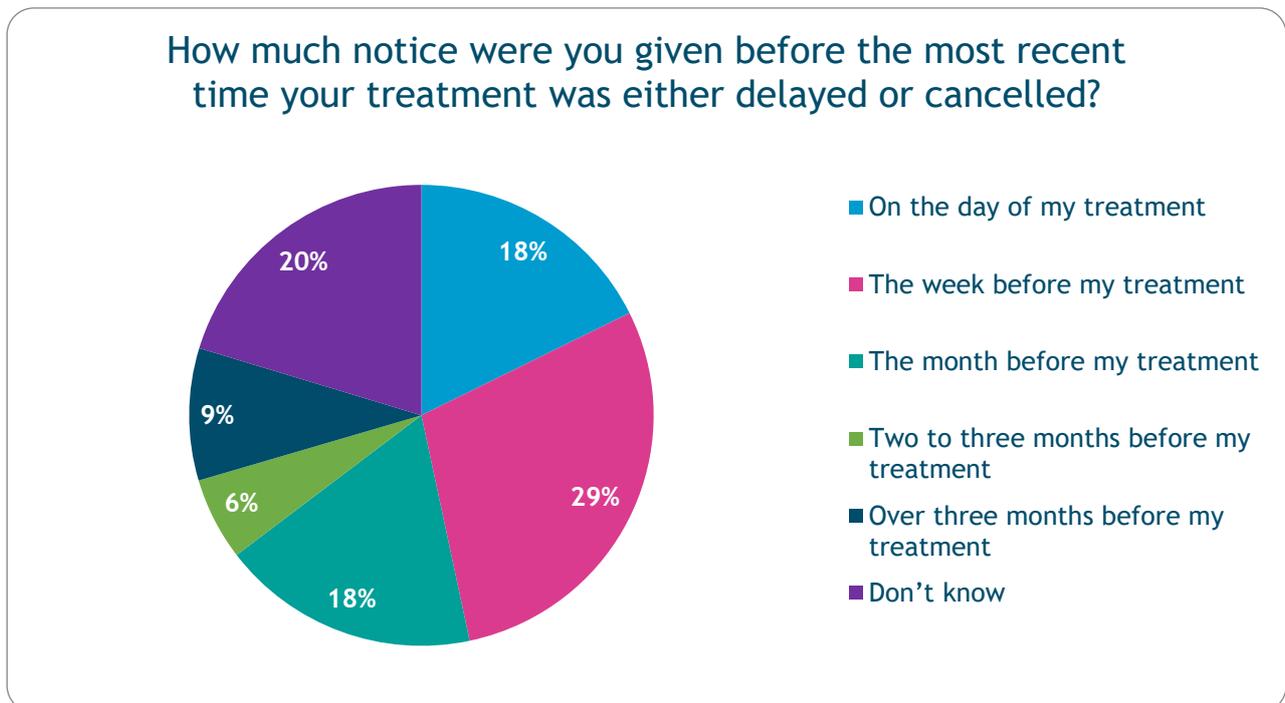


Our national survey corroborated these findings. While these long waiting times, especially for operations, are understandable due to the restrictions and limited resources throughout COVID-19, there have been issues with the frequency and short notice of cancellations.

The Healthwatch survey asked patients whether their care/treatment was cancelled at any point, 1,043 people answered:



People having treatment cancelled were often given very short notice, with only 15% given notice longer than a month before the care/treatment was to take place.



Compounding these issues is a feeling among patients that communication of cancellations is poor. Many individuals reported feeling forgotten.

"The first cancellation in July 2021, I was being wheeled down to surgery when they turned me around and took me back to the ward as no ICU bed available.

They promised to do the surgery on 26 July 2021 and would make sure no one took my bed. I started a week in isolation at home prior to surgery, only to receive a phone call three days before the procedure that it was cancelled and couldn't give me another date. I have heard nothing since about another date."

