



What people have told us about elective care delays

Published August 2022

Acknowledgments

Thank you

Healthwatch Suffolk would like to thank each and every partner organisation that has supported us to conduct this research. There are many local groups, networks and organisations that have helped to share communications about this work, or distributed surveys on our behalf. We could not hope to achieve the same reach without them. Particular thanks go to Lofty Heights, who have agreed to share their perspective on the impact of hospital waits on people they support. Please see their contribution later in the report.

For more information about just some of our local partners, please see this page on our website (see www.healthwatchesuffolk.co.uk/about-us/our-partnerships).

In addition, Healthwatch Suffolk would like to acknowledge the support of the West Suffolk NHS Foundation Trust, East Suffolk and North Essex NHS Foundation Trust, and the James Paget University Hospitals NHS Foundation Trust. Combined, their help and support ensured more than 9,000 patients waiting for care had the opportunity to participate in this research.

We would also like to thank the wider health and social care system in Suffolk. In particular, we have valued the support of local NHS and care leaders to develop the work, and will appreciate that continued support as we consider the recommendations for local Integrated Care Systems (ICS) after the report has been published. Our connection with the team responsible for the development of an Elective Care Equality and Health Inequalities Impact Assessment (EHIIA) for Suffolk and North East Essex ICS has been of particular value, and will ensure lasting impact from this research.

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About us

A little information about Healthwatch Suffolk, and how we work.



We are your health and social care champion.

If you use health services, or need social care, we want to learn about your experiences. We make sure NHS and social care leaders consider your feedback, and improve standards of care. We can also help you to find information and advice about local services and support.

For more information about us, or to feedback about your local services, please visit our website (www.healthwatchesuffolk.co.uk).

We want everyone to be a part of our work

This is our inclusivity statement:



Our differences are not always visible, and we embrace them all with respect and kindness. Healthwatch Suffolk wants everybody to feel equally valued, listened to, seen and heard.



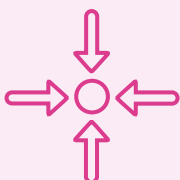
Developed in co-production, it is our promise to include everybody in our work. They're not just words – we take them seriously, in all aspects of what we do. From talking to people in communities, to planning our research, we strive to make sure no one is excluded from being a part of our work.

Our vision, mission and values



Our purpose is to...

Champion the views of local people to achieve excellent health and social care services in Suffolk.



We live and breathe...

Co-production in everything possible. We consistently aim to be inclusive, actively listening to our communities in transparent, accessible, accountable, responsive, and proactive ways. We are continually learning.

You can read more about our vision, mission, values and priorities in our strategy. Find it at www.healthwatchesuffolk.co.uk/about-us/ourstrategy.

Introduction

Read about the background to this research, and why it has been needed.



It is well known that COVID-19 has had a significant impact on hospital waiting times. In fact, the latest figures from the NHS show that the number of people waiting for NHS treatment has increased to over six million nationally – a new record. In Suffolk, the number of people currently waiting for hospital care or treatment stands at over 80,000.

Early in the pandemic, the NHS postponed non-urgent care. This helped to free up beds for COVID-19 patients who needed critical care, but the decision to close services has also led to a considerable backlog of elective care procedures. The issue has been compounded because many people delayed coming forward with new symptoms during the pandemic, which has led to significantly increased pressures within primary care services, and across health and care systems.

Nationally, in August 2022, NHS England announced that, with thanks to the hard work of NHS staff, the number of patients waiting more than two years for treatment had been reduced to just under 200 from more than 22,000. This excludes more than 2,500 people who are complex cases, or who chose not to travel for quicker treatment.

NHS England says this announcement represents the first major milestone in its plan to eliminate backlogs caused by COVID. However, despite this achievement, a record 6.6 million people are still waiting for hospital treatment. Eliminating 18-month waits by April 2023 is next on the government's agenda.

It is important to acknowledge that waits for hospital treatment were already rising before COVID-19. However, the pandemic has pushed NHS waiting lists to record levels while increasing health inequalities amongst those waiting for treatment; adding to many other ways that health inequalities are now known to have been exacerbated by the pandemic.

This worrying trend was highlighted by The King's Fund in September 2021, when it found that people living in the most deprived areas in England are nearly twice as likely to

experience a wait of over one year for hospital care than those in the most affluent areas of England. More than seven per cent of patients on waiting lists in the most deprived areas of the country had been waiting a year or more for treatment, compared to around four per cent of those in the least deprived.

The King's Fund analysis also shows that waiting lists are growing more quickly in deprived areas. From April 2020 to July 2021, waiting lists in the most deprived parts of the country had grown by 55% on average. This compared to 36% in the least deprived areas.

The government has announced additional money to tackle the problems with hospital delays, but it is widely accepted that there is no quick way to significantly reduce waiting times. The NHS lacks the staff to see people more quickly, and doctors, nurses and other clinicians take a long time to train.

If waiting is inevitable, what does this mean for those who are currently on a waiting list – or for people who may need planned hospital care in the future? What support have people been able to access whilst they are waiting, and how are these delays impacting upon people's lives? These are just some of the questions we have sought to address by completing this research.

The research has been a core-funded research project by Healthwatch Suffolk. That means the work has been delivered under the funding we receive from Suffolk County Council (Public Health Suffolk) to deliver our statutory activities.



8,000+

people waiting for elective care in Suffolk received a text message from their hospital with a link to take part in the survey. This has helped us to achieve a response rate of more than 1,300 people.

The aim has been to (not an exhaustive list):

- inform the plans and strategies of NHS and social care leaders responsible for addressing the backlog of care;
- shape an Elective Care Equality and Health Inequalities Impact Assessment (EHIIA) for Suffolk and North East Essex ICS;
- support NHS and local authority communication plans targeted at addressing the backlog of care;
- support our local hospitals to consider improvements to how people's care is managed whilst they are waiting;
- establish the best possible understanding about the impact of hospital delays on people's lives, and find out what has helped people to live well whilst they have been waiting for their treatment;
- explore people's experiences of communication from services, and how it could be improved.

This research has been supported by integrated care systems in Suffolk, and also acute hospitals serving Suffolk patients (West Suffolk Foundation Trust, East Suffolk and North Essex Foundation Trust, and James Paget University Hospitals Foundation Trust). Specifically, each of the trusts sent a digital link for the survey to patients currently waiting for hospital care using text messaging systems.

That included:

- 4,045 people currently waiting for procedures from West Suffolk NHS Foundation Trust for longer than six months;
- 1,490 people waiting over 25 weeks for procedures from James Paget University Hospitals NHS Foundation Trust, and who live within Waveney;
- 3,000 people waiting for orthopaedic procedures, and spinal surgery at the East Suffolk and North Essex Foundation Trust (waiting time unknown).

This method of reaching people for their views has proven to be a successful way of encouraging people to independently feedback about their experiences, and we are grateful for the support of the services to implement the approach.

The national Healthwatch survey

This project is a local adaptation of a national Healthwatch England project to explore the impact of elective care delays.

Healthwatch Suffolk (HWS) has taken time to adapt the national survey template with local professionals, and leaders, responsible for elective care delivery in Suffolk. Whilst this meant our data would not be included in national Healthwatch reporting on the subject, it will ensure that our work is able to have a stronger influence over local strategic plans

by the NHS to address the backlog of care.

In November 2021, Healthwatch England published a briefing for national health and social care stakeholders. It was informed by:

- the views of 1,441 people from national polling commissioned by Healthwatch England, and carried out by YouGov between 19–23 August 2021;
- the views of 1,075 people either waiting for treatment, or who had received treatment within an 18-month period, in a national survey between 6 September and 11 October 2021.

The above compares to a response rate to our local survey of 1,382 people.



People completed a survey about their experiences of waiting for elective care procedures in Suffolk.

Methodology

Explore more about how we conducted this research, and how the opportunity to take part was promoted to local people waiting for elective care procedures.



Surveys were chosen as the primary method for collecting data about people's experiences. However, Healthwatch Suffolk's inclusive approach to research meant that people had the flexibility to share their experiences in a way that suited their communication needs and preferences.

Two variations of the primary surveys were created and hosted online using the SmartSurvey platform. One of the surveys was for people currently waiting for hospital care, whilst the other was relevant to people who had already received their treatment or care. The surveys were available in other formats, including hard copy format, for anyone who could not access the survey online.

The surveys were adapted from a national survey that had been promoted by Healthwatch England. Data collection took place between January 2022 and May 2022.

Using the national template as a starting point, Healthwatch Suffolk sought to co-produce a revised survey together with integrated care systems, and leaders responsible for the delivery of elective care in Suffolk. The surveys were adapted in response to feedback from professionals, and this has helped to ensure that the insights from the surveys can usefully inform, and shape, local plans to address the backlog of planned hospital care in Suffolk.

Broadly, the surveys sought to identify:

- information about how long people had been waiting, and for which type of treatment or care;
- people's willingness to travel for treatment;
- experiences of cancellation;
- people's perceptions about the information and/or communications they had received about hospital delays;
- how waiting for hospital care had impacted upon many different aspects of people's lives;

- how well people have felt supported whilst they have been waiting for hospital care.

The opportunity to participate in the survey was promoted widely by Healthwatch Suffolk. Communication about the project included:


- a paid social media campaign
- content on the Healthwatch Suffolk website
- features in Healthwatch Suffolk newsletters
- promotional activity by providers (e.g. acute hospitals and local GP practices)
- community engagement activity by Healthwatch Suffolk Community Development Officers

The Healthwatch Suffolk team has also appreciated the support of staff responsible for the provision of an Elective Care Equality and Health Inequalities Impact Assessment (EHIA) for Suffolk and North East Essex Integrated Care System. The team were seeking to shape the EHIA through engagement with people from a diversity of local communities. The survey was shared with people as a part of this activity, including more than 100 hard copies with people who may have found it difficult to engage with the research using digital platforms.

In addition, information about the surveys was specifically shared with our database of more than 45 partner organisations. They are organisations that have jointly signed a partnership agreement with Healthwatch Suffolk (see information about our partners at www.healthwatchesuffolk.co.uk/about-us/our-partnerships/).

Healthwatch Suffolk has also shared the opportunity to participate in the research widely with stakeholders across health and social care. This has included (amongst other sharing):

- GP practice managers across Suffolk;
- all GP practice websites using 'Footfall' in Waveney;
- NHS communication teams within the Suffolk and North East Essex and Norfolk and Waveney integrated care systems;
- the membership of the Suffolk Voluntary and Statutory Partnership (VASP);
- a variety of local voluntary, community and social enterprise (VCSE); organisations shared the survey with people they support (e.g. Rural Coffee Caravan, Community Action Suffolk, Citizens Advice services, Parkinson's UK, Lowestoft Neighbourhood Watch, Disability Forums to name just a few).



"Paying for a private scan has shown the extent of my disease and delays in appropriate care and diagnosis by the NHS now means my endometriosis has impacted my bowel. I'm in constant daily pain but because endometriosis is a 'benign' disease, and my surgery is classed as 'elective' I'm at the bottom of the priority list. I feel hopelessly let down."

(Operation, waited over a year)

Findings

Explore the detail of how people responded to our survey, and what people told us about their experiences of waiting for hospital care.



1. The Sample

A total of 1,382 people responded to the Healthwatch Suffolk Elective Care survey. However, because 80 people shared more than one experience, the sample includes 1,462 experiences of waiting for planned care from an acute hospital.

Most people (98%/1,350) wanted to tell us about treatment they were currently waiting for, while the remaining 2% (32) told us about a wait they had experienced in the past.

Details of the sample

- Eight hundred and seven (58%) respondents were female, 452 (33%) were male, two people chose to describe their gender in their own way and 121 preferred not to say, or did not respond.
- Almost half (46%/666) of respondents were aged between 55 and 74.

	Respondents	Percentage
Not answered	118	9%
85+	20	1%
75-84	197	14%
65-74	347	25%
55-64	284	21%
45-54	196	14%
35-44	123	9%
25-34	62	4%
Under 25	35	3%
Total	1,382	100%



Table 1: The total number of respondents within each age category.

- One thousand, one hundred and sixty-seven (84%) respondents indicated that they were heterosexual, whilst 86 (7%) people chose to describe their sexuality in a different way. Nine per cent (129) did not answer the question.
- One thousand, one hundred and ninety-five (86%) people identified as 'White British', and a further 35 (3%) people selected 'White-Irish' or 'Any other-white' to describe their ethnicity. Twenty seven (2%) people said they were from a non-white ethnic background, and 125 (9%) of respondents did not answer the question.

	Total respondents
Babergh	74
East Suffolk	222
Ipswich	59
Mid Suffolk	148
Waveney	239
West Suffolk	415
Essex ('Colchester', 'Tendring')	61

Table 2: The location of respondents.

'Vulnerabilities'

Respondents were asked to indicate which of the following descriptions applied to them:

- 'I have a diagnosed mental health difficulty.'
- 'I am a Carer.'
- 'I have a disability.'
- 'I have a learning disability.'
- 'I am on the Autistic spectrum.'
- 'None of these apply to me.'

For the purposes of this report these are referred to as 'vulnerabilities', because they are factors known to indicate that someone may be at a disadvantage because of their personal circumstances.

- Only 1,232 respondents answered the question about 'vulnerabilities'. Amongst those who did respond, over half (61%/754) did not have any of the listed 'vulnerabilities'. A total of 377 people (31%) had one 'vulnerability', and 101 people (8%) indicated that they had two or more 'vulnerabilities'.
- The most reported 'vulnerability' was having a disability (288), followed by having a mental health difficulty (168), and 108 who indicated they were a Carer. See table three below for a full breakdown of responses against each 'vulnerability'.

	Respondents
'None of these apply to me'	754
'I have a disability'	288
'I have a diagnosed mental health difficulty'	168
'I am a Carer'	108
'I have a learning disability'	19
'I am on the Autistic spectrum'	15

Table 3: Respondents' 'vulnerabilities'.

Male respondents were the most likely to report that they did not have any of the listed vulnerabilities (69% compared to 57% of female respondents). Women were the most likely to say that they were carers (12%, compared to 2% of male respondents). They were also more likely to say that they had a disability (24%, compared to 21% of male respondents), and had experienced mental health difficulties (15%, compared to 10% of male respondents).

Younger respondents were more likely to report multiple vulnerabilities than older respondents, with those aged 35-44 having the highest proportion of multiple vulnerabilities (17%, compared to 8% of the total sample). Table four below includes the full breakdown of responses by age category.

	Under 25	25-34	35-44	45-54	55-64	65-74	75-84	85+	All ages*
No 'vulnerabilities'	59%	57%	49%	60%	60%	67%	63%	65%	61%
One 'vulnerability'	29%	30%	34%	25%	30%	30%	34%	35%	31%
Two or more 'vulnerabilities'	12%	13%	17%	14%	10%	3%	3%	0%	8%
Sample size	34	51	117	193	280	334	192	20	1,232

*Includes 1 person who did not give their age.

Table 4: The percentage of respondents who said they had a vulnerability by age category and number of vulnerabilities.

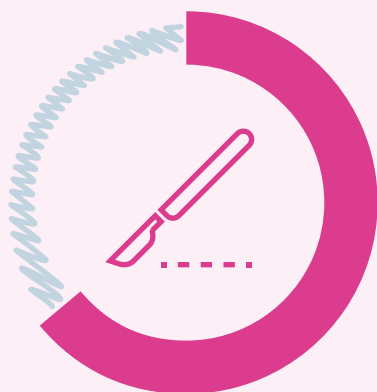
What treatment were people waiting for?

Most respondents were waiting for an operation (64%/942). Two hundred and thirty-three people (16%) were waiting for a first appointment, and 124 (8%) had received some treatment, but were waiting for more. The remaining respondents were either waiting for something else (77/5%), waiting for a diagnostic procedure (66/5%) or waiting for rehabilitation (5/0%). Fifteen people did not answer the question.

Key findings include that:

- women were more likely to be waiting for a first appointment (20% versus 8% for men);
- men were more likely to be waiting for an operation (74% versus 59% for women);
- respondents with a disability and those who had none of the listed vulnerabilities were more likely to be waiting for an operation (65% and 66% respectively) compared to those who were carers (56%) or those with a mental health diagnosis (58%).

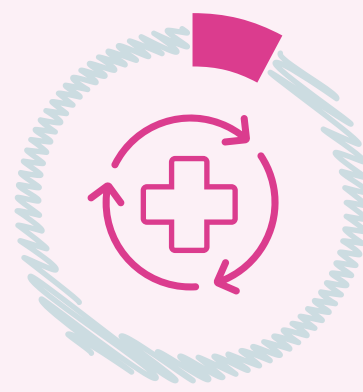
Most respondents were waiting for an operation...



Operation
(64%)



First appointment
(16%)



More treatment
(8%)

	Female	Male	Other	All respondents*
Operation	59%	74%	100%	64%
First appointment	20%	8%	0%	16%
More treatment	9%	8%	0%	8%
Something else	6%	4%	0%	5%
Diagnostic procedure	5%	3%	0%	5%
Rehabilitation	0%	0%	0%	0%
Not answered	1%	1%	0%	1%
Sample	858	480	2	1,462

*Includes 122 people who did not specify their gender.

