

Hospital Waiting Times

Patient's experiences of hospital waiting times from GP referrals to treatment. June 2024



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About us

Healthwatch County Durham is an independent organisation whose aim is to help people get the best out of their local health and social care services, whether it's improving them today or helping to shape them for tomorrow. Everything we say and do is informed by our connections to local people and our expertise is grounded in their experience. As a statutory watchdog, our role is to ensure that local decision-makers put the experiences of people at the heart of their care, and make sure those who buy (commissioners) and provide our services (NHS Trusts, local authorities, GPs, the voluntary sector, and independent providers) listen to what people tell us. The Healthwatch network currently consists of 153 Healthwatch organisations across each of the local authority areas in England. It also has a national body called Healthwatch England based in London. For more information about us please click on this link: <u>Healthwatch County Durham</u> or scan the QR Code:





Introduction

Hospital waiting lists affect thousands of people every year. In 2015 the NHS Constitution stated people should wait no longer than 18 weeks from referral to treatment*. Nationally, it is estimated that 7.5 million people are waiting for planned hospital care, with County Durham and Darlington Foundation Trust (CDDFT) reporting at the end of March 2023 there are 37,209 people currently on a waiting list for their care**.

We wanted to better understand people's experiences of hospital wait times for referrals for routine procedures and surgeries. And to find out how these delays were affecting them.



Method

We designed a survey and shared this with partner organisations such as Advice in County Durham, the Waiting Well team and the Patient Experience team at County Durham and Darlington Foundation Trust who distributed this for us. We also attended community and engagement events where we heard general comments about experiences of waiting times from attendees, promoted the survey by taking paper copies, and heard general comments about experiences of waiting times from attendees.

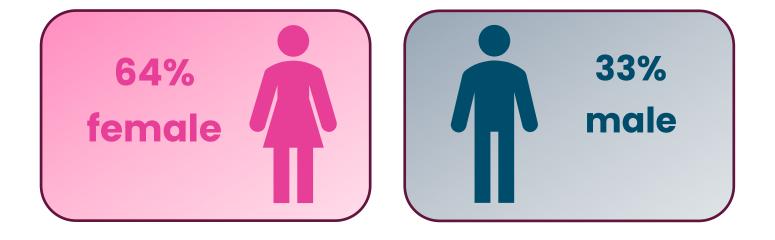
The survey went live from January 2023 until January 2024 and was promoted on our website, social media and our monthly e-bulletin via a link to Survey Monkey as well as being shared with partner organisations.

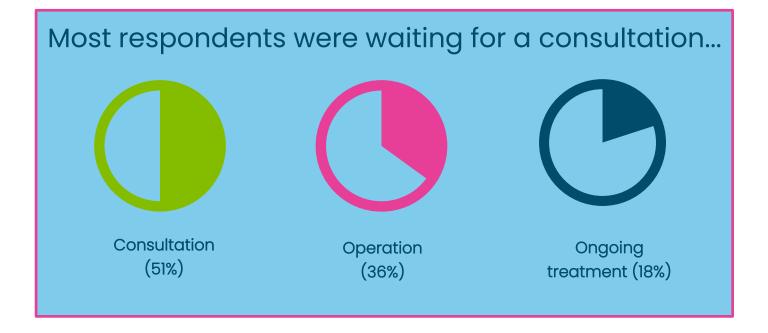
*NHS constitution - <u>NHS England » Referral to treatment</u>

** Data -Statistics » Referral to Treatment (RTT) Waiting Times (england.nhs.uk)

Who we spoke to...