People reflected this sentiment in the Healthwatch survey, which asked those with last-minute cancellations (on or after the day of admission) whether they were given a new date within 28 days of their original appointment date at the same or a different hospital. Nearly three quarters (72%) of people who answered this question said they did not.

Nearly three-quarters of people reporting this suggests that the elective waiting times policy is not being followed. Patients that are told of last-minute cancellations often face uncertainty over how promptly they would receive their delayed care.

We also asked individuals whether they thought the statement "I have the right to have treatment at another hospital of my choice if my local hospital cannot treat me within 26 weeks" was true or false. 70% answered that they did not know, while only 23% correctly identified the statement as true. This finding indicates that not only are patients facing uncertainty following cancellations, but there is a serious information gap relating to patients' rights to accessing care.

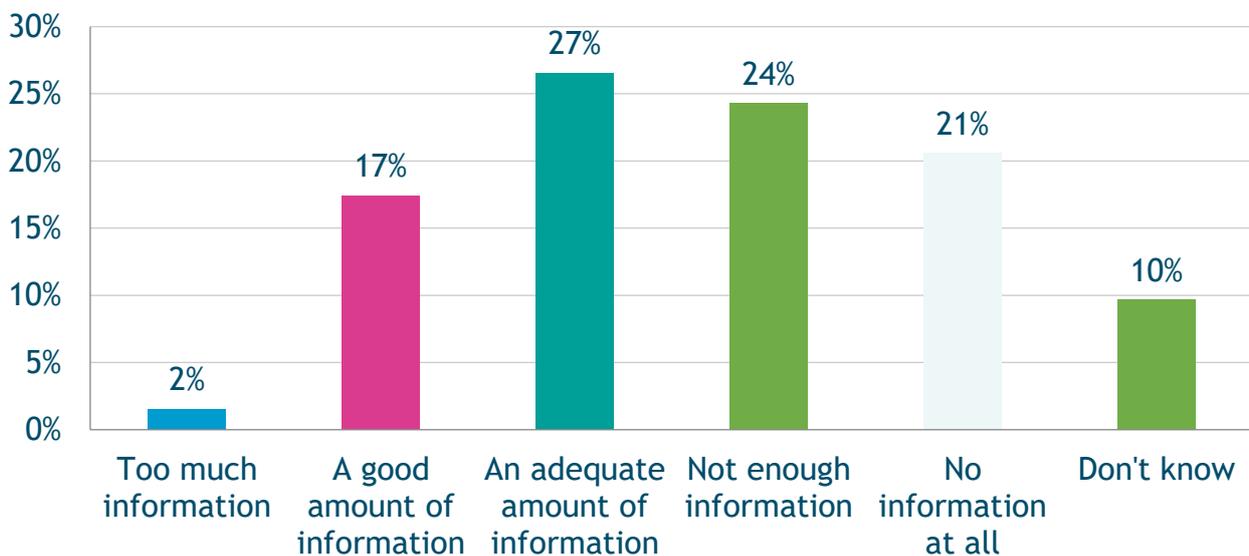
Quality of wait

The uncertainty surrounding appointment cancellations is just one element of the quality of wait. We also wanted to understand the impacts that waiting has on people's quality of life. We ensured that questions about communication, information provision and condition management were the focus of the YouGov poll and Healthwatch survey. We found that:

- The majority of patients report that the amount of supporting information provided during their waiting period was inadequate, especially in helping them manage their condition.
- Of those who received support, they reported the most valuable interventions to be information about conditions and treatment, and pain relief.
- Most patients do not think that communications from the NHS have been accessible and easy to understand.

The YouGov poll found that 45% of people said they received no information or not enough information whilst waiting for their treatment.

Thinking of the information you/they received from the NHS while waiting for treatment, including treatment details, timelines and any delays, how much information have you/they received



These findings were even starker in the Healthwatch survey, where 58% of people said they were given no information at all, and a further 21% said they received not enough information whilst waiting for care/treatment.