Table 5: The total number of respondents, what they are waiting for, and their gender.

Important information about interpreting our findings

It should be noted that there are many factors that may have influenced people's reported experiences within our survey, and some findings should be interpreted with caution. Please note more information about this under the headings below.

Sampling bias

The survey was sent directly to selected groupings of patients by acute hospitals across Suffolk. The criteria for the selection of patients were determined by each trust, and not by Healthwatch Suffolk.

Although the survey was promoted widely, direct text messaging by hospitals to more than 8,000 patients has proven to be the most successful method for increasing the volume of responses to the survey. It is likely, therefore, that responses within the survey will be influenced by the cohorts of patients that were identified by the trusts, and subsequently provided with the survey link. There was a lack of consistency between the trusts as to the groupings of patients included in those communications.

Factors affecting responses might include (not an exhaustive list):

- the length of time people had been waiting;
- the location of respondents (this question was omitted from the survey to protect the anonymity of respondents);
- the type of treatment or procedure that people had been waiting for;
- the diversity of the sample selected by the trusts (e.g., age, ethnicity, gender and other demographic criteria).

Healthwatch Suffolk does not have access to data relating to the demographic breakdown of each cohort of patients selected by the hospitals.

Low response

Some results should be treated with caution because of a low response rate.

For example, response rates from multi-ethnic communities are notably low. This means that, whilst our findings show differences between specific demographic groups, those differences are not necessarily indicative of wider trends, and they are not generalisable to the wider population of people waiting for elective care.

Whilst some of the findings are of interest, and align with known pandemic trends related to inequalities, more research would be needed to draw specific conclusions or recommendations from them.

2. Inequality

It is widely accepted that the pandemic has increased pre-existing inequalities, leading to poorer health and care outcomes for some people and communities.

It is therefore not surprising to note that our data suggests some groups within our sample do have a poorer experience of waiting for hospital care than other groups – although this was not true across all parts of the survey.

Whilst our findings have synergy with other research, we are limited as to the conclusions we can draw from them because of low sample size. This is particularly true of respondents from multi-ethnic communities, and those who identified with some of the vulnerability options presented in the survey (e.g., Autism and learning disability).

The limitation of sample size means that we cannot generalise our results to the wider population of people within those groups waiting for hospital care in Suffolk. However, despite this, it is our view that the findings are noteworthy, and warrant further consideration within local health and care systems.

Some findings indicating inequality include that:

- people waiting the longest are also those who are most likely to say they could not afford to pay for private treatment to be seen more quickly;
- fifty-nine per cent (19) of people from multi-ethnic communities said they had been waiting more than a year, compared to 40% (519) of those who were white;
- respondents from multi-ethnic communities were more likely to say all aspects of life included in the survey (except community life) had been detrimentally impacted by their wait for treatment;
- a higher proportion of respondents with learning disabilities or autism were waiting for a first appointment (26%) compared to respondents with any of the other listed vulnerabilities, or those who had no vulnerability (16%). Based on a sample of 35 respondents;
- respondents with any of the listed vulnerabilities were more likely to say hospital delays had impacted their lives;

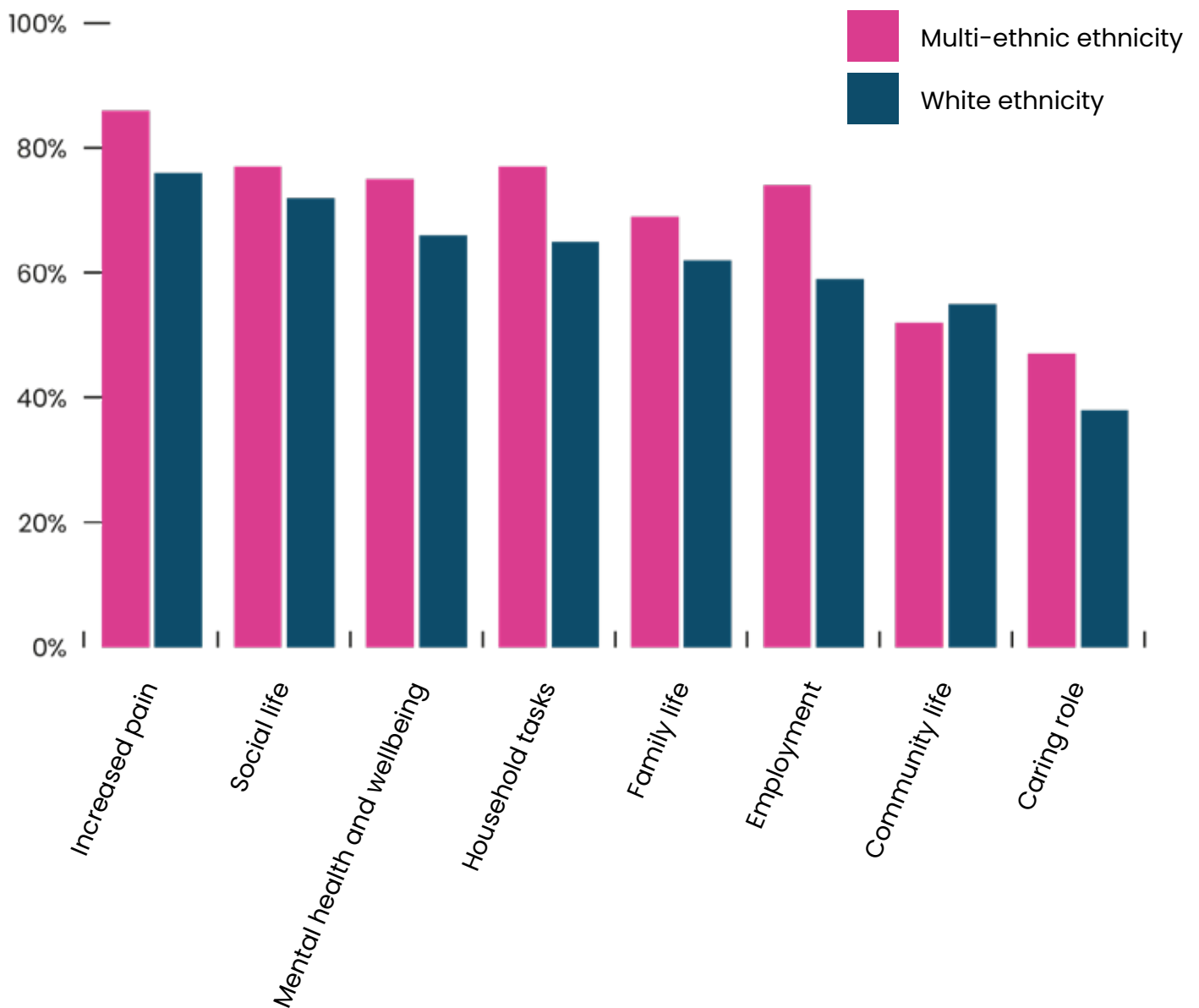
There are also findings that indicate people from multi-ethnic communities may have experienced higher levels of support from their GP/hospital, and experienced less deconditioning. Again, very small sample size means these results cannot be generalised.

Waiting more than a year



People from multi-ethnic communities were **19%** more likely to be waiting longer than year, however sample size was very low (19 respondents).

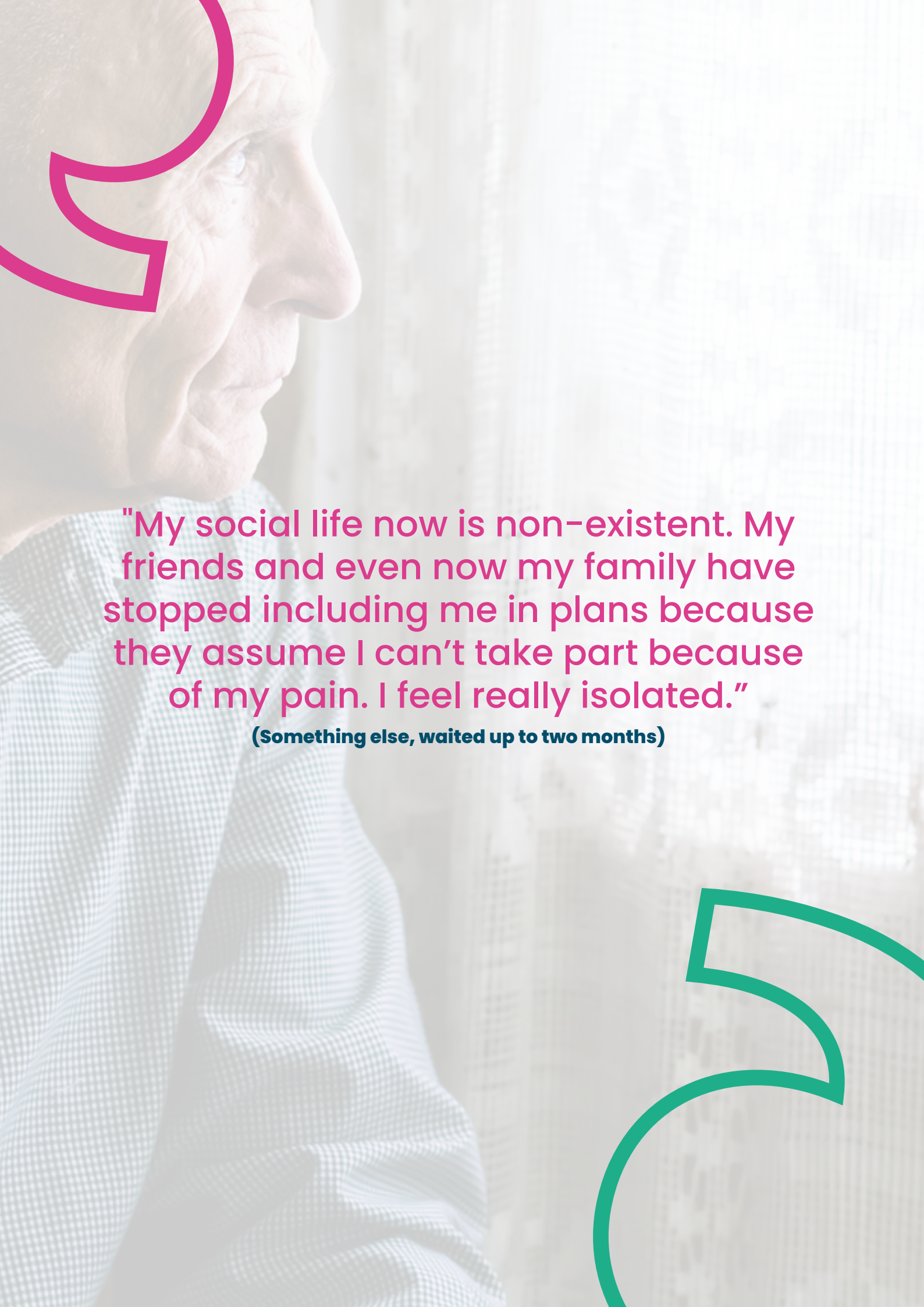
Graph 1: The percentage of respondents who indicated various 'aspects of life' had been impacted by their wait for hospital care, and their ethnicity.



These findings include that:

- respondents from multi-ethnic backgrounds were more likely to say they had been supported by their GP or hospital (59%, compared to 40% for those from a white background), based on a sample of 27 respondents;
- respondents from a white ethnic background were more likely to say their health had deteriorated compared to respondents from other ethnic groups (65%, compared to 53% of respondents from multi-ethnic communities).

Further information related to participant 'vulnerabilities' are outlined in more detail across this report. Sample size was much less of a concern for some of the 'vulnerability' categories used within the survey (e.g., having caring responsibilities, or a mental health diagnosis).



"My social life now is non-existent. My friends and even now my family have stopped including me in plans because they assume I can't take part because of my pain. I feel really isolated."

(Something else, waited up to two months)

3.Choosing a hospital

Allocated or chosen provider

Half of the sample were waiting for care from the West Suffolk NHS Foundation Trust. Just over a quarter were waiting for care from James Paget University Hospitals NHS Foundation Trust, and 16% were waiting for care from the East Suffolk and North Essex NHS Foundation Trust (ESNEFT). A majority of ESNEFT patients were waiting for care at the Ipswich Hospital site.

The table below shows the full breakdown of responses by hospital, including 60 respondents that indicated they were waiting for care from a hospital outside of Suffolk. Norfolk and Norwich University Hospitals NHS Foundation Trust (16 respondents), and Cambridge University Hospitals NHS Foundation Trust – Addenbrooke’s (10 respondents) were the most frequently mentioned.

Eighteen respondents indicated that there was a lack of clarity about where their treatment or care would be carried out. This was highlighted by comments such as:

“Was referred to Norfolk and Norwich, waiting list too long so moved to West Suffolk, who have now said Ipswich so who knows.” (Waiting for an operation, seven to 12 months)

“Bury St Edmunds or Ipswich? Bit of a mix up!” (Waiting for an operation, Don’t know how long I’ve waited)

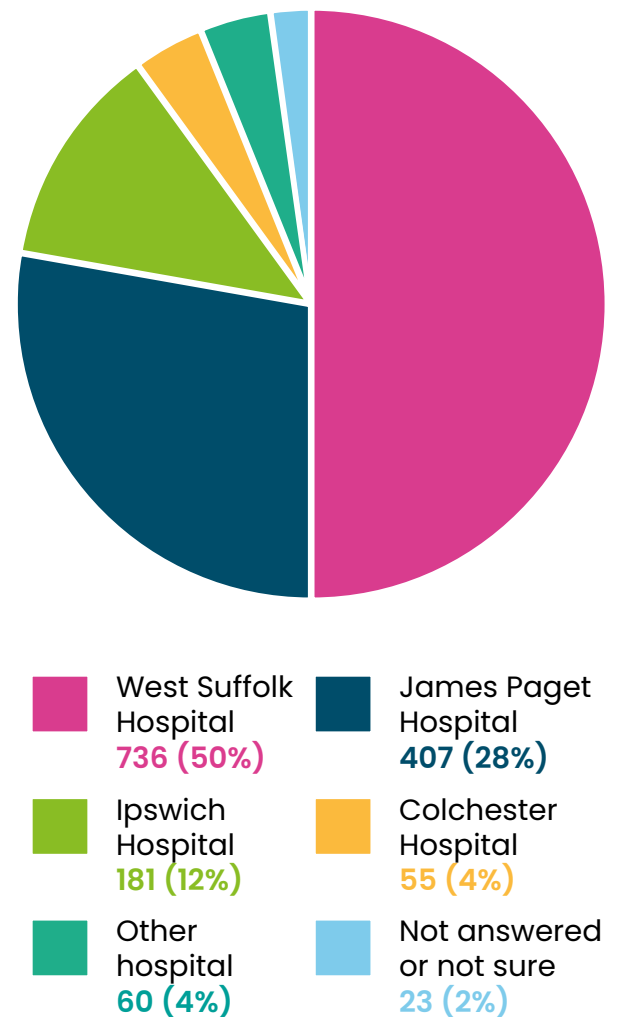
Type of treatment and care

There were distinct differences between the types of treatment patients were waiting for from each hospital. This reflected the different approaches each of the hospitals had taken when they promoted the survey to patients.

As a reminder, that included:

- four thousand and forty-five people currently waiting for procedures from West Suffolk NHS Foundation Trust for longer than six months;

Graph 2: The percentage of participants waiting for care from each trust.



- one thousand, four hundred and ninety people waiting over 25 weeks for procedures from James Paget University Hospitals NHS Foundation Trust, and who live within Waveney;
- three thousand people waiting for orthopaedic procedures, and spinal surgery at the East Suffolk and North Essex Foundation Trust (waiting time unknown).

In summary:

- most (82%) respondents waiting for care at West Suffolk Hospital indicated they were waiting for an operation;
- although most respondents waiting for care at James Paget were waiting for an operation (52%), just under a third of people were waiting for a first appointment;
- a higher proportion of respondents expecting care at Ipswich Hospital were waiting for a diagnostic procedure than at any other hospital;
- a lower proportion of respondents expecting care from ESNEFT (Ipswich and Colchester hospitals combined) were waiting for an operation compared to other hospitals, and a higher proportion were waiting for 'more treatment'.

	West Suffolk Hospital	James Paget Hospital	Ipswich Hospital	Colchester Hospital	Total sample*
Operation	82%	52%	33%	35%	64%
First appointment	4%	31%	27%	20%	16%
More treatment	6%	6%	19%	31%	8%
Diagnostic procedure	3%	4%	10%	4%	5%
Something else	4%	6%	8%	11%	5%
Not answered	1%	1%	3%	0%	1%
Rehabilitation	0%	0%	1%	0%	0%
Sample size	736	407	181	55	1,642

*Includes respondents waiting for care at any hospital

Table 6: The type of treatment or care respondents were waiting for from each trust.

