



















Long Waiting Times Survey Report September—October 2021

healthwatch Knowsley

Contents

Healthwatch Knowsley	3
Overview	4
Survey Responses	5
Demographics	13
Appendix 1—Survey	17
Control Sheet	19
Contact Us	19

Healthwatch Knowsley

What is Healthwatch?

We are the independent champion for people who use health and social care services in Knowsley. We're here to find out what matters to people and help make sure your views shape the support you need, by sharing these views with those who have the power to make change happen.

Our Values

- Inclusive working with all communities across Knowsley
- **Influential** we are responsive, setting the agenda and making change happen
- Independent we act on behalf of consumers, listening carefully then speaking loudly on their behalf
- Credible we value knowledge, seeking information and challenging assumptions with facts
- **Collaborative** we work in partnership with health and social care organisations to keep the debate positive and we get things done

People are at the heart of everything we do. We play an important role bringing communities and services together. Everything we do is shaped by what people tell us. Our staff and volunteers identify what matters most to people by:

- Visiting services to see how they work
- Undertaking surveys and focus groups
- Going out in the community and working with partner organisations
- Receiving patients views through our online Feedback Centre.

Our vision is simple

Healthwatch Knowsley will be an effective and clear voice for the community of Knowsley in relation to health and social care service provision and commissioning.

Our goals



Supporting you to have your say

We want more people to get the information they need to take control of their health and care, make informed decisions and shape the services that support them.



Providing a high quality service

We want everyone who shares experiences or seeks advice from us to receive a high quality service and understand the difference their views make.



Ensuring your views help improve health & care

We want more services to use your views to shape the health and care support you need today and in the future.

Overview

The COVID-19 pandemic has resulted in many people having their operations, treatment and appointments delayed. Over 5 million people are currently waiting for NHS hospital treatment in England, in response to this Healthwatch England wanted to understand how this has been affecting people and what can be done to better support people while they wait.

A key priority for Healthwatch Knowsley is Hospital Care and Discharge, due to continued and understandable restrictions due to COVID-19, Healthwatch has been unable to complete any outreach activities during within the local trusts, this has meant capturing experiences of hospital care has been a challenge.

From September 2021, Healthwatch England undertook a national campaign to look at people's experiences of long waiting times during the pandemic. As part of the campaign a toolkit was provided to all local Healthwatch's to support this activity on a local level, this included the production of a template survey.



Following on from this Healthwatch Knowsley used the template to produce

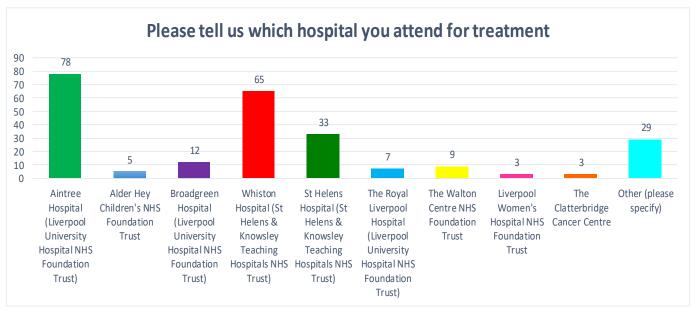
a Knowsley version of the survey was shared with community members, groups and organisations via the Healthwatch Knowsley e-bulletin, website and social media. The survey was also circulated at the Knowsley Older People's Voice (KOPV) roadshow events and has been circulated to GP surgeries, Knowsley CCG, Public Health, Liverpool University Hospitals Trust and St Helens & Knowsley NHS Trust.

In total, the survey received 244 responses, all the information from these responses has been captured within this report. The information captured has helped to provide feedback regarding accessing hospital care and treatment and a view of people's experiences during the pandemic.

This report will be shared with the relevant Hospital Trusts and if necessary or requested will be shared with:

- NHS Knowsley CCG
- Knowsley Health and Wellbeing Board
- Knowsley Metropolitan Borough Council
- Care Quality Commission
- Local Community via our Website
- NHS England
- Service Providers
- Healthwatch England

From the comments received, the graph below highlights the different individual hospitals mentioned, as well as the number of responses received in relation to each hospital. The most commented Trust is St Helens & Knowsley NHS Trust, with the combined responses of Whiston (65) and St Helens Hospital (33) at 98 responses. This is followed closely by Liverpool University Hospital NHS Trust, with a combined total of 97 responses for Aintree Hospital (78), Broadgreen Hospital (12) and the Royal Liverpool Hospital (7). Other hospitals mentioned include Alder Hey, The Walton Centre, Liverpool Women's Hospital and Clatterbridge Cancer Centre. With regard to the other services specified, this includes GP's, Dentists, Ophthalmology and Hospitals out of the area.