Lack of information was especially apparent for supporting people in managing their condition while waiting for care. Over three in five (62%) people said they were given no information on how to manage their condition in the meantime, and a further 17% said they were given some information. Still, it wasn't sufficient to manage their condition in the meantime. Just 6% said they were given adequate supporting information to manage their condition, including a clear point of contact in case their condition deteriorated.

Respondents with more disposable income were more likely to report being given information while waiting for their treatment. Only 3% of less financially secure respondents said they received a good amount of information.

The lack of supporting information for condition management can seriously affect an individual's quality of life.

"From being referred for a total hip replacement on 11 February 2020, I finally had my operation on 31 August 2021. That was a wait of over 18 months, during which time my condition and the excruciating pain accompanying it deteriorated significantly so that I became virtually housebound. At no time was I ever contacted by anyone with updates of any kind but was left to suffer in silence. Primary care was catastrophic, and trying to see a GP was nigh on impossible. It has been such a difficult time because I have no

family in the UK, let alone the Isle of Wight. I felt completely abandoned and alone, and there were times when I lost all hope and seriously felt I'd be better off dead."

Most pointedly, the Healthwatch survey asked, "Have you received support from the NHS whilst waiting for treatment?" Just 15% of people said yes, whereas 82% of people said no.

"I had to access the crisis team as the effect on my mental health due to the severe pain caused me to be suicidal. I am under the crisis team at a different hospital to the one I receive my spinal care from."

Of the number that did receive support, 32% said they found information about their condition useful, and 33% said they found information about the treatment itself useful. Over a quarter (27%) said they found support with pain relief helpful. The YouGov poll reflected this, where information about treatment and condition were the most commonly selected options at 17%, closely followed by support with pain relief at 14%.

"[I've had] two steroid injections in two months - was put on waiting list when consultant saw my x-ray during that procedure. Six months later, I requested a 2nd steroid injection as the pain had become unbearable. I got a month of my choice to allow me to be comfortable enough to enjoy a short break away. Through rest, it remains bearable."

Supporting people with personalised information is crucial to their physical and mental wellbeing. Quality of communication is also pivotal. The Healthwatch survey asked 'To what extent do you agree with the statement "The communications I received from the NHS about my treatment were clear, accessible and easy to understand"':

- 21% said they strongly or somewhat agree with the statement
- 59% said they strongly or somewhat disagree with the statement

Many patients felt let down, either with how often information was provided or via the methods of communication.

"I understand the service is so stretched, and I hate complaining knowing how busy they are. However, I feel that I have been left on my own to manage my condition. My double [vision] is getting worse, and I cannot learn to drive meaning I risk losing my job. The delays are understandable, but I just wish I could have some communication on even a rough estimate on how long it will be until I can be seen. My mental health is impacted as I am embarrassed to go out socially due to my squint."

Impacts on quality of life

Both the length and quality of wait have impacted the quality of people's lives. We wanted to understand how delays had impacted different areas of daily life. The Healthwatch survey found:

- 55% agreed that delays had impacted their ability to work
- 68% agreed that it had impacted their ability to carry out daily household tasks
- 40% agreed that it impacted their ability to care for someone else
- 73% agreed that it had increased the level of pain they had experienced
- 80% agreed that it had impacted their mental health or wellbeing

Disabled people (80%), carers (76%), or those with a long-term condition (76%) were more likely to agree that delays had an impact on the level of pain they had experienced than those who do not fall into those categories (60%).

Similarly, disabled people (69%), carers (63%) or those with a long-term condition (57%) were more likely to agree that delays had an impact on their ability to work than those who do not fall into those categories (46%).

Disabled people (80%) were also more likely to report an impact on their ability to carry out household tasks.

When looking at people's mental health, 90% of respondents under the age of 35 agreed that treatment delays had an impact, with the trend steadily decreasing up the age groups (72% of over-75s reported an impact).