Factors influencing the choice of provider

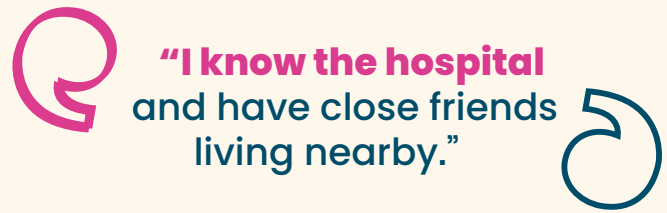
Twenty-four per cent (354) of respondents said they had made a choice of hospital for treatment and care. The main reasons people offered for selecting a specific hospital are outlined below.

Location

Location was an important factor identified in just over half (51%/184) of the comments from those who said they had made a choice about their hospital.

Their responses highlight the following:

- one hundred and twenty-five people mentioned that their choice had been influenced by the proximity of the hospital to their home address;
- a further 50 people offered responses such as 'my local hospital' or 'where I usually go';
- five people specifically referenced proximity to family members as a factor that had influenced their decision;
- four people simply gave 'location' as the reason for their choice.



Comments included:

"It was where I originally planned to have my operation because it is local. When offered to go on a list for Colchester it didn't seem suitable." (Operation, waited over two years)

"Closer and easier to get to." (Operation, waited five to six months)

"I chose this hospital because it was nearer for my husband to drive as he is 86 yrs. old." (Operation, waited seven to 12 months)

"It's the one I always go to." (Operation, waited over two years)

"I know the hospital and have close friends living nearby." (Operation, waited three to four months)

Previous experiences of care

One in five comments (20%/75) indicated that people had chosen a particular hospital because of previous experiences of care.

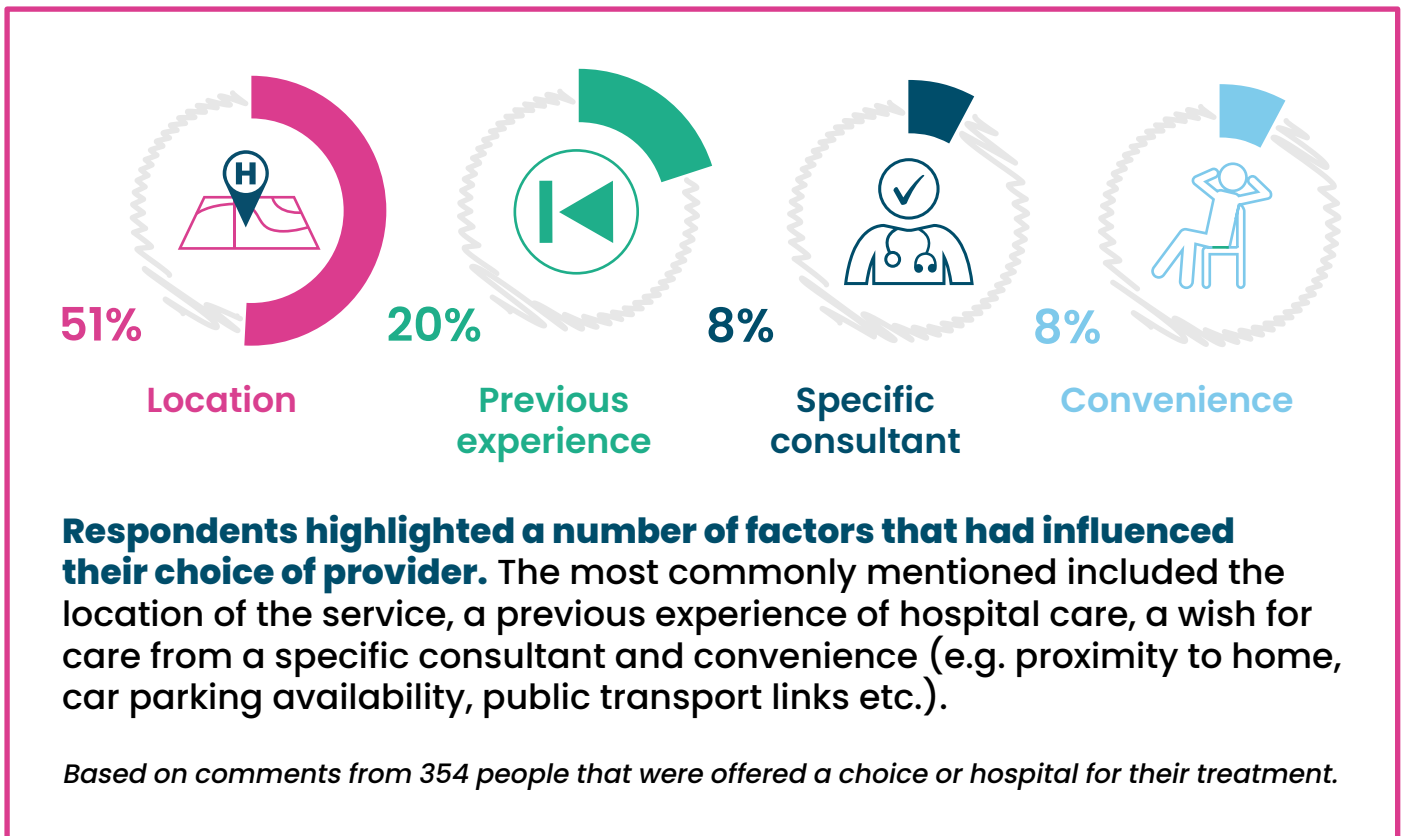
Of these respondents:

- half (35) were influenced by previous positive experiences of care;
- thirty-eight simply stated that they had received care at that hospital in the past, but did not apply any sentiment to their feedback;
- two were returning to address previous treatments that had failed.

Comments included:

"Having had excellent treatment in the past, mainly before COVID, felt confident to attend same hospital again." (More treatment, waited zero to two months)

"It is the nearest and I am familiar with it. I have had treatment there before and therefore



have confidence in the treatment I will receive.” (Operation, waited three to four months)

“It’s where I’ve been for most other things so I’m comfortable with going there.” (First appointment, waited seven to 12 months)

“Because this is where I had hip replacement that has gone wrong.” (More treatment, waited over a year)

Access to a specific consultant

Twenty-seven respondents (8%) said they had chosen their provider because they had wanted to be treated by a specific consultant.

The majority (17) of these respondents had previous experience of receiving care from the consultant in the past, either within the NHS or sometimes as a private patient.

Amongst the remaining comments:

- two people were referred to see a specific consultant;
- two had selected a consultant because of their reputation;
- two had been recommended a particular consultant;
- two people selected a consultant on the basis of their gender;



“No other hospital has a female surgeon to perform the operation that I have been accepted for.”

(First appointment, waited seven to 12 months)



- two simply gave ‘consultant’ as the reason for their choice of hospital.

Comments included:

“The consultant there has operated on my arthritic hands before and did such a good job.”
(Operation, waited seven to 12 months)

“Liked the surgeon who assessed me so to go to his hospital was a no-brainer.”
(Operation, can’t recall how long waited)

“Because it has excellent knee replacement specialists.”
(Operation, waited three to four months)

“No other hospital has [a] female surgeon to perform the operation that I have been accepted for.”
(First appointment, waited seven to 12 months)

Convenience

Twenty-seven respondents (8%) suggested a particular hospital was more ‘convenient’.

For these respondents, convenience was more than just proximity to the hospital. It was also about how easy the hospital was to get to by public transport, whether parking was easy to find, and how accessible the building was for those who were disabled.

Comments included:

“It is the most convenient to travel to.”
(Operation, waited over a year)

“It is the best one for me, I do not drive and there is a bus that goes into the hospital grounds. This makes it accessible to me, without too much trouble.”
(First appointment, waited seven to 12 months)

“Always attend there, easier to park & access, I’m disabled.”
(Operation, waited seven to 12 months)

“The most convenient.”
(Something else, waited five to six months)

Perception of waiting time

Fourteen respondents (4%) said they had selected a particular hospital because they believed they would be seen quicker there, or because they had been told that the hospital's waiting list was shorter.

"I was told it had a shorter waiting list for consultation i.e. 43 weeks from orthopaedic referral as opposed to 56 weeks." (First appointment, waited five to six months)

"Originally less waiting time than other hospitals." (Operation, waited seven to 12 months)

"After consultations with NHS physiotherapists, I was offered this hospital as it was suggested this would be the quicker route to have my procedure done." (Operation, waited three to four months)

"Because I thought I might get seen quicker than my local hospital where I'd been waiting two to three years." (Something else, waited seven to 12 months)

Reputation

Fourteen respondents (4%) suggested they had picked a hospital because of its reputation.

Their comments included:

"Has a very good reputation for the procedure I need." (Operation, waited five to six months)

"I've had a lot of good reports about [this hospital]. Not many bad ones." (Operation, waited seven to 12 months)

Familiarity

Twelve respondents (3%) indicated they had picked a hospital because of its familiarity to them.

They specifically noted that this meant they felt 'comfortable', and that familiarity with the environment had meant they felt more confident about being treated there.

"Because we know the layout so as to be able to cope with all the mobility problems." (First appointment, waited over a year)

"It is the nearest. I am familiar with it and parking isn't difficult." (First appointment, waited seven to 12 months)

"Local to me. I feel comfortable there and trust them." (Operation, waited seven to 12 months)

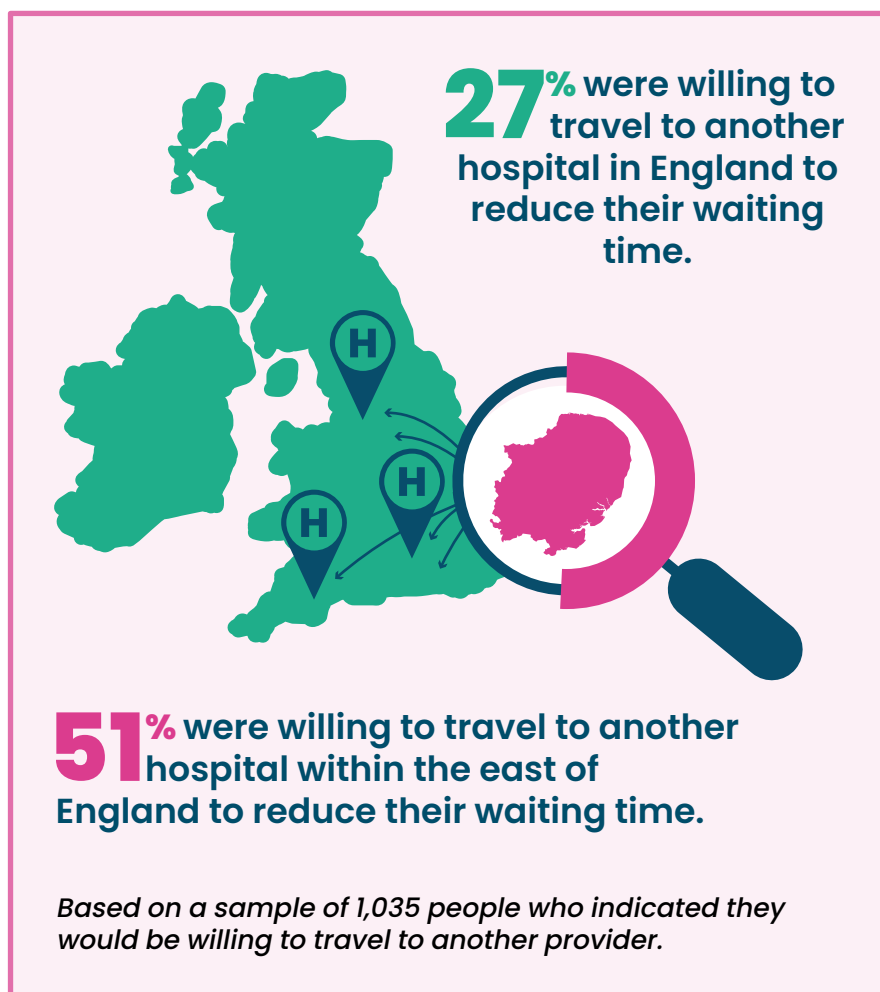
Willingness to travel for treatment

Given the importance of 'location' and 'proximity to home' in influencing people's choice of hospital, it is interesting to find:

1,035 (71%) respondents suggested they would be willing to travel to another hospital if it meant a reduction in their overall wait time.

Looking at the distance people were willing to consider travelling, over 50% of the sample said they would consider any hospital in the east of England if it meant they could access care more quickly. A much smaller, but still noteworthy number, of respondents (275/27%) indicated they would be willing to travel even further distances (to any hospital in England) to reduce their waiting time.

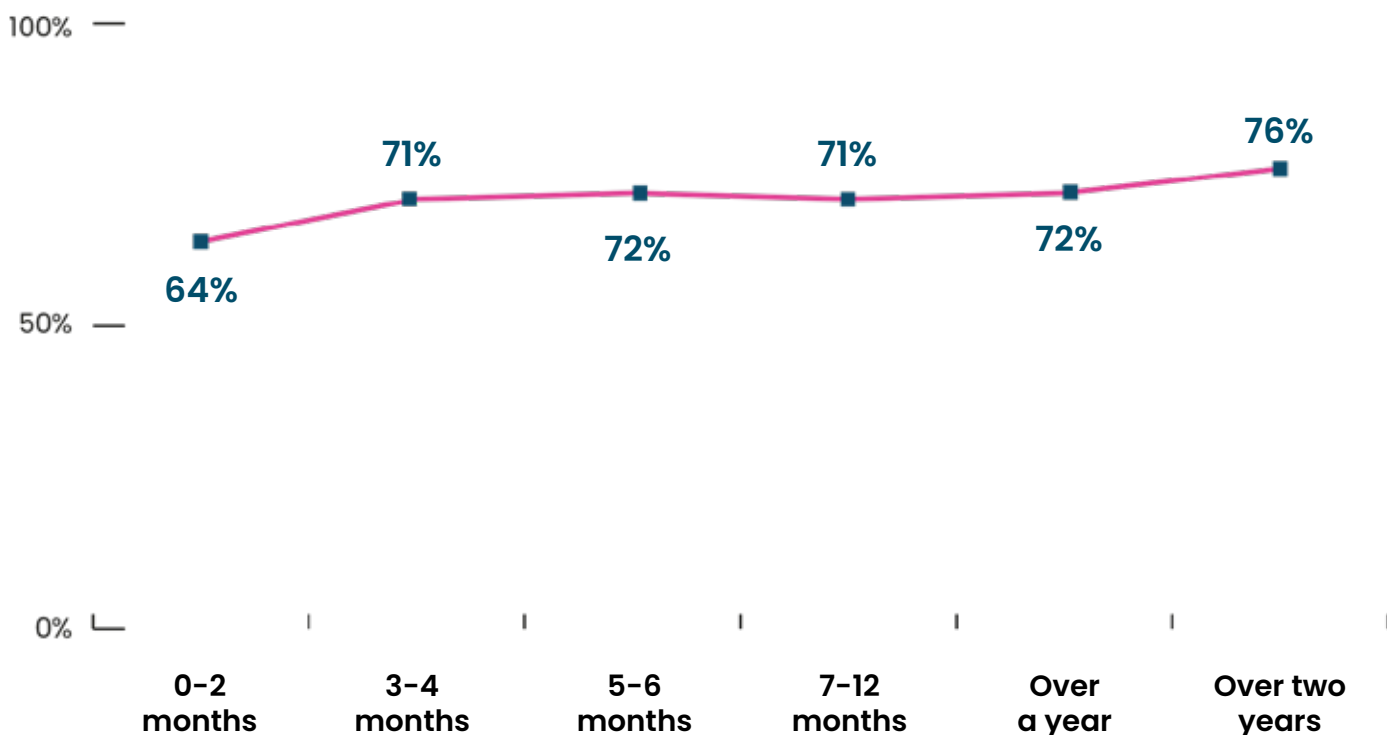
Less than a fifth of respondents (18%/190) indicated that having assistance from the NHS with travel would influence their willingness to receive treatment from another hospital, and 4% said having help with their caring responsibilities would make a difference.



	Respondents
Willing to travel to any hospital in East of England	51%
Willing to travel to other hospital in Suffolk	28%
Willing to travel to any hospital in England	27%
Willing to travel if NHS provided help with travel	18%
Willing to travel if family could visit	11%
Willing to travel if NHS provide support e.g. accommodation	9%
Willing to travel if help was provided for my caring responsibilities (other adults/children)	4%

Table 7: Respondents' willingness to travel to another hospital/location for their treatment and care.

Graph 3: The percentage of participants willing to travel, and their length of wait for hospital treatment.



The percentage of people suggesting they would be willing to travel to another hospital generally increased according to how long people had been waiting for care. This means that people who had been waiting more than two years were more likely to say they would consider travelling, compared to those who had only been waiting a few months.

Table eight also indicates that those who have been waiting longest (over a year) were more likely to consider travelling anywhere in England to be seen quickly.

	0-2 months	3-4 months	5-6 months	7-12 months	Over a year	Over two years	All respondents
Willing to travel	64%	71%	72%	71%	72%	76%	71%
Within England	25%	22%	23%	21%	32%	31%	27%
Within east region	46%	56%	51%	57%	50%	47%	51%
Only within Suffolk	35%	34%	29%	24%	25%	29%	28%

Table 8: Respondents’ willingness to travel to another hospital/location for their treatment and care, and their length of wait.