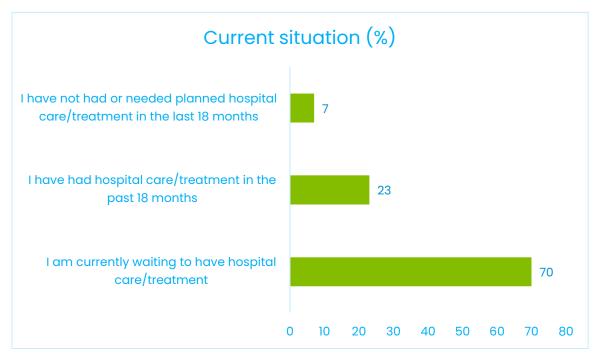




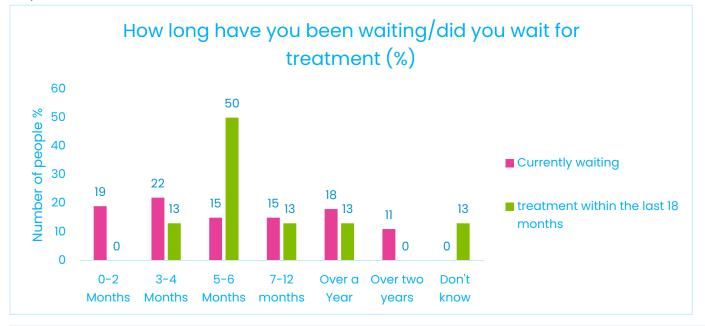


Findings

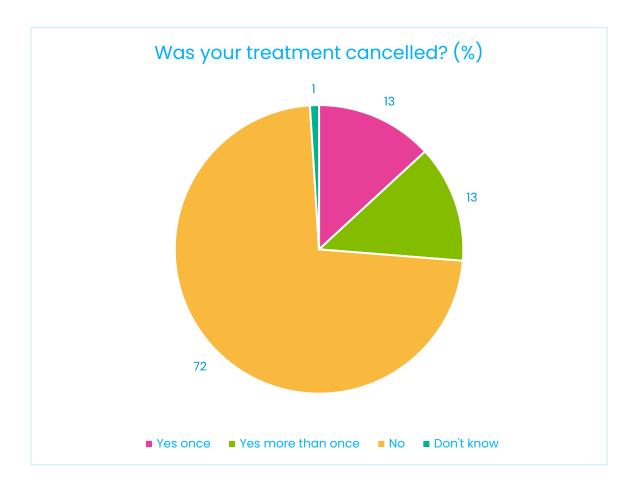
The majority of the people we spoke to were currently waiting for treatment or care (70%) followed by those people who had received care or treatment within the last 18 months (23%).



We compared waiting times by those people who had recently received care (within the last 18 months) and those who are still waiting. We can see if you have received your care within the last 18 months, waiting times were on average 5-6 months, and no one received their care within 2 months of referral. However, for those still waiting for treatment, 11% have been waiting over 2 years to date. Most people we heard from had been waiting around 3-4 months. We don't have any information about their expected treatment date.



Three-quarters of our respondents have not had their care cancelled. Of the seven people who gave more detail about their cancelled appointment, only one individual told us their care was cancelled on the day of treatment, just under half of the people we heard from were given at least 3 months' notice.



"I feel like you are waiting/ delaying me so I die and you don't have to help me"

We asked people to share their experiences of communication whilst they were waiting for their care and treatment. Unfortunately, people felt there was very little communication regarding regular updates or information about when they were likely to be seen. The few people that did receive a form of communication, found that it wasn't clear, accessible or easy to understand. Most (80%) received no support at all while waiting. For those that experienced a further delay to their care or treatment, the majority (68%) were not given any information to help them manage their condition whilst they were waiting, 16% were given some information but they found it to be inadequate.

74% of people didn't know 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."

"I was not given any information on when I was likely to be treated."

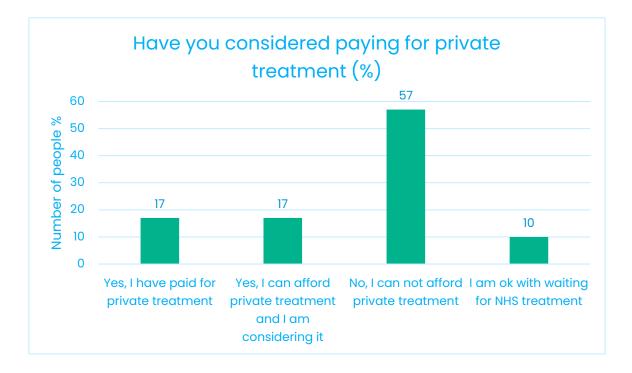


58% of people disagreed with the statement

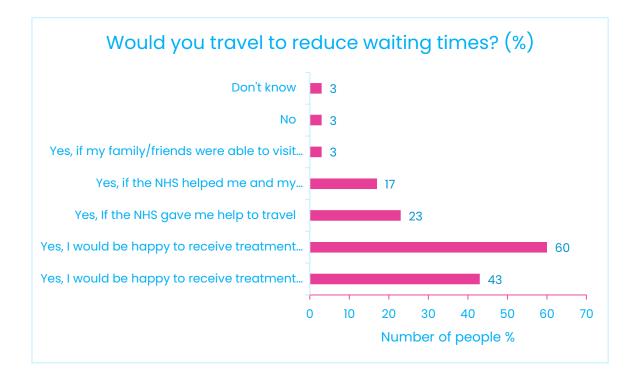
"The communications I received from the NHS about my treatment were clear, accessible and easy to understand."