And the least financially secure respondents reported a more significant impact for all outcomes due to delays when compared to those with large disposable incomes:

- Ability to work (89% vs 44%)
- Ability to carry out daily household tasks (80% vs 56%)
- Ability to care for someone else (54% vs 24%)
- Level of pain they had experienced (93% vs 49%)
- Mental health or wellbeing (89% vs 67%)

The highlighted effect on people's physical and mental wellbeing was also reflected in the comments provided to our national survey:

"My health and mobility is decreasing with every month that goes past. Without intervention, I will be wheelchair bound instead of me walking the dog every day. I will soon need help with personal care cleaning etc., because my conditions have not been adequately monitored and treated for 18 months."

"During heavy loss of blood, I have to take time off work. I do not receive sick pay. Financially I am suffering along with my mental health due to worry and lack of support from the NHS."

Health inequalities

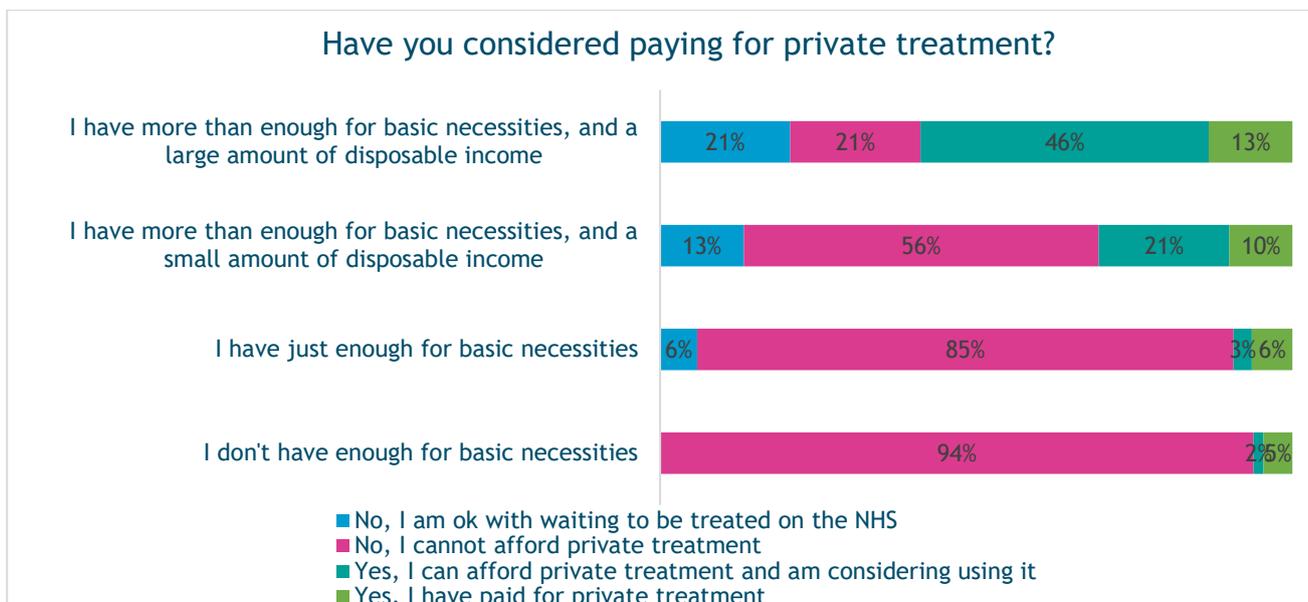
The above quality of wait and quality of life insights highlight several health inequalities in waiting for planned treatment.

While the number of people from minority ethnic communities who responded to our research was small, there is some indication that people from Black, Asian and ethnic minority backgrounds are experiencing similar issues to those on low incomes. Non-white British respondents were less likely to feel supported by the NHS and less likely to feel they were given clear, accessible and easy to understand information.

These indicative findings came through in the YouGov poll and Healthwatch survey and now require further research to understand the impacts of and solutions to waiting for care.