Choosing private care

Twelve per cent of respondents had considered, or were considering, paying privately to receive treatment sooner. Paying privately was not an option for most respondents because they could not afford it (65%/902).

Respondents who had been waiting the longest for treatment (more than two years) were more likely to indicate they would not consider paying privately because they could not afford it. These respondents were amongst the most likely to be waiting for an operation as opposed to any other type of treatment or procedure.

In total, 78% (183) of respondents who had been waiting more than two years were waiting for an operation, compared with only 34% (59) of those waiting zero to two months. Those waiting zero to two months were more likely to be waiting for a diagnostic procedure.

Comments that reference paying privately for treatment include:

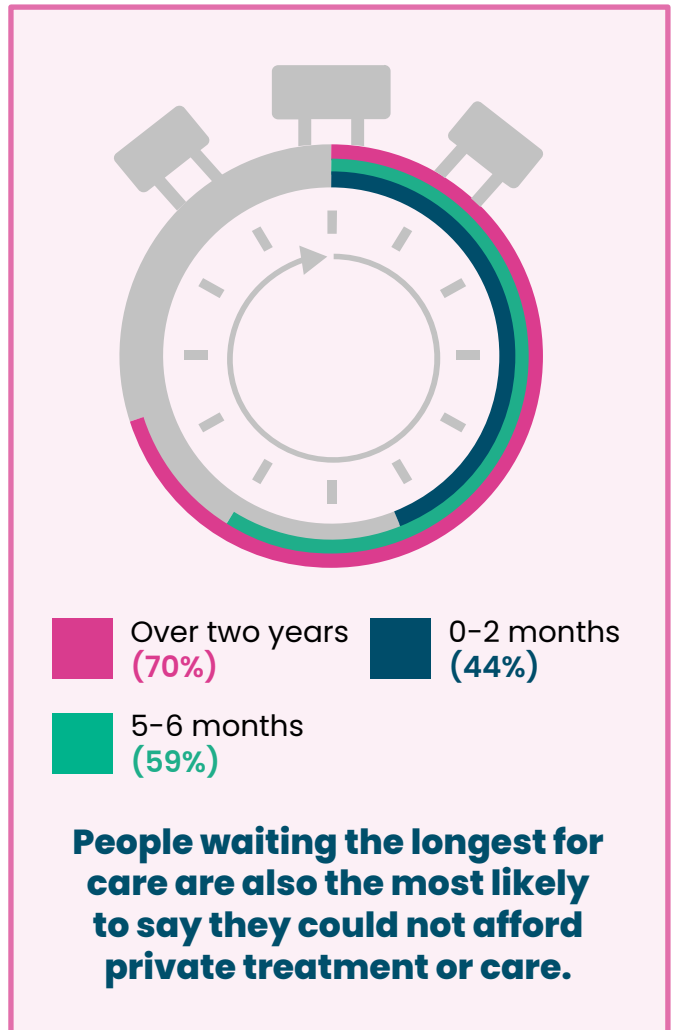
*"I was in pain constantly. I ended up using all of a small inheritance I received from my grandfather to have the operation done privately as I couldn't bear to wait any longer."
(First appointment, waited five to six months)*

*"My husband has recently had an operation which we paid for. So can't afford my operation."
(Operation, waited over a year)*

*"To be clear, my referral was cancelled by my GP, so I paid to see the consultant privately. He has said I am more than eligible for NHS treatment but is unable to say how long it will be. So, I have to find out which has the shortest waiting lists or pay for the procedure."
(Operation, waited three to four months)*

*"I saw a consultant privately not for surgery but advice on help to manage my lack of mobility."
(Operation, waited over a year)*

*"Paying for a private scan has shown the extent of my disease and delays in appropriate care and diagnosis by the NHS now means my endometriosis has impacted my bowel. I'm in constant daily pain but because endometriosis is a 'benign' disease and my surgery is classed as 'elective' I'm at the bottom of the priority list. I feel hopelessly let down."
(Operation, waited over a year)*

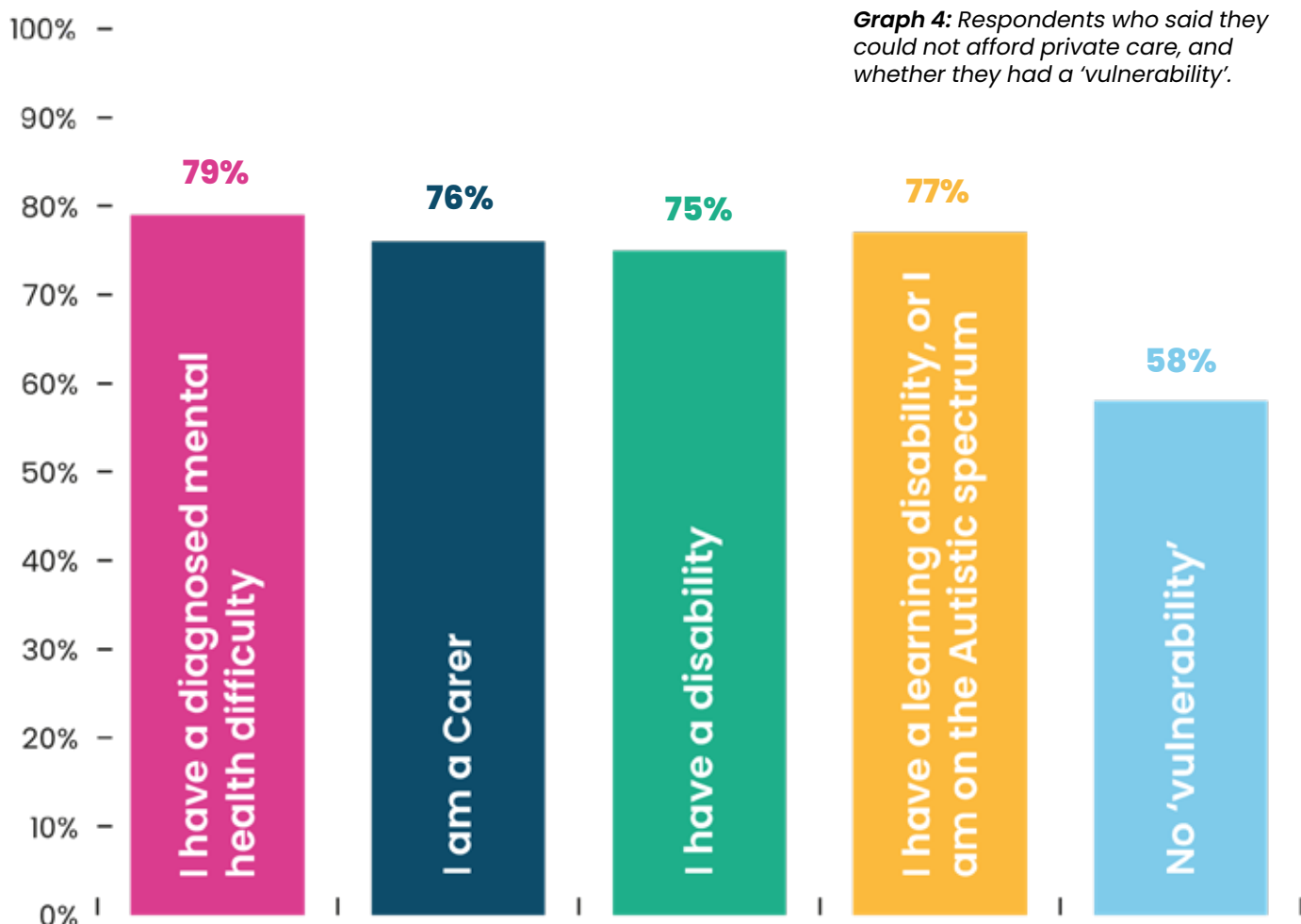


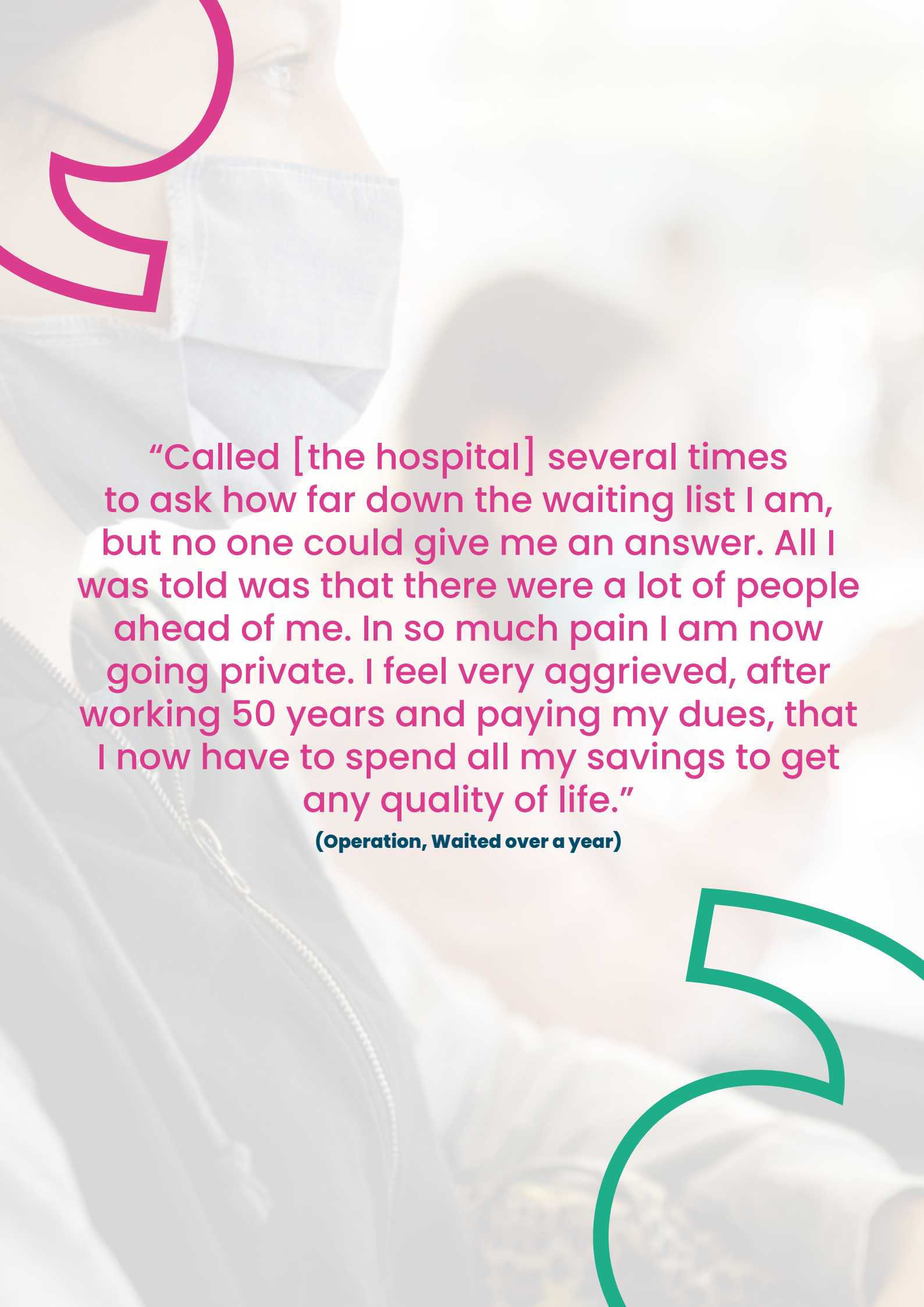
	0-2 months	3-4 months	5-6 months	7-12 months	Over a year	Over two years
No, I cannot afford private treatment	44%	57%	59%	66%	65%	70%
No, I am/was OK to wait for NHS treatment	31%	16%	18%	13%	15%	11%
Yes, I have or I am considering it	15%	16%	12%	11%	8%	8%
Don't know/Not answered	10%	11%	12%	10%	11%	10%

Table 8: Whether respondents had considered paying privately for treatment, and how long they had been waiting for treatment and care.

Another variation of note:


- Respondents who had any of the listed vulnerabilities were more likely to say they could not afford private treatment than those who did not (see graph four below).





“Called [the hospital] several times to ask how far down the waiting list I am, but no one could give me an answer. All I was told was that there were a lot of people ahead of me. In so much pain I am now going private. I feel very aggrieved, after working 50 years and paying my dues, that I now have to spend all my savings to get any quality of life.”

(Operation, Waited over a year)



48% said they had not been told how long they might have to wait for their treatment or care.

4. Waiting times

'Indicated' length of wait

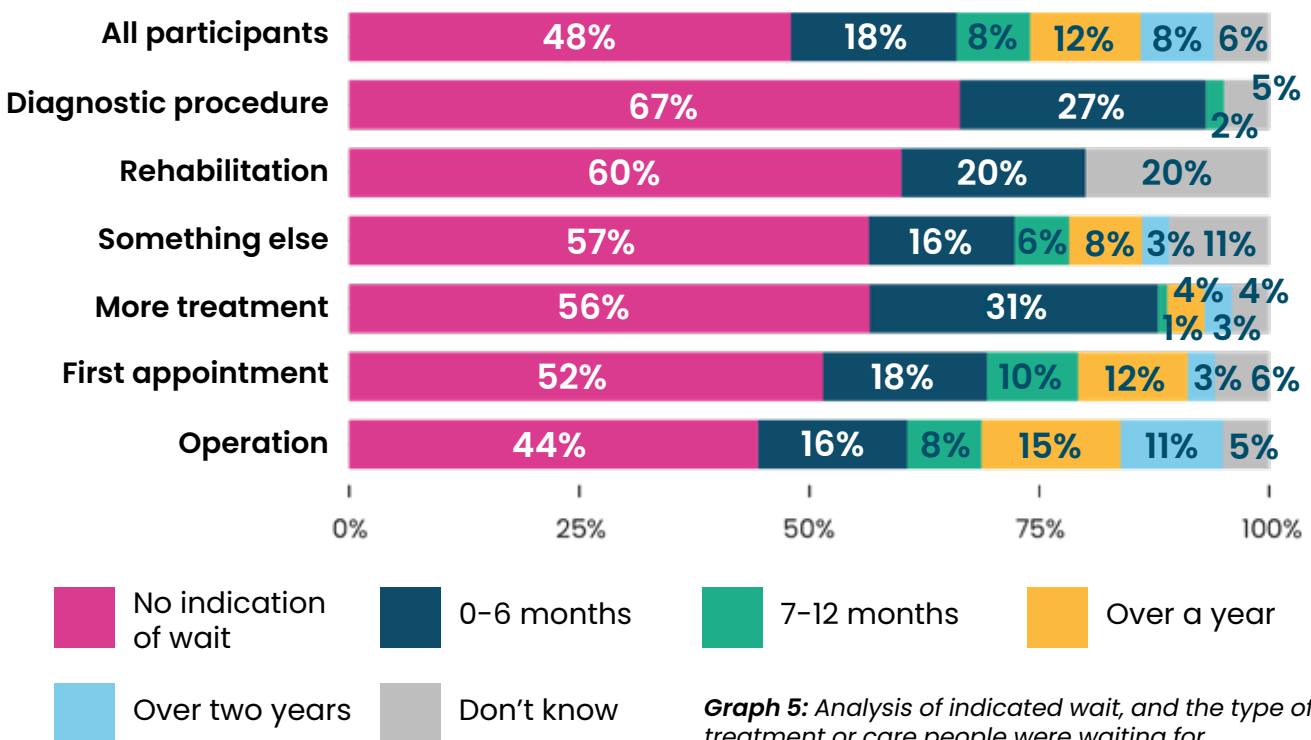
Respondents were asked whether they had been given any indication of how long they were likely to have to wait for their hospital treatment.

Nearly half of all respondents (48%/696) said they had not been told how long they might have to wait.

Amongst those who were waiting for a diagnostic procedure (X-ray, scans etc.) this figure rose to 67% (44). People who were waiting for an operation were most likely to indicate they had been told how long they might have to wait.

Other variations within the data:

- the indicated wait time for 'diagnostic procedure' and 'more treatment' was less than for other forms of treatment;
- over a quarter of people waiting for an operation were told they would have to wait more than a year;
- fifteen per cent of people waiting for a first appointment were told they would have to wait for more than a year.



Graph 5: Analysis of indicated wait, and the type of treatment or care people were waiting for.



“I was told it would be a wait of around nine to 12 months, but it has now been double that.”
(Operation, waited over two years)



Actual wait

At the time of completing the survey, most people who had been given an indicated wait time had either waited less than expected (41%/269), or the amount of time that had been indicated to them (31%/205). Only 28% (188) had already exceeded the time originally indicated. As most respondents were still waiting for treatment at the point of completing the questionnaire, their overall wait time will have continued to increase. For some, this will mean that they may eventually exceed their expected wait time.