Of which 39% strongly disagreed with this statement

Where people are experiencing long waiting times for their treatment we asked if they would consider paying to use a private service if it meant a reduced wait – Most people (57%) told us they couldn't afford to pay for private care. However, 33% had either paid for private care recently or were considering it in order to get the care they needed sooner.



"(I was) Informed there is a 44-week waiting list so have had a private consultation."



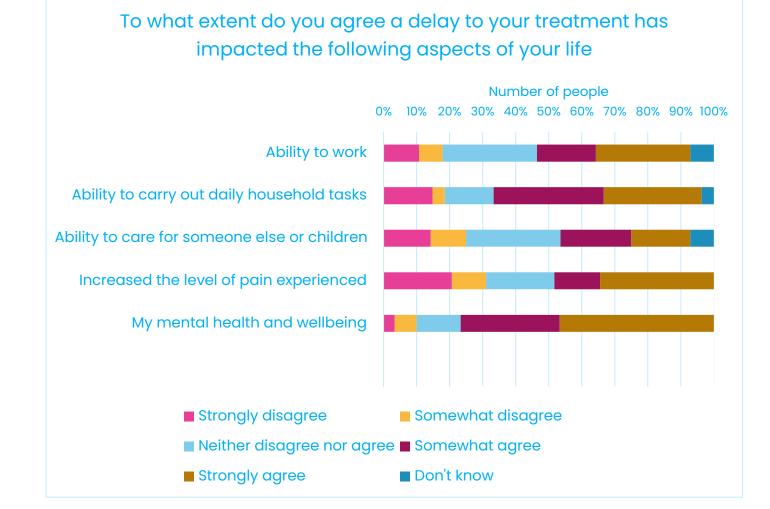
77% of people's mental health and wellbeing has been impacted because of their wait for Care. We asked people if they would consider travelling further afield to get the treatment and care they required sooner. From the responses we had, most people would consider travelling an option; 60% told us they would be willing to travel to any local hospital and 43% would travel to any hospital in England to reduce the waiting time of their care.

"The results of (the) biopsy took months, and treatment was due to begin a week after my mother-in-law (had) passed away"

We wanted to know if the delay in treatment had impacted their life. We asked people to rate how much they agreed a delay in their treatment affects the following aspects of their life

- Ability to work
- Ability to carry out daily household tasks
- Ability to care for someone else or care for children
- Increased the level of pain experienced
- Their mental health and wellbeing

We discovered the delay in people's care had affected every aspect of their life we asked about. The largest impact we saw was on people's mental health and wellbeing where 77% agreed that due to the delay in their care, their mental health and wellbeing had been affected, with 47% strongly agreeing with this statement compared to 3% who strongly disagreed. We heard the next aspect of life to be struck by the delays was people's ability to carry out their daily household tasks - 63% told us they had been affected in this way compared to 15% who strongly disagreed this had been impacted. An increase in pain (48%) and an ability to work (46%) were the next areas to be affected by the delay in care and 39% felt the delay had influenced their ability to care for someone else or children. These figures stress the impact on people's abilities to wait well for care during this period.



 Note
 Note

 Not
 Not

 Not

waiting for treatment

Conclusion

We heard from people across County Durham about their experiences of being on a hospital waitlist waiting for care. We found that the wait times are varied and can be extensive for some people.

There is a lack of communication about the length of time a person might wait. Only a quarter of the people we spoke to knew they had a right to choose an alternative hospital if their local hospital couldn't treat them within 26 weeks, highlighting the lack of choice and information being offered to patients. There is also a lack of information regarding their position in the queue, and how long they should expect to be waiting. This lack of knowledge increases stress and anxiety and decreases a person's overall well-being. We heard there is also a lack of support and information about maintaining their condition while they wait or what to do if there are any changes or a decline in their condition.

Most people we spoke to were not in a financial position to pay for treatment from a private provider. However, for those that can, some have, and some are considering paying privately to reduce the waiting time, exposing the inequalities in access to healthcare for those with less financial income.