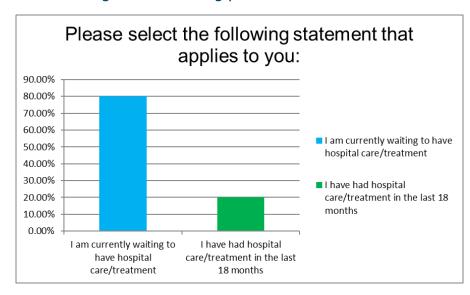


The survey also asks for further clarity on the hospital department for which the patient is waiting to receive treatment or care from. From the responses received the most mentioned department is Ophthalmology, with 16 people waiting for treatment and care in this area. Other departments highlighted included, Cancer Services, Surgical Care, Gynecology, Physiotherapy, Orthopedics, Ear Nose & Throat Services and Gastroenterology. This helped to provide an overview of the type of care patients are having to wait for long periods of time to receive.

People were then asked which statement relates to them:

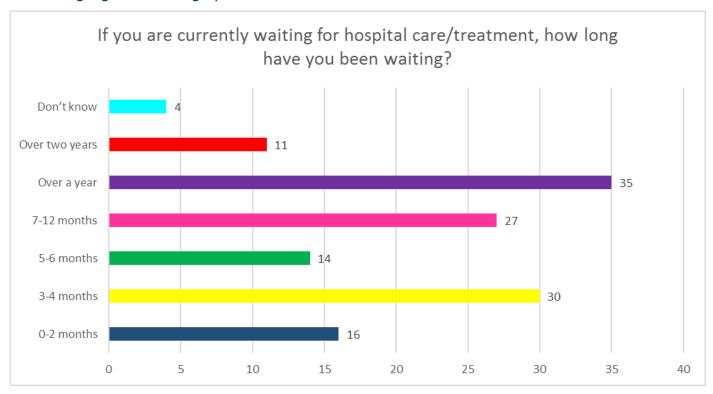
- I am currently waiting to have hospital care/ treatment
- I have had hospital care/ treatment in the last 18 months

From the responses received 80% of respondents were still waiting for care and only 20% stated they had received care or treatment over the last 18 months, as highlighted in the graph.

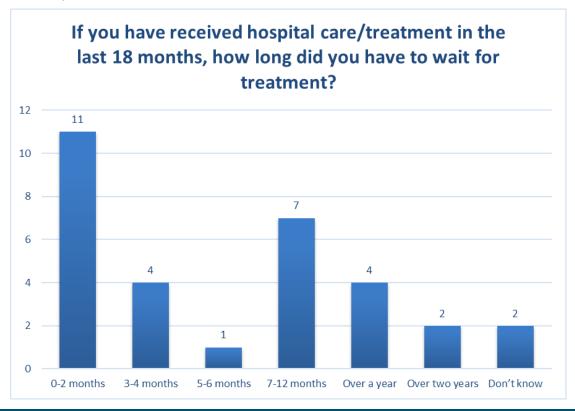


Waiting Times

In relation to the amount of time people had been waiting for treatment, the responses received highlighted that 35 respondents had been waiting over a year to receive any care or treatment. This is highlighted in the graph below.

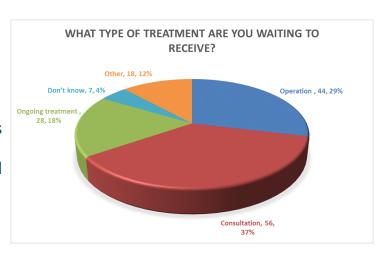


From the 20% of people who stated that they had received care or treatment over the last 18 months, 11 respondents had received care within 0-2 months.



Treatment and Care

The survey also asked what type of care or treatment the patient has been waiting to receive, options included; operations; consultations; ongoing treatment; rehabilitation and other. From the responses received, consultations received the highest number of responses (56), this was followed by operations (44) and ongoing treatment (28). In relation to other respondents included, dental extraction, blood pressure monitor, ultrasound scans and physiotherapy.



What condition/problem did you need treatment for?