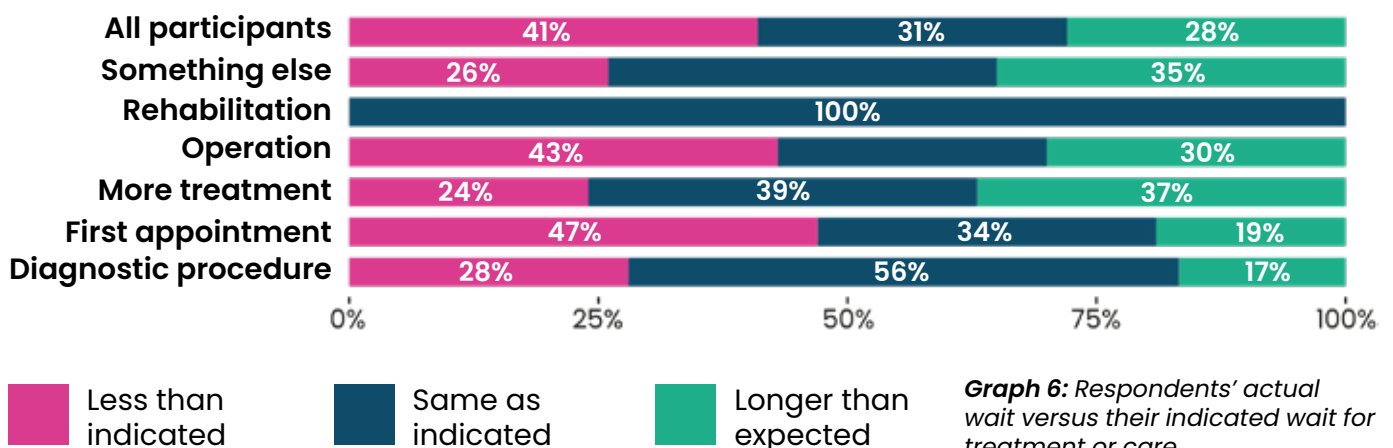
Respondents waiting for ‘more treatment’, an ‘operation’, or ‘something else’ were most likely to say they had already exceeded the indicated wait time (see graph below). Some comments highlight how the actual wait has differed from the expected wait for some respondents.

Their comments include:

“The timescale. I was referred for consultation in December 2020. I signed consent for my operation in May 2021 and was told it would be around three to four months. It’s now nine months later and I still don’t have a date for the operation.” **(Operation, waited seven to 12 months)**

“I was told that the operation would be within three months. It’s now been over two years and I was also told I would be put on the emergency list.” **(Operation, waited over two years)**

“The consultant told me I needed the operation, and it would be within two months. I didn’t hear anything after three months so contacted them as I need to consider time off work for the operation. They said the consultant shouldn’t have given that time frame, and looking at the waiting list, it wouldn’t even be within a year.” **(Operation, waited seven to 12 months)**



Amongst the 788 respondents who said they had not been given an indicated wait time, 44% (352) had already been waiting over a year at the point they completed the survey.

Of particular note:

- fifty-one (38%) respondents waiting for a first appointment said they had been waiting for more than a year;
- almost a quarter of people waiting for an operation had been waiting more than two years;
- those waiting for diagnostic procedures have waited less time than those waiting for other types of treatment or care.

Wait times by hospital trust

The variations in wait times at each of the four main hospitals in the region were generally related to the types of care that people were waiting for. The table below highlights the differences and shows that 82% of respondents waiting for care at West Suffolk Hospital were waiting for an operation, compared to 35% at Colchester and 33% at Ipswich. West Suffolk, however, had a much lower proportion of respondents waiting for a first appointment than the other three hospitals, while Colchester hospital had a higher proportion of respondents waiting for 'more treatment'.

The variations in the types of care respondents were waiting for reflect the different approaches the hospitals took in promoting the survey amongst their patient groups.

	Colchester Hospital	Ipswich Hospital	James Paget Hospital	West Suffolk Hospital	Total sample*
Operation	35%	33%	52%	82%	65%
First appointment	20%	27%	31%	4%	16%
More treatment	31%	19%	6%	6%	8%
Something else	11%	8%	6%	4%	5%
Diagnostic procedure	4%	10%	4%	3%	4%
Rehabilitation	0%	1%	0%	0%	0%
Not answered	0%	3%	1%	1%	1%
Sample size	55	181	407	736	1,642

*Includes respondents waiting for care at any hospital.

Table 9: The proportion of respondents waiting for each type of treatment or care by hospital.

Given the differences in the types of care patients were waiting for at each hospital, it is not surprising that there are differences in the indicated and actual wait times for patients.

Indicated wait time

Key findings include that:

- a higher percentage of respondents waiting for care at Colchester Hospital said they had not been given an indication of how long they may have to wait, compared to patients at other hospitals;
- respondents waiting for care at ESNEFT (Colchester and Ipswich Hospitals) were more likely to say they had been given an indicated wait time of zero to two months, compared to those waiting at James Paget or West Suffolk;
- West Suffolk Hospital had the highest proportion of respondents who had been given a wait time of over two years.

	Colchester Hospital	Ipswich Hospital	James Paget Hospital	West Suffolk Hospital	Total sample*
No-one indicated how long I might have to wait	56%	47%	46%	47%	48%
0-2 months	16%	14%	5%	6%	7%
3-4 months	7%	7%	7%	5%	6%
5-6 months	4%	8%	6%	4%	5%
7-12 months	4%	7%	8%	7%	7%
Over a year	7%	8%	15%	13%	12%
Over two years	2%	2%	4%	12%	8%
I don't know / I can't recall / Not answered	4%	7%	8%	5%	6%
Sample size	55	181	407	736	1,642

* Includes respondents waiting for care at any hospital

Table 10: Respondents indicated wait time by hospital.

Actual wait times

In general, respondents waiting for care from ESNEFT (Ipswich and Colchester Hospitals) had been waiting for less time than those waiting for care from West Suffolk or James Paget hospitals. Around 50% of patients from an ESNEFT hospital said they had waited less than four months. In comparison, almost 50% of respondents waiting for care at West Suffolk Hospital said they had waited more than two years.

	Colchester Hospital	Ipswich Hospital	James Paget Hospital	West Suffolk Hospital	Total sample*
0-2 months	35%	29%	7%	9%	12%
3-4 months	15%	19%	8%	8%	10%
5-6 months	18%	14%	14%	10%	12%
7-12 months	9%	9%	32%	22%	23%
Over a year	9%	13%	28%	28%	24%
Over two years	13%	13%	9%	20%	16%
I don't know / I can't recall / Not answered	2%	4%	2%	2%	3%
Sample size	55	181	407	736	1,642

*Includes respondents waiting for care at any hospital.

Table 11: Respondents' actual time waited by hospital.

Indicated versus actual wait

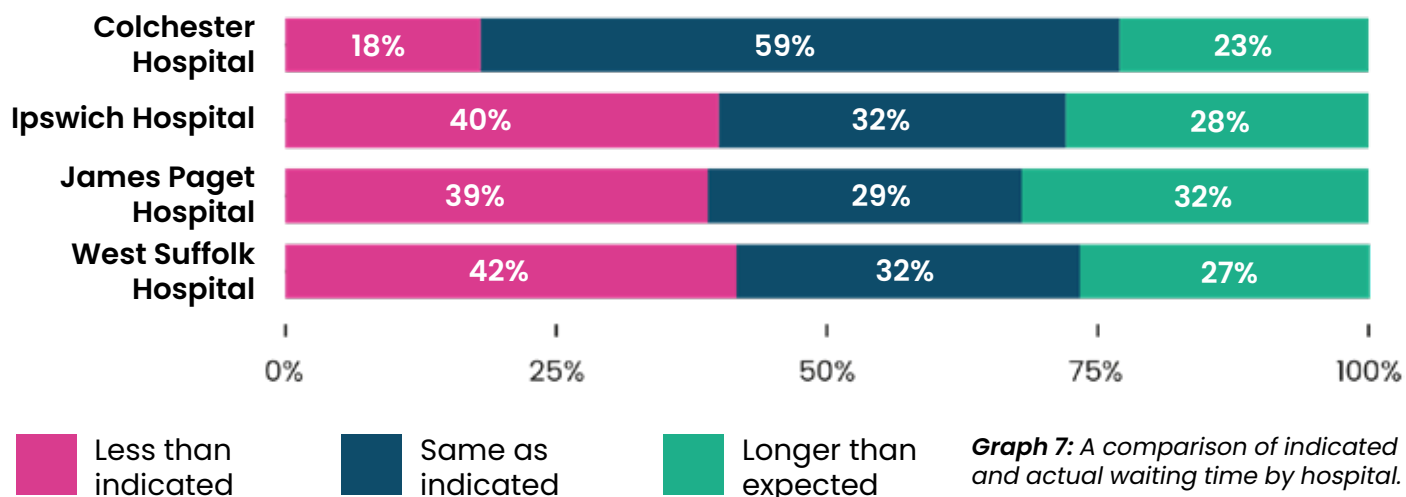
Comparing indicated wait times against actual wait times across the four main hospitals in the region shows that, with the exception of Colchester Hospital, the hospitals are generally performing similarly.

Around 40% of respondents indicated they had waited less than expected, and around 30% indicated they had already exceeded their indicated wait time. A higher proportion of respondents said they had been waiting the same amount of time that had been indicated to them at Colchester Hospital.

Wait times by gender

There is evidence of variations in wait times by gender within the data, however this may simply be a reflection of the differences in the types of procedures men and women were waiting for (men were more likely to be waiting for an operation, and women were more likely to be waiting for a first appointment).

A comparison of indicated wait time and actual length of wait, reveals that women were more likely to say that they had been waiting less than expected, while men were more likely to say



they had waited the same length of time as had been indicated.

Amongst those who had not been given an indication of wait length, men were more likely to say they had been waiting over two years (25% compared to women (16%). Again, this may simply be a reflection of the procedures men were waiting for.

Information about expected waiting time

Of those who had not been given any indicated wait time, 53% had said they had not received any information from the hospital about their wait.

Nearly half of these respondents (47%/197) have been waiting more than a year. Overall trends in provision of information were fairly similar across the four main hospitals within the region i.e., more respondents said they had not received information than said they had.

A higher proportion of respondents waiting for care at Ipswich Hospital said they had not received information about their wait.

	Colchester Hospital	Ipswich Hospital	James Paget Hospital	West Suffolk Hospital	Total sample*
Did not receive any information	48%	62%	52%	53%	54%
Received information	45%	33%	39%	43%	40%
Can't recall if received information	6%	4%	8%	5%	6%
Not answered	0%	1%	1%	0%	1%
Sample size	55	98	220	390	788

*Includes respondents waiting for care at any hospital.

Table 11: A comparison of people's perception of received information from hospitals if they had not been given an indicated wait time.

“Since I was referred in summer 2020, I have heard nothing, so any information or appointment would have been good!” (First appointment, waited over a year)

“Called [the hospital] several times to ask how far down the waiting list I am but no one could give me an answer. All I was told was that there were a lot of people ahead of me. In so much pain I am now going private. I feel very aggrieved after working 50 years and paying my dues that I now have to spend all my savings to get any quality of life.” (Operation, waited over a year)

“The fact that there’s no Comms between the consultant, hospital, GP, is horrendous! How long does it take to write a sentence?” (Operation, waited over a year)

Cancellations

One in five respondents (20%/286) said they had experienced a delay or cancellation to their planned appointments/procedures.

The proportion of respondents who experienced a delay were generally the same regardless of what procedure/treatment they were waiting for, with the exception of first appointment where only 8% of respondents said they had experienced a delay.

A slightly higher percentage of respondents waiting for care at Colchester Hospital reported they had experienced a cancellation (25% compared to 18/19% at each of the other three hospitals in the region), however the small sample size means this data should be treated with caution.

One in four respondents with a disability said they had experienced a cancellation, compared to one in five for those who were Carers, or who had a diagnosed mental health difficulty.

Whilst most respondents were notified at least a week before their procedure, this had not been the case for 44 (15%) respondents. They highlighted how cancellations had occurred on the day, and only eight of these respondents were given a new date for their appointment/procedure within 28 days of the original date.

Comments about cancellations of hospital care include:

“I had to take several days unpaid leave not to attend appointments that were cancelled on the day or new appointments sent followed by a cancellation letter and another appointment and cancellation all in one postman round.” (Diagnostic procedure, can’t recall how long waited)



“I got the cancellation by a TEXT with no return number. I felt very upset as I have been badly injured a long time & in much pain.”

(Something else, waited over a year)



“My operation was cancelled but I received no information and only found out when I turned up for the pre-admission Covid test in December 2020. Since then, I’ve heard nothing.” (Operation, waited over a year)

“It was just an unknown. We got new dates each time, but not at the time of cancellation, literally the night before though and had to travel again, only for it to be cancelled a few hours after we were there.” (Operation, waited over a year)



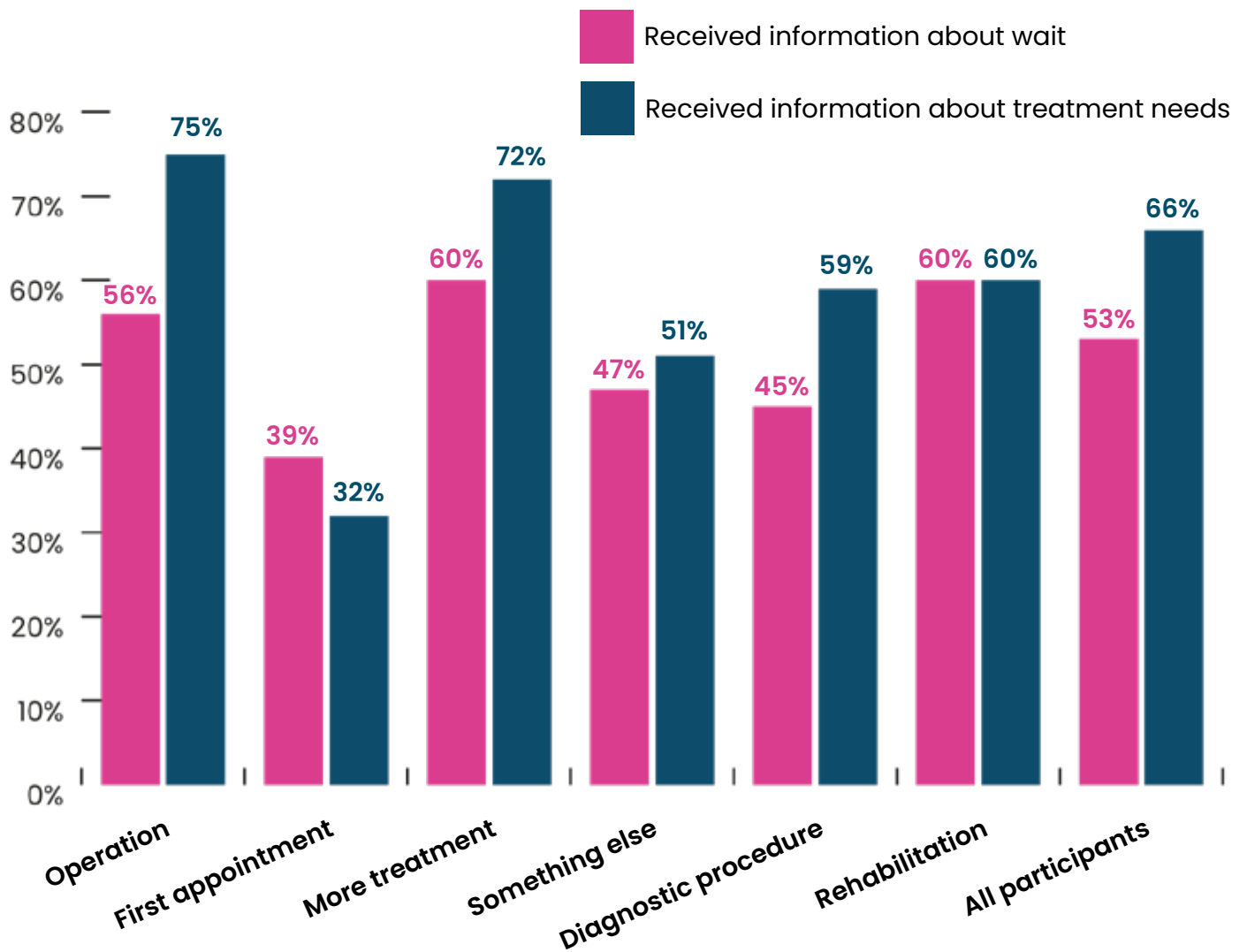
1 in 5 said they had experienced a delay or cancellation to their planned appointments.