The concern people face whilst waiting for care was emphasised by the number of people who stated they would be willing to travel in order to receive their care sooner, even considering travelling across England to reduce the wait.

We heard people have been impacted across all areas of their lives whilst waiting for their care, particularly their mental health and well-being which have been greatly affected. This is a real concern as not only could this be hindering the individual's quality of life currently but also go on to impact their recovery after the care they are waiting for.

Recommendations and/or next steps

Introduce a good communication standard for people on a waitlist.

To include:

- Information about the care or treatment they are waiting for and how to manage their pain or discomfort whilst waiting.
- Ensure individuals know where to go for additional support, such as pain management and mental health.
- Ensure people are given regular updates about their expected wait time, or if not possible, provide an update about the national guidelines and ensure they don't feel they have been forgotten.
- Open communication channels and a clear pathway so individuals know who to contact about their care and who to update about their condition if their health is declining or they need to cancel or change appointments. This channel needs to be accessible and clearly communicated to the individual.
- Regular check-ins could be provided to manage any changes to their condition and wellbeing.
- Communication needs to be clear, honest, accurate and in line with the Accessible Information Standard.

Managing expectations is vital, this would help to reduce people experiencing health anxieties.

Ensure people have the option to choose an alternative hospital if they are able to travel in order to reduce their wait times. These options need to be clear and any implications outlined to the individual.

Incorporate holistic support to include social, financial, housing and other areas not directly linked to the physical health issue requiring care but impacting all aspects of the individual's life.

Utilise partnership working across the county to include health, social care and community, voluntary and social enterprise sectors to improve the overall wellbeing of individuals whilst they are waiting for their care and treatment.

Identify those patients who may benefit from a prehabilitation or waiting well programme; this could help reduce the distress whilst waiting but also improve the recovery after treatment.

Responses

From County Durham and Darlington NHS Foundation Trust (CDDFT)

County Durham and Darlington NHS Foundation Trust (CDDFT) would like to thank Healthwatch County Durham for carrying out this survey. The Patient Experience Team have reviewed this report prior to it being finalised and will look to improve the process if possible. There has been ongoing work for some time now to reduce the backlog the covid pandemic caused to NHS waiting lists and acknowledge and empathise how this has affected our patients. This backlog is a national problem, and we are proud that CDDFT are amongst some of the high performing Trust's in the country which have reduced wait times significantly, however, are aware there are further improvements needed and some people have waited a significant amount of time.

We acknowledge that communication has been highlighted throughout the report as a factor and has certainly impacted our patient's experience. The Patient Experience Team here at County Durham and Darlington NHS Foundation Trust will work together with our waiting list teams to see how we can improve further. The introduction of our Patient Experience Portal may offer a solution to improving how we communicate with our patients when delays or changes are made.

An update will be offered to Healthwatch County Durham on our findings within 3 months.

Acknowledgements

Many thanks to everyone who took part in this research, including:

• The patients, families, and carers who took the time to tell us about their experiences.

• The Patient Experience Team at County Durham and Darlington Foundation Trust

- Advice in County Durham.
- Waiting Well Team.

Appendix

Survey questions

Are you waiting for NHS treatment or care? Share your story with us

Are you one of the seven million people waiting for hospital treatment or care? We want to know your experience waiting for the care you need, and what advice, information, or support the NHS has given you while you wait.

We want to know:

- Whether you have experienced delays to your hospital treatment
- Whether you have been given a choice about your treatment
- What you think about the communication you have received during delays to your treatment.

Please tell us about your most recent experience. Or, if you have been waiting for multiple treatments, or received one and you're waiting for another to take place, you can complete the survey more than once.

Everything you tell us is confidential and will help the NHS understand how it can better support people like you waiting for treatment. So, whether your experience is good or bad – we want to hear it.

Your experiences of delays

Q1. Please select the following statement that applies to you:

- □ I am currently waiting to have hospital care/treatment [Skip to Q2]
- □ I have had hospital care/treatment in the last 18 months [Skip to Q3]
- □ I have not had or needed planned hospital care/treatment in the last 18 months

Q2. If you are currently waiting for hospital care/treatment, how long have you been waiting?

- □ 0-2 months
- □ 3-4 months
- □ 5-6 months

- □ 7-12 months
- Over a year
- Over two years
- Don't know
 - [Go to Q4]

Q3. If you have received hospital care/treatment in the last 18 months, how long did you have to wait for treatment?