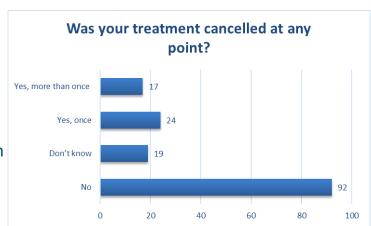
When asked about their condition/problem, respondents provided a variety of conditions they have been waiting to receive treatment or care for. From the comments received the most mentioned conditions included:

- Back related pain
- Hernia
- Issues relating to the heart
- Cataracts
- Skin cancer
- Hip and knee issues
- Cysts
- Foot pain
- Prostate issues

Other conditions related to gynecology; gastroenterology; dentistry; long term COVID and gender identity.

Cancellations

When asked if their treatment had been cancelled at any point, 92 people stated that their treatment had not been cancelled. Although 41 people still noted that their treatment had been cancelled, as highlighted in the graph. When there had been more than one cancellation, people stated this had been due to COVID.



The survey then asked how much notice they

were given before the most recent time their treatment was either delayed or cancelled, from those who responded a majority of people had been given notice of the delay/cancellation either on the day or the week before their treatment.

When asked when their treatment had been cancelled how much notice they had received, most

people said that they had been informed on the day of their treatment. Following on from this the survey asked if they had received a new date at the same or different hospital within 28 days, in this case 76% of respondents stated they hadn't received a new date for their treatment.

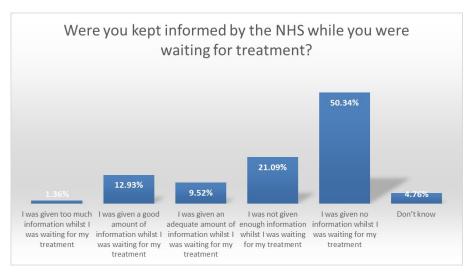
When asked if they knew that they have the right to have treatment at another hospital of their choice if their local hospital cannot treat them within 26 weeks, over 79% stated that they were not aware that they had the right to receive treatment at another hospital.

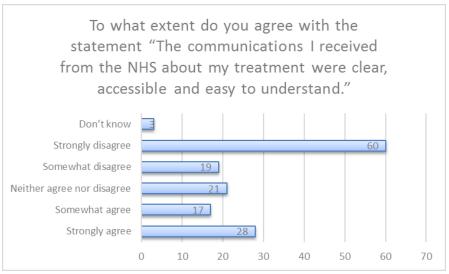
Communication

This area of the survey specifically asks about what information and communication they had received from the NHS in relation to waiting for their care or treatment. From the responses received over 50% mentioned that they had received no information while waiting for treatment, as highlighted in the graph.

When asked whether they agreed with the following statement: "The communications I received from the NHS about my treatment were clear, accessible and easy to understand", most people strongly disagreed with this statement (60 responses). This is highlighted in the graph on the right.

The survey also asked if they had received any support from the NHS whilst waiting for treatment, 83% of people stated that they



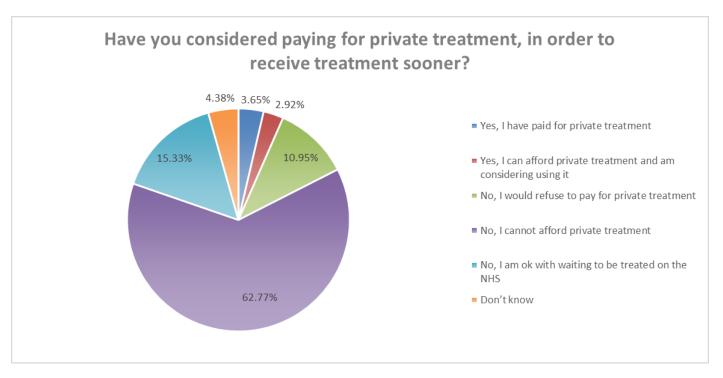


hadn't received any support during that time. For those who had received support, the information they had found most useful, had been; information about their condition; information about their treatment; access to physiotherapy; information about delays; mental health support and pain relief.

Most respondents (68%) highlighted that while they were waiting for treatment they had received no information about how to manage their condition. Although some people did acknowledge they had received adequate supporting information and a clear point of contact, whereas others had received information with no contact information and some people felt they hadn't received enough information about their condition.