5. Information and communication

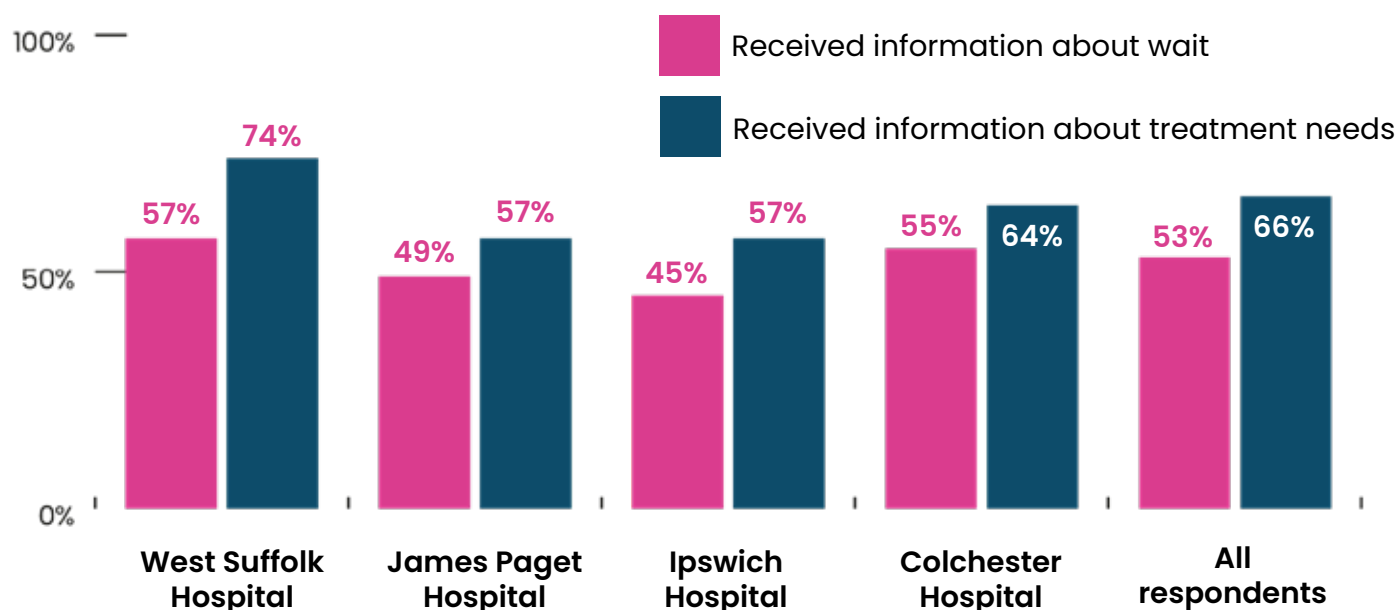
Provision of Information

Respondents were asked about the information they had received from hospitals about both their wait, and also their treatment needs or condition. It is important to note that Healthwatch Suffolk has not had access to the information, or communication, hospitals have shared with their patients. Our analysis, and the conclusions identified from them, are based entirely on people’s responses within the survey, and their free text feedback.

While 960 (66%) people said they had received information about their treatment needs, only 771 (53%) said they had received any information about their wait or delay. This disparity in the provision of information was consistent regardless of what people were waiting for, with the exception of respondents waiting for a first appointment where the provision of any information was particularly sparse.



Graph 8: A comparison of whether respondents had received information about their wait or treatment needs, and the type of treatment or care they were waiting to receive.



Graph 8: A comparison of whether respondents had received information about their wait or treatment needs, and their hospital.

Analysing the data by hospital similarly highlights that patients were more likely to have received information about their treatment needs versus the delay to their care. Other variations of note:

- patients at West Suffolk Hospital were more likely to have received information about either their treatment or their wait, than patients at other hospitals;
- Within ESNEFT, patients at Colchester Hospital were more likely to have said they had received information than those waiting for treatment from Ipswich Hospital (however the sample size for Colchester Hospital was much smaller).

Quality of information

Respondents were asked to indicate whether information they received was:

- clear to understand;
- sufficient/enough;
- provided in a way that was easy for them to access and took account of their communication needs.

Respondents' assessment of the information provided by hospitals was the same, regardless of whether it was in relation to their wait or their treatment, namely:

- Sixty per cent of respondents indicated the information was clear and easy to understand.
- Around 50% felt they had received enough information.
- Only one in five (20%) respondents reported that the information was easily accessible, and met their communication needs.*

*Question wording may have resulted in some under-reporting here. However, feedback received through our 'Your Care Your Way' campaign, exploring how services are implementing the accessible information standards across the NHS, has highlighted that people can experience difficulties with accessing information from services.

This includes that failure to account for people's communication needs and preferences is adversely impacting upon their experiences of waiting for hospital care.

An example of this type of feedback includes:

"I kept receiving phone calls from the hospital, but I could not answer—due to my deafness. Eventually, my hearing daughter answered the phone for me. The caller refused to accept my consent... She asked the hospital to write a note on my file, that I am deaf, and to please not phone and to instead send a letter. From there, I found out that I was on the waiting list for 62 weeks.

"...The pain was occurring again, so I saw my GP... I made several attempts to call the hospital and book an interpreter for my consultation but failed to get through. I went to my appointment anyway and, when the doctor found out that I was deaf, they seemed visibly irritated and threw their hands up out of frustration - which I found very offensive.

"... Afterwards, I was informed that I was on the priority list for an operation. I have since heard nothing from the hospital."

Our 'Your Care, Your Way' data highlights that many people can struggle to engage with services effectively when their needs for accessible information and support have not been met, and this must be an important consideration within the context of elective care delays. Some examples of feedback from people who are d/Deaf or hard of hearing include:

"Communication issues at appointments. Staff lower their face, and I can't understand. They insist on a phone consultation. My wife helps but that is not fair. Dentist is the same."

"My daughter (HoH) constantly feels demoralised at appointments for herself and her children as she can't understand. It affects her mental health. Taking in all the information is exhausting and feels demoralising."

"When I don't understand what staff say, I pretend I do as it's easier and less embarrassing. If I do say I don't understand I am deaf, they either talk really slowly exaggerated or give me a pity look. I don't want a label."

"There is lack of clarity between patients and Health and social care services, including surgeries and hospitals, about who is responsible for ensuring that interpreters are available to facilitate access and treatment for their deaf and deafened patients."

Healthwatch Suffolk will be sharing more data from the campaign on our website, please refer to: www.healthwatchesuffolk.co.uk/your-care-your-way/



“All information given was relevant and easily understood.”
(Operation, waited over a year)



Analysis of information by Hospital trust

Respondents waiting for care from ESNEFT (Colchester and Ipswich hospitals) were least likely to say the information they had been given about their wait had been clear and easy to understand. Conversely when it comes to information about their treatment, respondents waiting for care from Ipswich Hospital were more likely to say that it was ‘clear and easy to understand’.

More detail is included in table 12 and 13 below.

Information on wait


	Colchester Hospital	Ipswich Hospital	James Paget Hospital	West Suffolk Hospital
Clear information I could understand	50%	57%	60%	61%
Enough information given	57%	51%	48%	51%
Easy to access/took account of communication needs	17%	17%	16%	20%

Table 12: Respondents’ perception of the quality of information provided to them about their wait by each hospital.

Information on treatment

	Colchester Hospital	Ipswich Hospital	James Paget Hospital	West Suffolk Hospital
Clear information I could understand	40%	64%	61%	61%
Enough information given	60%	50%	48%	51%
Easy to access/took account of communication needs	23%	26%	20%	20%

Table 13: Respondents’ perception of the quality of information provided to them about their treatment by each hospital.



“I understand that there are long waiting times due to COVID, but a letter, or some kind of communication, confirming that people are still on the waiting list and that we haven’t been forgotten about would be helpful – rather than us having to call to check this.”

(Diagnostic procedure, waited over a year)

Improvements to information

Respondents were asked what could have improved the information they had received from the hospital. The following key themes emerged from the analysis of the free text responses provided by 706 people.

Theme	Count	Percentage
Information about wait time	425	45%
Regular updates & insufficient information	161	17%
Other	61	6%
Consistency	59	6%
Information about treatment/care/condition	50	5%
General positive	40	4%
No information received	39	4%
Information about cancellations	25	3%

Table 14: Table of themes identified from respondents' free text responses about improvements to communication and information about their wait and treatment.

Information about wait time

Four hundred and twenty-five respondents (45%) said they wanted improved information about their wait time.

Comments in this theme were subdivided into:

- Those who wanted more information about wait times for an operation (82 mentions).

"A rough idea when my operation was going to be." (Operation, waited over a year)

"Clear communication about waiting times. I was due to have a second hip replacement within 6 months of the first on - May 2021. No information forthcoming." (Operation, waited seven to 12 months)

- Those who wanted more information about a diagnosis, first appointment or other treatment (28 mentions).

"An initial call to advise when I would most likely be seen and what the consultation would involve." (First appointment, waited three to four months)

"They could have written or called me to tell me how long I would have to wait for my first appt. Instead, I telephoned them to be told the waiting list was 6 months and I have now been waiting for nearly 11 months.," (First appointment, waited seven to 12 months)

- General comments about wait times, not related to a specific procedure (315 mentions). Across all comments within this theme, some key messages emerged. Respondents said they wanted:
 - » More, or better, information about the length of their wait. This was often linked to a need for respondents to 'plan their life'.

"They sent a letter apologising for the delay .. but can give no time as to how long I will wait." **(More treatment, waited over two years)**

"I would like to know how long I will have to wait as have a son with down's, and I am a full time carer." **(Operation, waited over a year)**

"Not knowing how long I have to wait, I cannot plan my holidays or days out." **(Operation, Waited five to six months)**

- » Information about their position on a "waiting list".

"An actual indication of where I stand on the waiting list for hip replacement surgery." **(Operation, waited over two years)**

"Having an expected duration of wait time rather than just being told I am 'on the list'. No indication of where I am on the list or how big the list is." **(Operation, waited over two years)**

- » Reassurance that they were still on the waiting list.

"Confirmation that I am still on the waiting list would be beneficial." **(Operation, waited over a year)**

"A simple letter to keep us updated on current waiting times and just



"I would like to know how long I will have to wait as have a son with Down's [Syndrome], and I am a full time carer."

(Operation, waited over a year)



425 people said they wanted to see improvements to information about their wait time. Many were left unsure about when their procedure might take place, or even if they remained on the waiting list.

acknowledge we were still even on the list!" (Operation, waited over a year)

"I understand that there are long waiting times due to COVID, but a letter, or some kind of communication, confirming that people are still on the waiting list and that we haven't been forgotten about would be helpful - rather than us having to call to check this." (Diagnostic procedure, Waited over a year)

- » An accurate, or realistic, estimate of date for when they could expect to receive treatment. Some respondents commented that, having waited months with no information, they suddenly received notice that their procedure was going ahead in a matter of days or weeks.

If I was given a timescale or a minimum amount of time i.e. it won't happen till after 'x' date." (Operation, waited over two years)

"Given an estimated date of procedure rather than 'wait for a phone call, you're 21st in line'. Then when I got the phone call, it was to have it done the next day." (Diagnostic procedure, waited seven to 12 months)

"Went from being told over a year to hearing nothing for over a year, then to be told its in five weeks time." (Operation, waited over a year)

Regular updates and Insufficient information

Closely linked to the section above, comments under this theme specifically mentioned the need for regular 'updates' on waiting times. Comments also highlighted the need for hospitals to take a proactive approach to providing information, and not leaving it to the patient to repeatedly chase for updates.

It is clear that many people have felt that there has been an absence of information. It is worth noting that some respondents mentioned how the stress and anxiety of 'not knowing' was having a direct impact on their mental health and emotional wellbeing. In total, 161 comments were included in this theme.

Examples of feedback include:

"An update every three to six months on what is happening/approx length of delay, if possible, would have been appreciated and help toward alleviating stress already caused by constant pain." (Operation, waited over two years)

"To keep updated. It's not good for the patient to keep calling for updates. It's their duty to inform us as patients have too much stress & in pain with the backlog of waiting for ops." (Operation, waited over two years)

"A simple letter to keep us updated on current waiting times, and just acknowledge we were still even on the list!" (Operation, waited over a year)

"I have not been contacted about delays I have just been left waiting, I have tried calling and the phone rings out." (First appointment, waited 7-12 months)

“When cancelling a reason would have been nice, so I understood more.” (Operation, waited over two years)

Consistency of information provided

Fifty-nine respondents commented on a lack of consistency in the information they had received, leading to confusion and frustration for many. Comments also highlighted a lack of communication between primary and secondary health care, and between departments within the hospital.

Examples of feedback include:

“Cancelling a f2f appointment for a telephone appointment and then the consultant saying ‘Oh you need to be seen’ isn’t helpful.” (More treatment, waited over two years)

“Last appt with knee surgeon was early June 2021. I was told my operation would be six to nine months as I was on the emergency list. When checking with appointments, I was told I was on the general list and my op could be two years.” (Operation, Waited over a year)

“Explained to me about stopping hrt meds. Got 2 weeks’ notice for an appointment to go in to have 2 hernias repaired but couldn’t because had to stop HRT four weeks prior to admission. Lack of communication.” (Operation, waited seven to 12 months)

“There is a lack of communication between doctors and consultants, and administration. When trying to get information from consultants – if you have a problem with your procedures, it’s always leave a message and they’ll get back to you. They never do. Or if they do, you are told to go to A&E.” (More treatment, waited five to six months)

“I have been told on three occasions that my test results will be sent to myself and my GP following a primary care mis-diagnosis.” (Something else, waited up to two months)

“I need a medication review which the GP will not do because the Hospital consultant has not fed back results. The hospital says the staff member to do this is off unwell. Communication ability has to be a must in these situations. After finally getting the tests, it is incompetent not to be able to feed them back to the patient and primary care.” (Something else, waited up to two months)

A further twenty-three respondents highlighted the need for there to be more clarity when using terms such as ‘emergency’ or ‘urgent’.

“I was advised by the consultant that I’d been put on his urgent list in September 2019, I have heard NOTHING since...” (Operation, waited over two years)


“I was referred for an ‘urgent’ biopsy seven months ago and haven’t heard anything since.” (Diagnostic procedure, waited seven to 12 months)

“In September 2020, the specialist told me that the operation was ‘urgent’ and, despite my weight, he would go ahead in the next few months. Then there was the Delta outbreak and after that had died down, I contacted the hospital and was told that it could take another

two years plus before the operation.” **(Operation, waited over a year)**

“I was told it was ‘emergency’ surgery and I would have it in July. Still waiting February 2022 ???” **(Operation, Waited seven to 12 months)**

“I was told that the operation would be within three months, it’s now been over two years and I was also told I would be put on the emergency list.” **(Operation, waited over two years)**



“The leaflets I was given at my pre assessment about my procedure and recovery were generic, and not in line with the information that the specialist had given me. It made it harder to plan for my recovery and notify my work of how long I would be absent.”

(Operation, waited up to two months)

Information about treatment/care

Fifty respondents said they would like to have received more information about their procedure. Suggestions included information about their consultant's name, what to expect, and how to manage pain and/or symptoms whilst they were waiting.

Examples of feedback include:

"Explanation of what to expect in the form of health deterioration." (Operation, waited seven to 12 months)

"More thorough understanding of possible side effects of my condition." (Something else, waited over a year)

"Telling me what my appointment is for and who it is with." (First appointment, can't recall how long waited)

"I was not made fully aware of the potential for severe pain if I went for the procedure with local anaesthetic. It was only after conducting my own research that I found this out." (Operation, waited three to four months)

"It is a clinical standard letter of notification that an appointment has been arranged or cancelled and rearrange. There is no care information, or information about where or how to access advice to manage the condition while waiting." (First appointment, waited seven to 12 months)

"What to do if the situation becomes more uncomfortable. How to deal with anxiety and stress over the pain in your tummy – is it getting worse." (Operation, waited seven to 12 months)

General positive

Forty respondents indicated that they were generally happy with the information received, and did not provide any suggestions for further improvements.

"My treatment by the Hospital could not have been bettered, and I was given clear information." (Diagnostic procedure, waited up to two months)

"I have had the confirmation that I'm on the pathway and, to be honest, I'm quite happy with that." (Operation, waited five to six months)

"They worked so hard in keeping me up to date. At that time, it was impossible to improve on their efforts. All their efforts were much appreciated." (Operation, waited over two years)

No information received

Thirty-nine respondents highlighted the general lack of information they had received from the hospital.



“No one has contacted me regarding my operation. It was cancelled in February 2021. I have phoned once, but got no information.”

(Operation, waited 7 - 12 months)



“I have had no communication since the day of my last appointment a year ago.”
(Operation, waited over a year)

“I have been told I need my gall bladder removed, no further advice or information given.”
(Operation, waited five to six months)

“Expected to undergo a procedure/small operation within a few weeks - signed consent forms in September 2020, and heard nothing else.” **(Operation, waited over a year)**

“I was told in August 2021 that I would receive keyhole surgery to assess the problem with my failed knee operation within three months. I have heard nothing since.” **(Something else, waited seven to 12 months)**

Information following cancellation

Twenty-five respondents commented on the need for improved communication following a cancelled procedure or appointment.

Respondents said they wanted:

- more notice that their procedure was going to be cancelled;
- better information about why treatment had to be cancelled;
- a date or timescale for when their procedure would be rearranged.

“My operation was cancelled, but I received no information and only found out when I turned up for the pre-admission COVID test in December 2020. Since then, I’ve heard nothing.” **(Operation, waited over a year)**

“It was just an unknown. We got new dates each time, but not at the time of cancellation, literally the night before though and had to travel again, only for it to be cancelled a few hours after we were there.” **(Operation, waited over a year)**

“The hospital should have communicated to me to explain that they were not able to conduct my operation, rather than letting me go to all of the assessments and procedures of admission, and then sending me back whilst I was already in the theatre room. After being starved all day. And then send home without valid explanation.” **(Operation, waited over two years)**

6. The impact of hospital delays

In this section we explore the impact delays in treatment have had on people’s lives.