Our data also highlights inequalities in terms of people's access to private treatment. The Healthwatch survey found that 8% of people had paid for private treatment, whilst 14% said they are currently considering it and could afford it. Nearly two thirds (65%) said that they would not go private as they could not to, and only 10% said they were not considering going private and were ok with waiting to be treated on the NHS.

The more financially secure the respondent, the more likely they were to say they can afford treatment and are considering it; however, those who are most well off appear to potentially be ok with waiting to be treated on the NHS.



Some also described borrowing money and using up savings to get care/treatment.

" I was advised if I did not have cardiac ablation as soon as possible, my paroxysmal atrial fibrillation could become chronic. So I took out a loan for £10k plus £7k savings to pay for the ablation."

This is also true of how people have dealt with the quality of life impacts, such as mental wellbeing.

" I have actually found hospital treatment has been brilliant throughout the pandemic - I am not an emergency case, and the hospital (Colchester, Essex) kept me updated and informed. However, for mental health issues, I pay privately - I wouldn't even consider trying the NHS. It takes years."

One way to address this inequality moving forward is to create more spatially diverse access points for patients who urgently need treatment. We asked people if they would be willing to travel to receive treatment to reduce their waiting time. The YouGov poll highlighted that 29% of people would under and circumstances, while many others said they would if they had various provisions. Only 14% said no, and 14% did not know.

The Healthwatch survey also reflected this:

- 29% of people said they are happy to receive treatment at any hospital in England
- 45% said they are happy to receive treatment at a local hospital
- 13% said they would travel to another hospital if the NHS provided help with travel
- 6% said yes if the NHS helped them and friends/family with other support, such as accommodation

- 2% said yes if they got help to look after the person/children they are caring for
- 4% said yes if their family were able to visit them
- 10% said no
- 6% said don't know

These findings show an overwhelming willingness to travel if it means that waiting times reduced, though there were differences in response depending on age. 41% of respondents under the age of 35 would be happy to receive treatment at any hospital in England, compared with just 17% of over-75s.

Financial stability also had a bearing on responses, with the least financially secure twice as likely to require travel support for themselves or their family (35%) compared to those with large disposable incomes (17%).

Recommendations

| Communication recommendations | | |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------|
| Recommendation | Why | Who |
| <p>Implement the good patient communications guidance to provide people with regular information and advice about their treatment. This information should include how to access support services, how to manage their pain and how to access benefits such as Statutory Sick Pay (SSP).</p> <p>Where appropriate, this might include signposting to social care and welfare teams or link workers in primary care.</p> <p>Communications should be clear, accessible, easy to understand and personalised to each individual's condition and preferences.</p> | <p>Good communication would reduce health inequalities and the potential for health anxieties. It would also help prevent people from feeling forgotten while supporting them to ensure they are not waiting in pain or struggling to pay household bills.</p> | <p>NHS England (NHSE), NHS trusts, local authorities and Primary Care Networks (PCNs).</p> |
| <p>Put systems in place to allow regular updates to patients on their position on the waiting list. Where the NHS cannot give treatment dates with certainty, services should provide</p> | <p>To reassure patients by providing information on other people's experiences and</p> | <p>NHSE and NHS trusts.</p> |