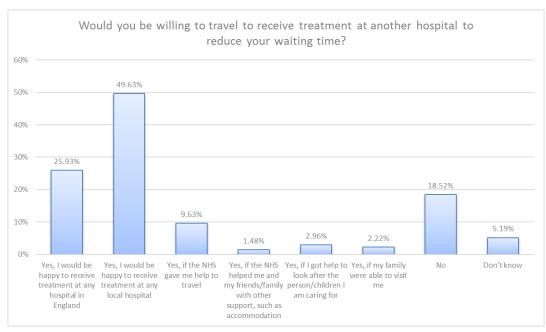
Accessing Private Treatment

When asked if they had considered accessing private treatment in order to receive quicker care, 62% of people said no, as they couldn't afford private care. Over 15% were happy to wait rather than access private treatment and over 10% stated they would refuse to pay for private treatment.



Travel

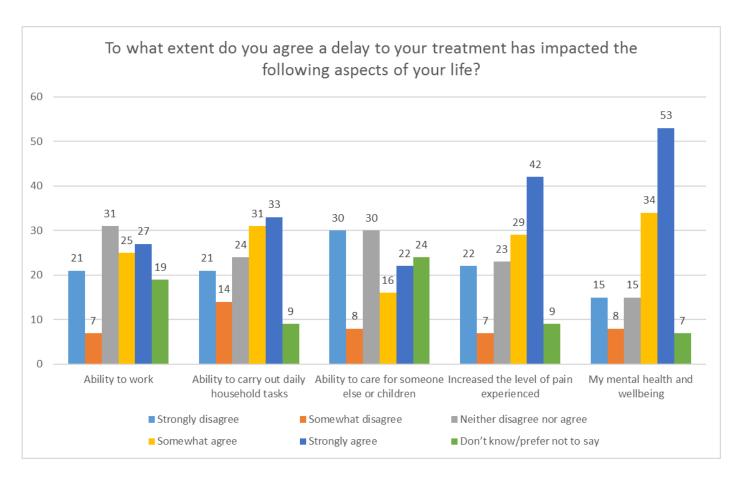
In terms of travelling to receive care from another hospital, over 49% of respondents stated that they would be willing to travel to another local hospital in order to reduce their waiting time. Some people stated they would be willing to travel to any hospital in England, others said they would not travel whereas over 9% of respondents stated they would be willing to travel if they received help from the NHS.



Impact of delays

The survey also provided an opportunity to ask respondents how the waiting times had affected their day to day life through five different areas; ability to work; ability to carry out household tasks; ability to care for someone else or children; increased level of pain and mental health. This is highlighted further in the graph below.

- In relation to ability to work, the majority neither agreed or disagreed with this statement, though this was followed closely by people who strongly agree and somewhat agree with this statement.
- For people to carry out daily household tasks, most people (33) agreed that waiting for treatment had affected their ability to complete their daily household tasks.
- With regard to caring for someone else or children, most people felt that this hadn't impacted them (30) or they neither agreed or disagreed (30) with this statement.
- Most people (42) strongly agreed that they had experienced an increased level of pain and it had impacted their lived based on the delay in any treatment for their condition.
- Mental health and wellbeing shows the highest number of responses with 53 people feeling that the delays in treatment had impacted their own mental health.



Further details

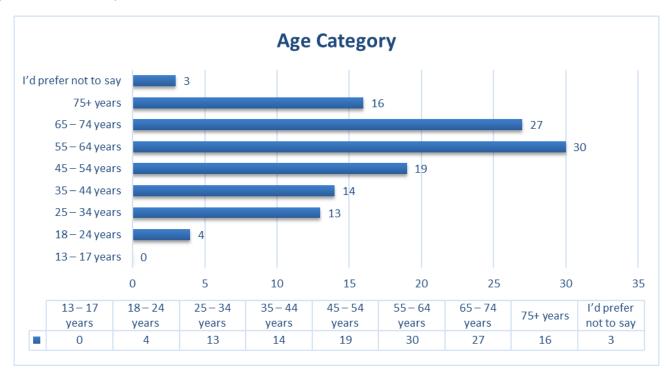
This part of the survey asked to provide an open ended response to provide any further details about their experience of waiting for treatment or care. Please find examples of the comments provided:

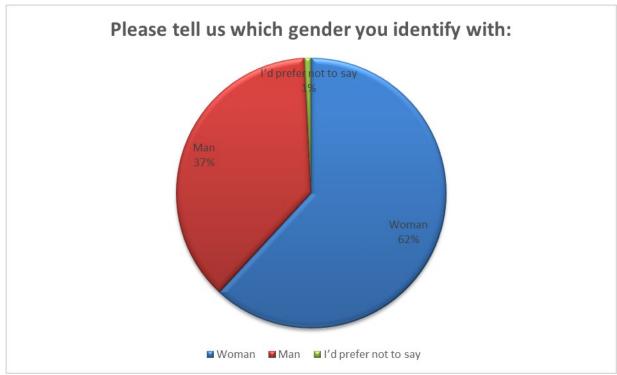
- "Waited over year and half for hip treatment to be told I havnt been referred and I have to have physio which is no good for me."
- "The treatment i receive is ongoing and specialised there are limited trained practitioners in NHS. The symptoms flare up and need immediate treatment not able to wait even for a couple of days. I even have to travel for treatment no local help in gp surgeries or walk in."
- "I've found it really stressful as well as dealing with symptoms and feeling worried, having to chase for an appointment, update or advice."
- "Waited over year and half for hip treatment to be told I haven't been referred and I have to have physio which is no good for me."
- "It was cancelled whilst I was sat waiting having paid £20 for a taxi there and then another £20 home."
- "When someone you love got vascular dementia we need more help when person doesn't want to listen what do you do I need help and more support at the moment im not all i do is ring and ring i need someone come to me i say stop worrying we hear now."
- "I think NHS is very good under the pressure I feel really lucky to be able to have it I never complain about the treatment I've had ."
- "I'm worried that the spot on my nose is cancerous and because I've been waiting so long for the biopsy that the cancer could spread to other parts of my body."
- "Well i am worried as the doctor said it was likely to be cancerous and needed a biopsy. Have had no contact since. Rang several times to be told if my appointment was not for the week commencing then to call back, but was told to call if i have not heard in 6 weeks! I am worried as the first place skin cancer usually travels to is the lymph nodes. My mental heath is depleting and i am worried sick."
- "I've been struggling with my issue for ten years and am so mentally and physically exhausted. Covid is not the only reason the NHS is struggling to provide care. It's been like this for years."
- "After previously having a really bad time physically and mentally due to back pain it is really distressing to have to wait over 3 months for an appointment and only to informed via text I don't even know if I have a face to face appointment but don't see how a diagnosis can be made by phone."

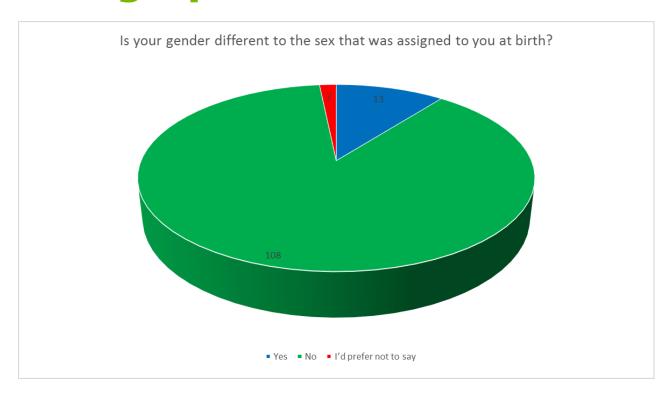
- "Total lack of empathy, consideration. No face to face contact. No opportunity to properly discuss illness or treatment."
- "Cancelled after pre-op first time and then 3 more cancellations in the last year. Has made my life a pain filled nightmare. After so many set backs, I have felt so desperate, having no sleep, having to rely on others as I can't walk unless aided."
- "I am typing this suffering severe anxiety as I constantly do. Do to this horrible condition My life is ruined and feel like nobody cares. As they don't have time for me I'm feeling as though I'm just a number but this is my life suffering and my families."
- "Phone consultation is not a proper appt!! A doctor that you've never met should never access you without a f2f appt."
- "Apart from the dental issues I believe the nhs and my gp have done everything they probably could have done under the current climate of covid-19, but have been in absolute agony with repeated abcess in my jaw cheek eyes and teeth due to rotting teeth left in situ, the dental services have totally collapsed in my experience."