Changes in condition

Respondents were asked whether their condition had changed whilst they waited for treatment.

Many respondents (62%/911) felt their condition had got worse whilst waiting for treatment.

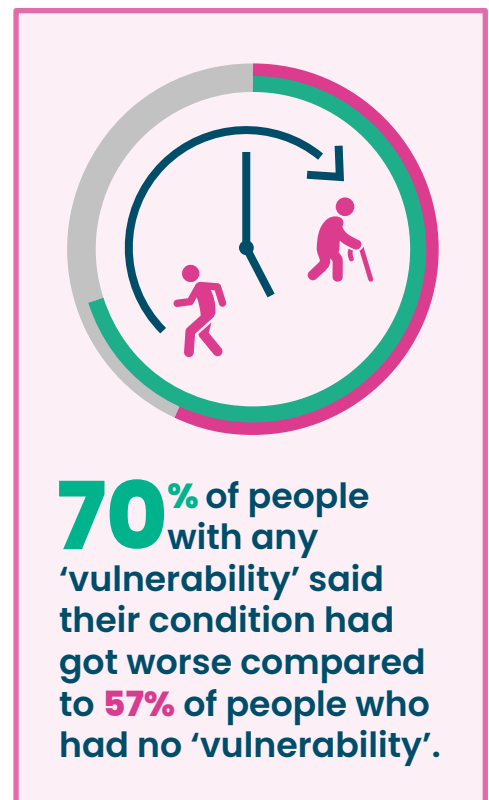
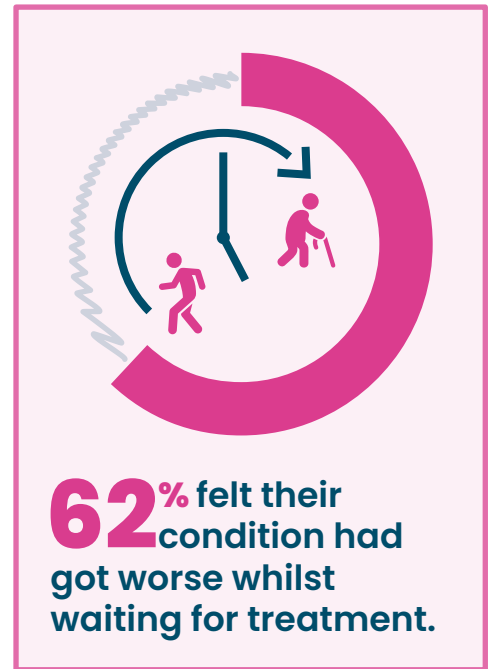
This was followed by 388 (27%) respondents who had not noticed a change to their condition. Only 3% of respondents felt their condition had got a little better, with one respondent noting “the delay has given my body more time to heal”.

	Respondents	Percentage
Yes, it’s got worse	911	62%
No, it hasn’t changed	388	27%
Yes, it’s got a little better	44	3%
Don’t know/Not answered	119	8%
Total	1,462	100%

Table 15: Respondents’ self-assessment as to whether their condition had changed whilst they were waiting for hospital care.

Respondents who had been waiting the longest, those waiting for an operation, and those who had one or more of the listed ‘vulnerabilities’ were more likely to say that their condition had deteriorated during their wait:

- Seventy-four per cent of respondents who had waited over two years said their condition had deteriorated, compared to 62% of all respondents.
- Seventy per cent of respondents waiting for an operation said their health had got worse, compared to 56% for those waiting for a diagnostic procedure and 47% each for those waiting for ‘a first appointment’, ‘more treatment’ and ‘something else’.
- Seventy per cent of respondents who had one or more ‘vulnerability’ said their condition had got worse, compared to 57% of those who had no ‘vulnerabilities’.



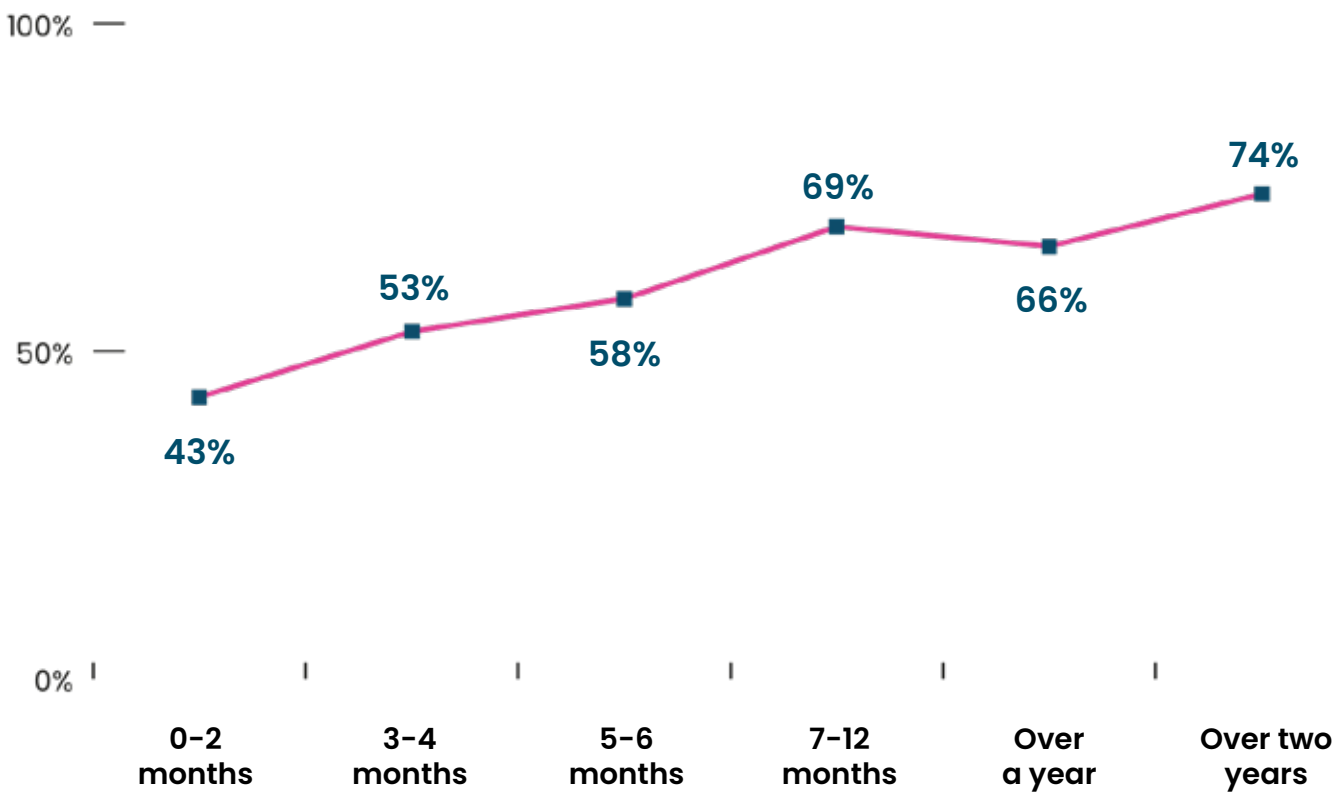


"I have gone from a very fit and active person to a person who can barely leave the house because of mobility and pain issues. I need help to bathe, get dressed, my housework and cooking. Every factor of my former life is gone."

(Operation, waited over two years)



Graph 9: The percentage of respondents who said their condition had got worse, and their length of wait.



Life aspects

Respondents were asked what impact the delay in treatment had on the following eight aspects of their lives:

- Ability to work
- Ability to carry out daily household tasks
- Ability to care for someone else or children
- Increased the level of pain experienced
- Affected my mental health and wellbeing
- Affected my family life
- Affected my social life
- Affected my ability to be part of my community

One thousand and forty-seven (70%) of respondents reported that the wait for treatment had impacted multiple aspects of their lives. On average, respondents indicated that the wait had impacted 3.7 different areas, and almost a third of respondents (31%/463) said that six or more aspects of their life had been affected.

	Count	Percentage
Zero	271	19%
One	144	10%
Two	131	10%
Three	124	8%
Four	145	10%
Five	174	12%
Six	197	13%
Seven	168	11%
Eight	98	7%
Grand total	1,462	100%

Table 16: The number of life aspects people indicated had been impacted by their wait for hospital treatment or care.

Respondents in the following groups reported the biggest impact on their lives (measured by the average number of aspects affected):

- those who had been waiting over two years for their treatment (average of 4.6), compared to those, waiting 0-2 months (average of 2.5);
- those who said that their condition had got worse whilst they waited (4.7), compared to 2.7 for those whose condition had not changed);
- those who had any of the listed vulnerabilities (4.5), compared to those who did not (3.2);

"My entire life, and my family's lives, revolve around my illness which is extremely stressful and can be isolating as not everyone understands."

(Operation, waited over a year)

- those aged 25-64, compared to those in either the youngest or oldest age groups.

Overall, increased level of pain was the aspect most frequently mentioned by respondents (77%). This was followed by impact on social life (72%), impact on mental health and wellbeing (66%), and ability to carry out daily household tasks (65%).

Summary of impacts

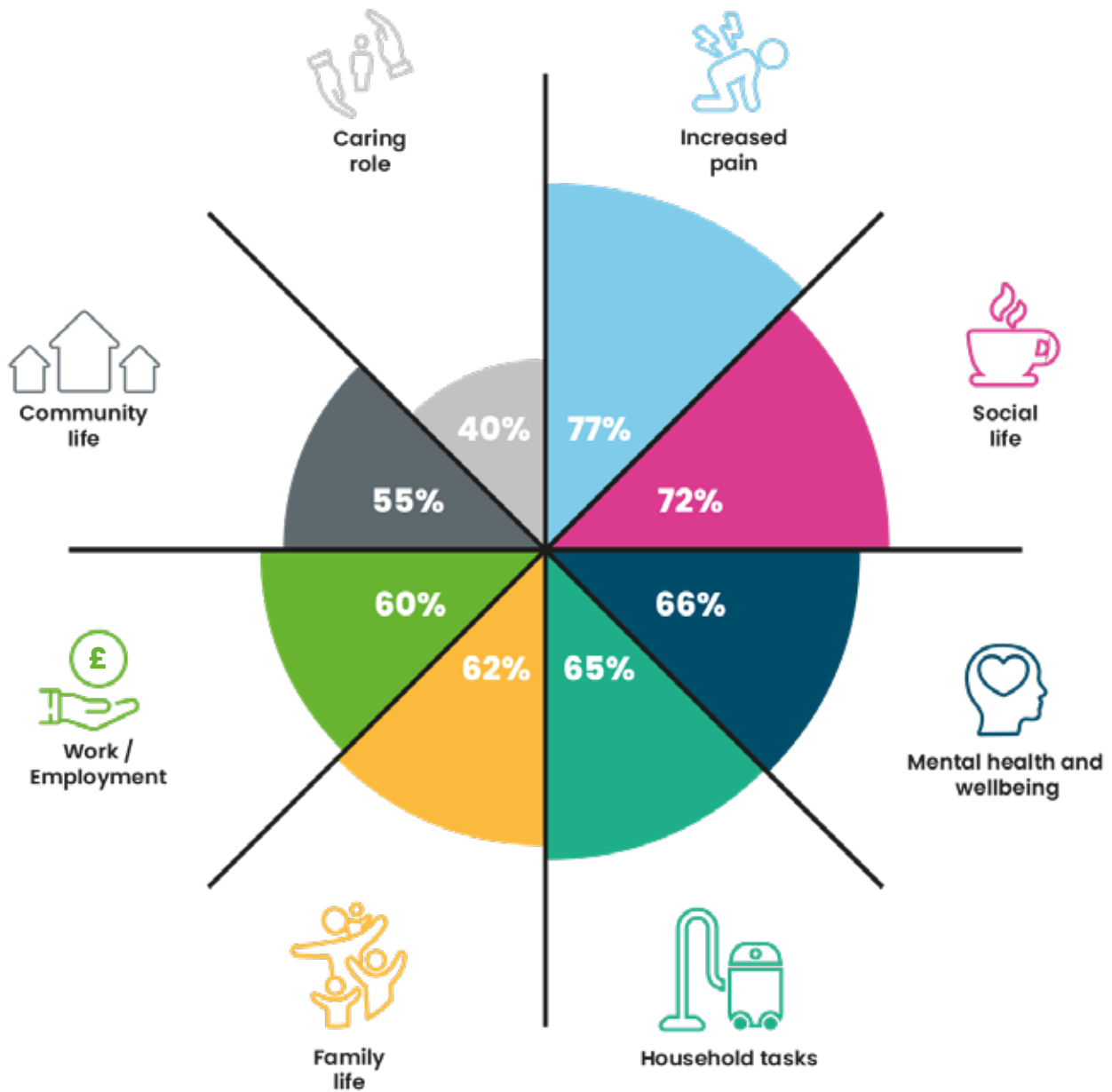
	Total	Gender		Ethnicity		Vulnerabilities				
		Female	Male	Non-white	White	Mental health	Carer	Disability	LD/autism	None
Pain	77%	76%	77%	86%	76%	84%	76%	89%	84%	72%
Social life	72%	73%	70%	77%	72%	82%	78%	86%	71%	66%
Mental health	66%	69%	60%	75%	66%	87%	72%	77%	83%	59%
Housework	65%	66%	63%	77%	65%	75%	72%	88%	74%	56%
Family life	62%	64%	58%	69%	62%	71%	68%	76%	69%	56%
Work	60%	58%	61%	74%	59%	69%	76%	82%	68%	51%
Community life	55%	57%	51%	52%	55%	67%	64%	76%	70%	46%
Caring role	40%	40%	37%	47%	38%	43%	60%	68%	42%	29%

Table 17: The percentage of people who indicated each life aspect had been affected by their wait for hospital care, including their gender, ethnicity, and whether they had identified with any of the 'vulnerabilities' in the survey.

Our findings were generally in line with those of the Healthwatch England report on waiting for elective care:

- the proportion of respondents who reported they had experienced an increase in levels of pain whilst waiting for care was similar across both surveys (77% for Healthwatch Suffolk, and 73% for Healthwatch England);
- sixty-eight per cent of the Healthwatch England sample reported that their wait had impacted on their ability to undertake day-to-day household tasks, compared to 65% within the Suffolk sample;
- the percentage of respondents who said their ability to work had been affected was comparable across the two surveys, although slightly higher for people living in Suffolk (60%, compared to 55% for Healthwatch England);
- exactly 40% of both samples said their ability to care for someone else had been impacted.

The results of the two surveys, however, differ on the proportion of people who reported their mental health and wellbeing had been impacted. Healthwatch England data indicated as many as four in every five people had experienced an impact on their mental health and wellbeing (80%), whereas data for Suffolk was closer to one in three (66%).



77% of people mentioned that increased pain was having an impact on their life because of their wait for treatment or care.

Other frequently mentioned aspects of life impacted by hospital delays included **social life (72%)**, **mental health and wellbeing (66%)**, and **ability to carry out daily household tasks (65%)**.

The influence of other factors on the impact of waiting for hospital care

Age

Key findings included that:

- although the percentage of respondents reporting increased pain levels was high across all age groups, older respondents (aged 55+) were most likely to say their levels of pain had been affected;
- respondents aged under 65 were more likely to report that their mental health and wellbeing had been affected compared to older respondents (aged 65+);
- people aged between 25 to 34 were most likely to say their mental health had been impacted (85%);
- older respondents aged 75+ were more likely to say that they were struggling to manage household tasks;
- over three quarters of people aged 85+ said their family life had been impacted, and older respondents were also more likely to say that their social lives and ability to take part in their community had been affected. For some, this had resulted in a growing sense of social isolation.

	<25	25 - 34	35 - 44	45 - 54	55 - 64	65 - 74	75-84	85+	Total
Increased pain	71%	75%	69%	74%	81%	76%	81%	79%	77%
Social life	68%	73%	65%	69%	75%	72%	74%	74%	72%
Mental health and wellbeing	70%	85%	76%	73%	71%	57%	55%	58%	66%
Household tasks	47%	64%	53%	62%	63%	68%	75%	76%	65%
Family life	50%	58%	66%	65%	61%	60%	63%	76%	62%
Work	38%	60%	58%	54%	62%	61%	70%	60%	60%
Community life	45%	54%	48%	48%	55%	54%	65%	62%	55%
Caring role	14%	44%	39%	31%	39%	42%	52%	29%	40%

Table 18: Aspects of life impacted by elective care delays, and the age of respondents.

Vulnerabilities

Key findings included that:

- respondents with any of the listed vulnerabilities were more likely to say hospital delays had impacted their lives;

- respondents diagnosed with a mental health difficulty were much more likely to say they had experienced increased pain (84%), that their mental health and wellbeing (87%), and their social lives, had been affected (82%);
- Carers were the most likely to say their ability to care for someone else had been impacted (60%), and a high proportion of people with a disability also said their ability to provide care had been affected (68%);
- respondents with a disability were more likely to report that the wait for treatment had led to an increase in pain (89%), and that delays to treatment had affected their ability to undertake household tasks (88%);
- increased pain, and impacts on mental health, were the aspects of life most affected amongst people with Autism or a learning disability.