| | | |
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| <p>other updates to patients and their carers to provide context. Updates could include national and local data such as waiting times for other patients with relevant conditions or interventions, or information on when they should next expect to hear about their treatment date.</p> <p>Updates could take the form of a monthly statement from the NHS to help avoid patients feeling lost and forgotten.</p> | <p>potentially reduce no-shows or 'did not attends' (DNAs) through improved expectations management.</p> | |
| <p>Use all possible communication channels to allow patients to regularly feedback on their condition and how they are feeling while waiting. This could be over the phone, via newly procured digital solutions, or through adaptations to the current NHS App, whereby patients could submit symptoms or changes in their condition on a daily basis.</p> <p>Doing this would also provide patients with an easy process to provide updates when they no longer need care and wish to cancel an appointment. Communication channels in these instances must then follow up to understand why patients are cancelling and provide appropriate support where necessary.</p> | <p>Doing this would improve remote monitoring systems and potentially reduce the need for as many follow-up appointments for patients.</p> <p>It could also minimise DNAs, allow patients an easier route to cancel, and provide opportunities for trusts to provide the support some patients need to attend an appointment they otherwise couldn't make (e.g. transport costs).</p> | <p>NHSE, NHS trusts and PCNs.</p> |
| <p>Acknowledge that we don't just need more doctors and nurses to tackle the backlog, but more well trained and compassionate admin staff to manage waiting lists better.</p> <p>These teams should be supported to implement and manage the above patient communication recommendations. This includes serving as a single point of contact for patients to access information on their</p> | <p>Doing this would provide hospital trusts and/or PCNs with an administrative hub for patient communications, relieve pressure on GP services, and help in managing waiting lists and communicating with those waiting for planned care.</p> | <p>Government, Department of Health and Social Care (DHSC), NHSE, NHS trusts and PCNs.</p> |

planned care proactively, so that they don't need to contact general practices for updates.

There should be greater investment in the recruitment and retention of administrative staff to manage these new support services.

It would also help reduce variation across the country in the number and utilisation of administrative staff.

Support recommendations

| Recommendation | Why | Who |
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| <p>Support patients while they wait by making physiotherapy, pain management and mental health services more widely available.</p> <p>This could be done by investing funds allocated to tackling the backlog into these services that support people while they wait.</p> <p>To ensure support is as accessible as possible, particularly while COVID-19 remains a threat, services should explore ways of delivering help both as physical services and remotely. Consideration should also be given to how the NHS and social care services could provide more care via home visits.</p> | <p>Our insights highlight the impact waiting has on people's ability to carry out household tasks, the level of pain they're experiencing and their mental health. Greater access to support would allow people to wait in more comfort for their planned care and help ensure they are in the best possible shape to receive treatment when the time comes.</p> | <p>NHSE, NHS trusts, local authorities, Integrated Care Systems (ICSS) and PCNs.</p> |
| <p>Commission voluntary sector organisations and local Healthwatch who can support signposting and access to local support services.</p> | <p>As well as helping local people access the interim care they need, these organisations can also bring insights into where there are gaps in support.</p> | <p>NHSE and local authorities.</p> |
| <p>Provide financial and organisational support with travel and accommodation for patients asked to travel to a regional surgical hub for diagnostics or treatment. This support should</p> | <p>Our insights highlight that some people would require additional support to travel for care. Implementing this recommendation would</p> | <p>Government, DHSC, NHSE and ICSS.</p> |

include support for carers, chaperones or other loved ones where appropriate.

prevent health inequalities, in particular for people living on low incomes.

Medium-term recommendations

| Recommendation | Why | Who |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------|
| Consider widening Statutory Sick Pay (SSP) eligibility thresholds. | To support the increasing number of people struggling to work due to growing waiting lists and longer treatment delays. | Government, local authorities and Department of Work and Pensions. |
| <p>Continue to provide additional dedicated funding to support hospital discharge to assess arrangements.</p> <p>Previous Healthwatch work has shown how important this funding has been to facilitating good patient flow and getting people home from hospital quickly and safely.</p> | To support consistent implementation of current guidance and increase the likelihood of hospitals freeing up bed space where appropriate. | Government, DHSC and the Treasury |
| <p>Restart the clinically led review of access standards. As part of this review, consider:</p> <ol style="list-style-type: none"> How to limit the anxiety of waiting in silence for patients. This could involve splitting the 18-week referral-to-treatment (RTT) pathway into separate measures for diagnosis and treatment. How to improve data and demand management processes that prioritise the sickest patients on elective waiting lists while not exacerbating health inequalities faced by those facing long waits. How to prevent long waits occurring, for example, via the introduction of a more publicly understood backstop to ensure | To develop longer-term solutions for managing the elective care backlog, considering factors across all health and social care. | NHSE |

there is a limit to the length of time
someone can wait for elective care.