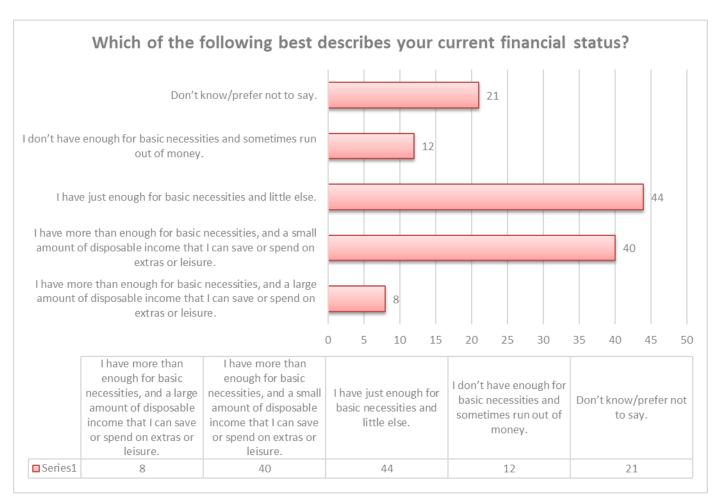
It is clear from some of the comments received that long waiting times has had a severe impact on people's lives, particularly on mental health and pain management. It is worth noting that within the survey, people were given the opportunity to share their details if they required any further support from Healthwatch Knowsley, over 40 respondents provided their contact details. In these cases, Healthwatch Knowsley staff contacted them directly either via email or telephone and provided advice and support where needed, a number of people were signposted to the PALS team within the relevant trust.

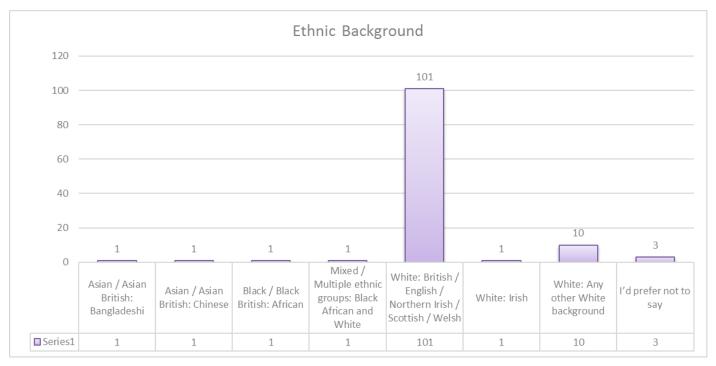
Please find the demographic information of respondents below, please note that all monitoring questions were optional.

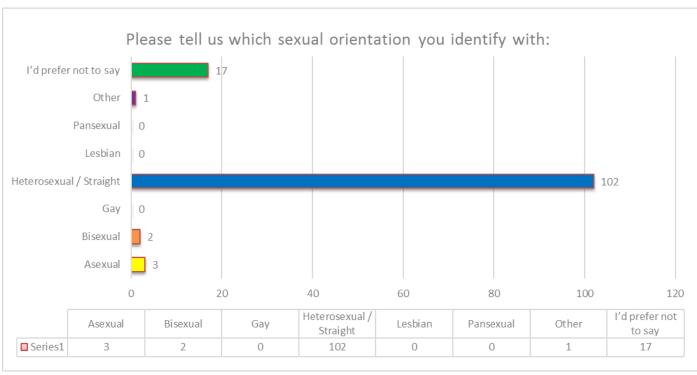


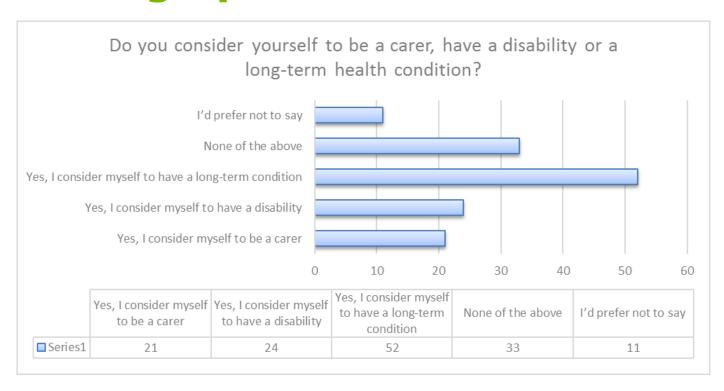














Survey questions

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

Are you one of the five million people waiting for hospital treatment or care because of COVID-19? 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.