- □ 0-2 months
- □ 3-4 months
- □ 5-6 months
- □ 7-12 months
- Over a year
- Over two years
- Don't know

Q4. What type of treatment are you waiting to receive?

- Operation (for example, surgery, biopsy or other procedure)
- Consultation (for example, an outpatients appointment without an intervention or procedure)
- Ongoing treatment (for example a pre-planned review of a long-term condition)
- Rehabilitation
- Don't know
- □ Other [please specify]

Q6. Was your treatment cancelled at any point?

- □ No [Skip to Q9]
- □ Don't know [Skip to Q9]
- □ Yes, once
- □ Yes, more than once (please specify)

Q7. How much notice were you given before the most recent time your treatment was either delayed or cancelled?

- On the day of my treatment
- □ The week before my treatment [Skip to Q9]
- □ The month before my treatment [Skip to Q9]
- Two to three months before my treatment [Skip to Q9]
- Over three months before my treatment [Skip to Q9]
- Don't know [Skip to Q9]

Q8. If your treatment was cancelled at the last minute (on or after the day of admission) were you given a new date, at the same or a different hospital, within 28 days of the original date?

- Yes
- 🗆 No
- Don't know

Q9. "I have the right to have treatment at another hospital of my choice if my local hospital cannot treat me within 26 weeks." Is this statement:

- True
- False
- Don't know

Your experiences of communications during the delays

Q10. Were you kept informed by the NHS while you were waiting for treatment, including treatment details, timelines and any delays?

- I was given too much information whilst I was waiting for my treatment
- □ I was given a good amount of information whilst I was waiting for my treatment
- □ I was given an adequate amount of information whilst I was waiting for my treatment
- □ I was not given enough information whilst I was waiting for my treatment
- □ I was given no information whilst I was waiting for my treatment
- Don't know

Qll. 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."

- Strongly agree
- Agree
- Somewhat agree
- Neither agree nor disagree
- Somewhat disagree
- Disagree
- Strongly disagree
- Don't know

Q12. Have you received support from the NHS whilst waiting for treatment?

- Yes
- □ No [Skip to Q14]
- Don't know [Skip to Q14]

Q13. What support have you received from the NHS, which you found helpful during your waiting time? [Select multiple]

- Information about my condition
- Information about my treatment
- Information about delays
- □ Support with pain relief
- Mental health support
- Access to physiotherapy
- Access to groups who provide social and emotional support
- Additional help from social care services with day to day tasks
- □ Support to help me get ready for surgery
- Don't know
- □ I didn't find any of the support offered helpful
- □ Other [please specify]

Q14. If your treatment was subject to delay were you given supporting information on how to manage your condition whilst waiting for care?

- I was given adequate supporting information to manage my condition including a clear point of contact in case my condition deteriorated
- I was given adequate supporting information to manage my condition but no clear point of contact in case my condition deteriorated
- I was given some information, but it wasn't sufficient to manage my condition in the meantime
- □ I wasn't given any information to manage my condition in the meantime
- My treatment was not subject to delay The impacts on your quality of life

Q15. Have you considered paying for private treatment, in order to receive treatment sooner?

- Yes, I have paid for private treatment
- Yes, I can afford private treatment and am considering using it
- No, I cannot afford private treatment
- □ No, I am ok with waiting to be treated on the NHS
- Don't know

Q16. Would you be willing to travel to receive treatment at another hospital to reduce your waiting time? [select multiple]

- Ses, I would be happy to receive treatment at any hospital in England
- Ses, I would be happy to receive treatment at any local hospital
- □ Yes, if the NHS gave me help to travel
- Yes, if the NHS helped me and my friends/family with other support, such as accommodation
- □ Yes, if I got help to look after the person/children I am caring for
- Yes, if my family were able to visit me
- 🗆 No
- Don't know

Q17. To what extent do you agree a delay to your treatment has impacted the following aspects of your life?

	Strongly disagree	somewh at disagree	neither disagree nor agree	somewh at agree	strongly agree	don't know/pr efer not to say
Ability to work						
Ability to carry out daily household tasks						
Ability to care for someone else or children						
Increased the level of pain experienced						
My mental health and wellbeing						

Q18. If there is anything else you'd like to tell us about your experience of waiting for hospital treatment, please use this box:

healthwatch County Durham

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