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 tell us which hospital you attend for treatment				
Ainten Hamital (Liverna Hairmita Hamital NHC Foundation Tourt)				
☐ Aintree Hospital (Liverpool University Hospital NHS Foundation Trust)				
☐ Alder Hey Children's NHS Foundation Trust				
☐ Broadgreen Hospital (Liverpool University Hospital NHS Foundation Trust)				
☐ Whiston Hospital (St Helens & Knowsley Teaching Hospitals NHS Trust)				
☐ St Helens Hospital (St Helens & Knowsley Teaching Hospitals NHS Trust)				
☐ The Royal Liverpool Hospital (Liverpool University Hospital NHS Foundation Trust)				
☐ The Walton Centre NHS Foundation Trust				
☐ Liverpool Women's Hospital NHS Foundation Trust				
☐ The Clatterbridge Cancer Centre				
☐ Other [please specify]				
Q2. Which department are you receiving treatment from?				
Q3. Please select the following statement that applies to you:				
☐ I am currently waiting to have hospital care/treatment [Skip to Q4]				
☐ I have had hospital care/treatment in the last 18 months [Skip to Q5]				

Q4. 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
[Skip to Q6]
Q5. 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
Q6. 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)
 □ Ongoing treatment (for example a pre-planned review of a long-term condition) □ Rehabilitation
 □ Ongoing treatment (for example a pre-planned review of a long-term condition) □ Rehabilitation □ Don't know
 □ Ongoing treatment (for example a pre-planned review of a long-term condition) □ Rehabilitation □ Don't know
 □ Ongoing treatment (for example a pre-planned review of a long-term condition) □ Rehabilitation □ Don't know □ Other [please specify]
 □ Ongoing treatment (for example a pre-planned review of a long-term condition) □ Rehabilitation □ Don't know □ Other [please specify]
□ Ongoing treatment (for example a pre-planned review of a long-term condition) □ Rehabilitation □ Don't know □ Other [please specify] □ Q7. What condition/problem did you need treatment for? □ Q8. Was your treatment cancelled at any point?
□ Ongoing treatment (for example a pre-planned review of a long-term condition) □ Rehabilitation □ Don't know □ Other [please specify] □ Q7. What condition/problem did you need treatment for? □ Q8. Was your treatment cancelled at any point? □ No [Skip to Q11]
□ Ongoing treatment (for example a pre-planned review of a long-term condition) □ Rehabilitation □ Don't know □ Other [please specify] □ Q7. What condition/problem did you need treatment for? □ Q8. Was your treatment cancelled at any point? □ No [Skip to Q11] □ Don't know [Skip to Q11]
□ Ongoing treatment (for example a pre-planned review of a long-term condition) □ Rehabilitation □ Don't know □ Other [please specify] □ Q7. What condition/problem did you need treatment for? □ Q8. Was your treatment cancelled at any point? □ No [Skip to Q11] □ Don't know [Skip to Q11] □ Yes, once
□ Ongoing treatment (for example a pre-planned review of a long-term condition) □ Rehabilitation □ Don't know □ Other [please specify] □ Q7. What condition/problem did you need treatment for? □ Q8. Was your treatment cancelled at any point? □ No [Skip to Q11] □ Don't know [Skip to Q11]
□ Ongoing treatment (for example a pre-planned review of a long-term condition) □ Rehabilitation □ Don't know □ Other [please specify] □ Q7. What condition/problem did you need treatment for? □ Q8. Was your treatment cancelled at any point? □ No [Skip to Q11] □ Don't know [Skip to Q11] □ Yes, once

Q9. How much notice were you given before the most recent time your treatment was either delayed or cancelation?
 □ On the day of my treatment □ The week before my treatment [Skip to Q11] □ The month before my treatment [Skip to Q11] □ Two to three months before my treatment [Skip to Q11] □ Over three months before my treatment [Skip to Q11] □ Don't know [Skip to Q11]
Q10. If your treatment was cancelled 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
Q11. Did you know that you have the right to have treatment at another hospital of your choice if your local hospital cannot treat you within 26 weeks? Yes No
Your experiences of communications during the delays
Q12. 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
Q13. 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 □ Somewhat agree □ Neither agree nor disagree □ Somewhat disagree □ Strongly disagree □ Don't know
Q14. Have you received support from the NHS whilst waiting for treatment?
☐ Yes ☐ No [Skip to Q16] ☐ Don't know [Skip to Q16]

Q15. What support have you received which you found helpful during your waiting time? [Select all that apply]
□ 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]
Q16. 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 got worse ☐ I was given adequate supporting information to manage my condition but no clear point of contact in case my condition worse ☐ I was given some information, but it wasn't enough 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
Q17. 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 would refuse to pay for private treatment □No, I cannot afford private treatment □No, I am ok with waiting to be treated on the NHS □Don't know

Q18. Would you be willing to travel to receive treatment at another hospital to reduce your waiting time? [Please select all that apply]
□Yes, I would be happy to receive treatment at any hospital in England □Yes, 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
Q19. To what extent do you agree a delay to your treatment has impacted the following aspects of your life?
Ability to work Strongly disagree Somewhat disagree Neither disagree nor agree Somewhat agree Don't know/prefer not to say
Ability to carry out daily household tasks Strongly disagree Somewhat disagree Neither disagree nor agree Somewhat agree Strongly agree Don't know/prefer not to say
Ability to care for someone else or children Strongly disagree Somewhat disagree Neither disagree nor agree Somewhat agree On't know/prefer not to say
Increased the level of pain experienced Strongly disagree Somewhat disagree Neither disagree nor agree Somewhat agree Strongly agree Don't know/prefer not to say

My mental health and wellbeing Strongly disagree Somewhat disagree Neither disagree nor agree Somewhat agree Don't know/prefer not to say		
Q20. If there is anything else you'd like to tell us about your experience of waiting for hospital treatment, please use this box:		
If you would like any support from Healthwatch Knowsley regarding your experience, please provide your contact details below:		

Tell us a bit more about you

By telling us more information about yourself, you can help us better understand how people's experiences may differ depending on their personal characteristics. However, if you do not wish to answer these questions you do not have to.

We will share the data with our local Healthwatch network, but we will remove any data that will identify you beforehand

Q21. Please tell us which age category you fall into:
□ 13 – 17 years
□ 18 – 24 years
□ 25 – 34 years
□ 35 – 44 years
□ 45 – 54 years
□ 55 – 64 years
□ 65 – 74 years
☐ 75+ years
☐ I'd prefer not to say
Q22. Please tell us which gender you identify with:
☐ Woman
☐ Man
□ Intersex
□ Non-binary
□ Other
☐ I'd prefer not to say
Q23. Is your gender different to the sex that was assigned to you at birth?
□Yes
□No
□I'd prefer not to say
Q24. Which of the following best describes your current financial status?
☐ I have more than enough for basic necessities, and a large amount of disposable income that I
can save or spend on extras or leisure.
☐ I have more than enough for basic necessities, and a small amount of disposable income that I
can save or spend on extras or leisure.
☐ I have just enough for basic necessities and little else.
☐ I don't have enough for basic necessities and sometimes run out of money.
□ Don't know/prefer not to say.

Q2	5. Please select your ethnic background:
	Arab
	Asian / Asian British: Bangladeshi
	Asian / Asian British: Chinese
	Asian / Asian British: Indian
	Asian / Asian British: Pakistani
	Asian / Asian British: Any other Asian / Asian British background
	Black / Black British: African
	Black / Black British: Caribbean
	Black / Black British: Any other Black / Black British background
	Gypsy, Roma or Traveller
	Mixed / Multiple ethnic groups: Asian and White
	Mixed / Multiple ethnic groups: Black African and White
	Mixed / Multiple ethnic groups: Black Caribbean and White
	Mixed / Multiple ethnic groups: Any other Mixed / Multiple ethnic background
	White: British / English / Northern Irish / Scottish / Welsh
	White: Irish
	White: Any other White background
	Another ethnic background
	I'd prefer not to say
Q2	6. Please tell us which sexual orientation you identify with:
	Asexual
	Bisexual
	Gay
	Heterosexual / Straight
	Lesbian
	Pansexual
	Other
	I'd prefer not to say
	7. Do you consider yourself to be a carer, have a disability or a long-term health condition?
(Ple	ease select all that apply):
	Yes, I consider myself to be a carer
	Yes, I consider myself to have a disability
	Yes, I consider myself to have a long-term condition
	None of the above
	I'd prefer not to say

Thank you for taking the time to complete this survey!

Control Sheet

Date Submitted	
Date Response due	
Date Response Received	

Submitted to:

Service Provider	
NHS Knowsley CCG	
Local Authority Commissioner	
Cabinet Member for Health & Wellbeing	
NHS England Quality Surveillance Group	
Overview & Scrutiny Committee	
Care Quality Commission	
Healthwatch Knowsley Website	

healthwatch Knowsley

Healthwatch Knowsley
The Old Schoolhouse, St Johns Road,
Huyton,
Knowsley,
Merseyside
L36 OUX
www.healthwatchknowsley.co.uk

t: 0151 449 3954

e: enquiries@healthwatchknowsley.co.uk

- @HWKnowsley
- Facebook.com/Healthwatch.Knowsley
- Instagram.com/hwknowsley/