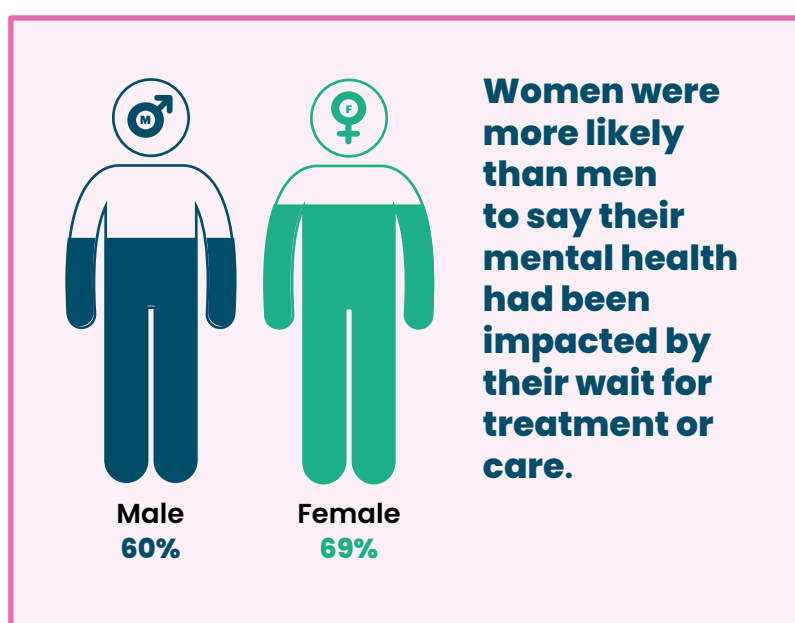
	Total	Vulnerabilities				
	Sample	Mental health	Carer	Disability	LD/autism	None
Increased pain	77%	84%	76%	89%	84%	72%
Social life	72%	82%	78%	86%	71%	66%
Mental health and wellbeing	66%	87%	72%	77%	83%	59%
Household tasks	65%	75%	72%	88%	74%	56%
Family life	62%	71%	68%	76%	69%	56%
Work	60%	69%	76%	82%	68%	51%
Community life	55%	67%	64%	76%	70%	46%
Caring role	40%	43%	60%	68%	42%	29%

Table 19: Aspects of life impacted by elective care delays, and respondent vulnerabilities.

Gender

Key findings included that:

- women were more likely to report that their mental health and wellbeing had been impacted by the wait for care (69%, versus 60% for men);
- women were also more likely to say that their family life (64%), and community life, had been affected;
- men were more likely to say that their ability to work (61%) had been affected compared to women (58%).



Qualitative insight – the impact of waiting

A total of 77% of respondents told us that they had experienced increased pain during their wait.

They commonly used words or phrases such as ‘agonising’, ‘severe’, ‘chronic’, ‘unbearable’, ‘immobilising’, and ‘extreme’ to describe the pain they had been experiencing. For some, the pain had become so severe that they were finding it difficult to walk, work, and participate in everyday activities. This highlights the significant impact pain can have on all aspects of a person’s life, including their mental health, their mobility (and therefore ability to exercise or keep healthy), their ability to work, and to socialise.

Comments included:

“The pain is constant nearly every day, I just got used to it, sometimes reducing me to tears.” (Operation, can’t recall how long waited)

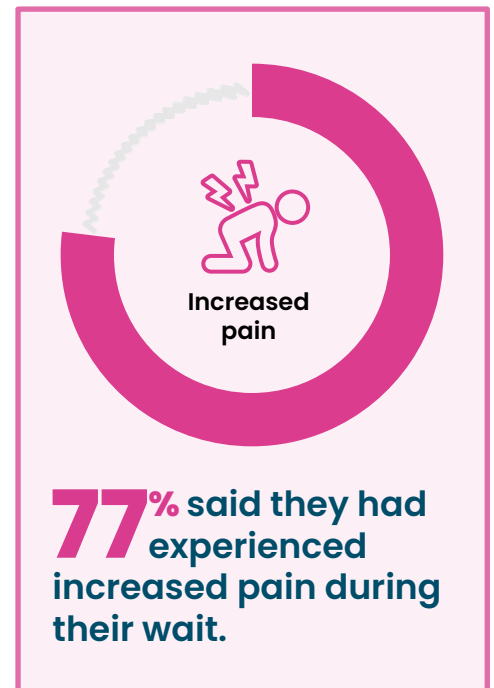
“I have suspected endometriosis and an endometrioma that needs removing. Because the pain has become so unbearable, I have had to switch my work contract to bank so I can work around the pain. I have had to take painkillers so regularly (which isn’t something I like to do), which had let to other parts of my body becoming affected. It’s been really hard mentally dealing with this and trying to be the mum I want to be whilst in pain and feeling uncomfortable.” (Operation, waited seven to 12 months)

“... No updates on wait times, nothing at all. My condition is worsening (endometriosis and fibroids) and pain increasing. There was not even a recognition of the results of my internal scan which I had after the appointment. I am in agony, and nobody cares. Absolutely not good enough. Typical for women’s health.” (Operation, waited over a year)

“I feel so very low and in constant pain. I just want my life back and not be in pain anymore.” (Operation, waited seven to 12 months)

“I want to exercise. Following a previous heart attack, I need to exercise, but instead I tend to rest and put on weight! I would like to explain this to someone but there is nobody to tell.” (Operation, waited over a year)

“The pain that I experience causes me to wish that when I go to bed, I don’t wake up to another day to face.” (Operation, waited over two years)



“The pain can be so unbearable that I am in danger of passing out or throwing up and so cannot leave the house.”

(More treatment, waited 7 - 12 months)





"I am now frightened of eating. I look at a plate of food and filled with fear. The pain experienced and not being far from a toilet after eating significantly impacts my social life that I no longer wish to socialise with friends."

(First appointment, waited 7 - 12 months)



Seventy-two per cent of respondents said their social life had been impacted whilst they wait for treatment.

Those who chose to describe an impact on their ability to be social also tended to highlight other factors in their comments that were limiting their ability to leave their home, participate in their local communities, or to interact with their family and friends. This included increased pain, reduced mobility, and poor mental health and wellbeing. The quotes below highlight the growing sense of isolation that some people experienced.

"Unable to participate in any social activity that involves dancing, walking or volunteering." (Operation, waited over two years)

"I don't leave my home as condition has got so much worse. I don't socialise at all." (Operation, waited seven to 12 months)

"Cannot go out for social meals etc. as either choke on food or vomit, so avoiding food is the better option for me. This is impacting my life as reluctant to go out." (Operation, waited seven to 12 months)

"My social life now is non-existent. My friends and even now my family have stopped including me in plans because they assume I can't take part because of my pain. I feel really isolated." (Something else, waited zero to two months)

Sixty-five per cent of respondents said they found it difficult to undertake household tasks.

In some cases, this had resulted in an increased reliance on family members to provide care. Respondents who referred to an inability to undertake household tasks, also commonly mentioned limiting factors such as increased pain levels, and reduced mobility.

"I can no longer walk any distance and to complete upkeep of everyday mending or DIY tasks around the home." (First appointment, waited five to six months)

"Shopping is difficult, bed changing, vacuuming, window cleaning, meal preparation, gardening and most everyday tasks." (Operation, waited over a year)

"I am unable to do anything physical for more than about half an hour, and sometimes even visiting the local supermarket can be agony. This also affects my ability to do



"I have become more reliant on my daughter who is a single parent for household chores i.e. cleaning, getting rid of household rubbish and taking me to hospital appointments."

(Operation, waited over a year)

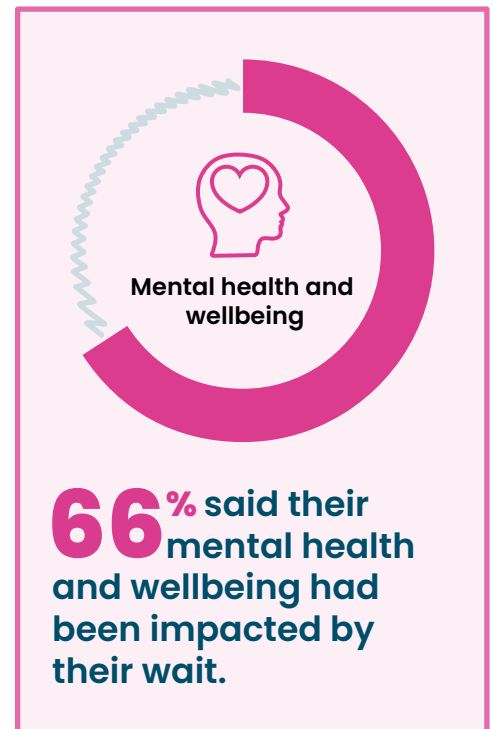
gardening, decorating, housework, and car cleaning.”
(Operation, waited over a year)

“Housework has become a huge challenge due to my increase in pain and lack of mobility.” **(First appointment, waited three to four months)**

“It has made everyday tasks much harder and I’ve had to rely on my teenage children to care for me.”
(Operation, waited seven to 12 months)

Two-thirds of respondents (66%) said their mental health had been negatively impacted.

People reported being ‘depressed’ and ‘withdrawn’, and some highlighted impacts on their ‘self-esteem’ and ‘confidence’. Other limiting factors mentioned by respondents who said their mental health had been affected included lack of sleep, weight gain and increased pain. Some respondents reported that they had experienced suicidal thoughts.



“It’s very worrying, I am immunosuppressed and at higher risk of developing skin cancer.”
(Diagnostic procedure, waited seven to 12 months)

“Since 2016, I have had many, many suicide attempts because I could not stand this pain in my mental health any longer. Since 2013, my mental health has been taking a nosedive, and I am amazed that I am here writing this today. For me personally, it would be a blessed relief achieving stopping my life going forward any longer. People do not understand mental health...” **(Something else, waited over two years)**

“I’ve been consistently misdiagnosed by the NHS for 15 years. Paying for a private scan has shown the extent of my disease and delays in appropriate care and diagnosis by the NHS now means my endometriosis has impacted my bowel. I’m in constant daily pain but because endometriosis is a ‘benign’ disease, and my surgery is classed as ‘elective’ I’m at the bottom of the priority list. I feel hopelessly let down.” **(Operation, waited over a year)**

“The stress of not having support for my child has made my mental health a little poorer, I have anxiety and am emotional as cannot help him. Especially as my husband has cancer.”
(First appointment, waited five to six months)

“Continuous interrupted sleep several times a night is debilitating.” **(First appointment, waited over a year)**

Sixty-two per cent indicated that waiting for elective care had affected their family life, and the relationships they have with their friends and relatives.

The comments from respondents highlight that waiting for elective care has a direct impact on the person who is waiting for treatment and care, but that it can also affect the people

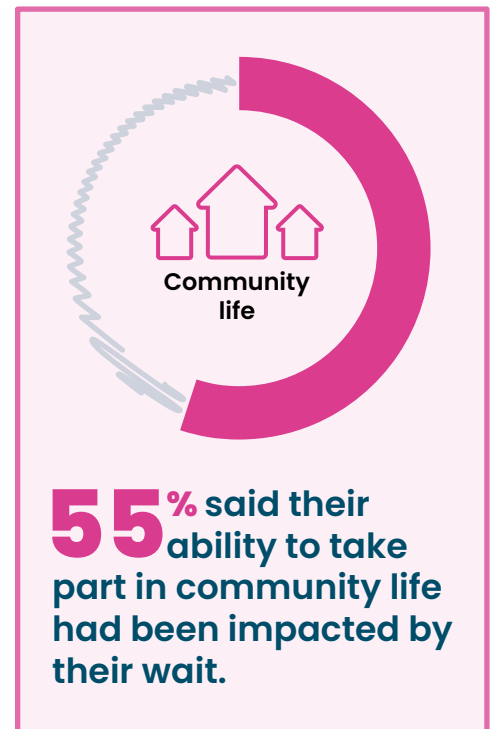
around them too.

"My family suffer because I won't go out for dinner or out with friends. I have a disabled daughter I care for as well." (Something else, waited seven to 12 months)

"I was stuck in bed in pain constantly. It took such a toll on my marriage, we ended up separating." (First appointment, waited five to six months)

"I can't play or do things for my children, it's affected my mental health and I already have PTSD. It's affected my relationship because I'm always depressed." (Something else, waited over two years)

"My whole life has been put on hold. I met my husband in late 2014. Since 2017. I have become increasingly disabled and frustrated that we cannot do the things a couple in a new relationship should be doing." (Operation, waited over a year)



Fifty-five per cent said their ability to take part in community life had been impacted by their wait for treatment or care.

The comments from respondents reveal how this has had a detrimental impact on people's ability to keep healthy, active, and socially connected within their community. This includes, for example, limiting the extent to which people can participate in grassroot groups, hobbies, and volunteering activities that are known to have a positive impact on general wellbeing.

"My hands are constantly swollen and painful all the time. Which prevents me taking part in anything in my local community. I just want to stay in and not head out anywhere." (Operation, waited five to six months)

"I am an active retired man who is part of a few organisations and the pain restricts me from being fully active." (Operation, waited over a year)

"I belong to [a local] volunteer service but have been frustrated that I was unable to help out... due to the length of time required [to stand], and have been unable to participate in the litter picks organised by my local residents' association." (Operation, waited over a year)

"Cut off from group activities i.e. family carers group." (Diagnostic procedure, waited three to four months)

"I find it almost impossible to carry out my charity work." (Operation, waited seven to 12 months)

Sixty per cent of respondents felt their ability to carry out tasks at work had been negatively impacted by their wait for treatment.



"I cannot work and I am finding it very difficult to manage financially. I can't drive very far as the problem is my right knee. I am in great pain most of the time so cannot really live a normal life."

(Operation, waited 7 - 12 months)



For some, the impact of their wait for treatment meant they had needed to leave work or retire early. This had also negatively impacted their wellbeing for several reasons, including financial stress or insecurity, and social withdrawal. Respondents described how their condition had left them unable to lift heavy objects, drive for long periods of time, be on their feet, carry out usual tasks due to pain, and commit to regular working hours.

In some cases, the respondents' condition had meant their performance at work was negatively affected. This was leading to considerable stress and anxiety.

"I have spent a lot of time feeling too ill to do much, which has had an impact on every part of my life. The pain has also affected my ability to concentrate which has made even working from home difficult, and me making mistakes due to this has really had a negative effect on my mental health." **(First appointment, waited five to six months)**

"It's hard for me to work but I have to go through the pain barrier as I can't afford to not work." **(Something else, waited zero to two months)**

"I'm under pressure at work to do my workload, which I cannot manage." **(Operation, waited over a year)**

"I haven't worked for two years and find it impossible to get help, the only financial help is universal credit so things are really tough... My mental health has suffered tremendously." **(Operation, waited over a year)**

Forty per cent said their ability to care for others had been impacted.

Their comments highlight how this was having a negative impact on the care and support of others (e.g. elderly relatives or grandchildren), and also other aspirations (e.g. family planning). Comments were often qualified by limiting factors such as levels of pain and lack of energy.

"I have an elderly parent whose care has suffered because of my pain." **(Operation, waited over a year)**

"My pain levels mean that it's incredibly hard to care for my children." **(Something else, waited zero to two months)**

"Cannot care for my family." **(Operation, waited over a year)**

7. Provision of support whilst waiting

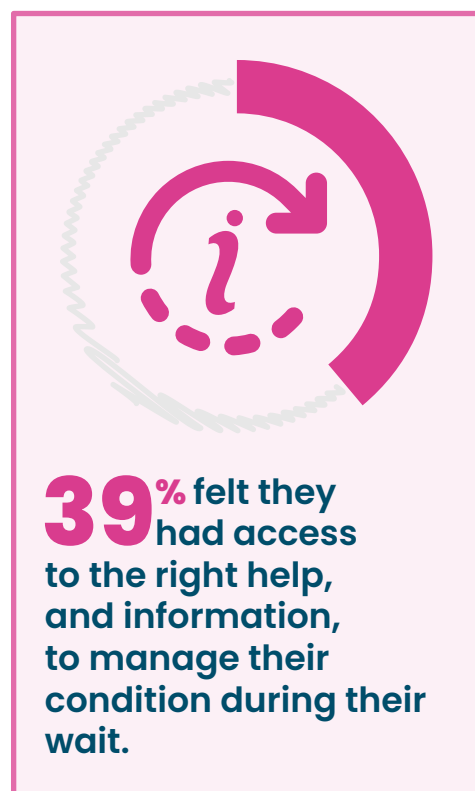
Respondents were asked about the support they had been offered whilst waiting for care, including how they had been helped to manage their condition and their symptoms.

Support to manage condition

Only 563 (39%) respondents felt they had access to the right help, and information, to manage their condition during their wait.

Variations of note include that:

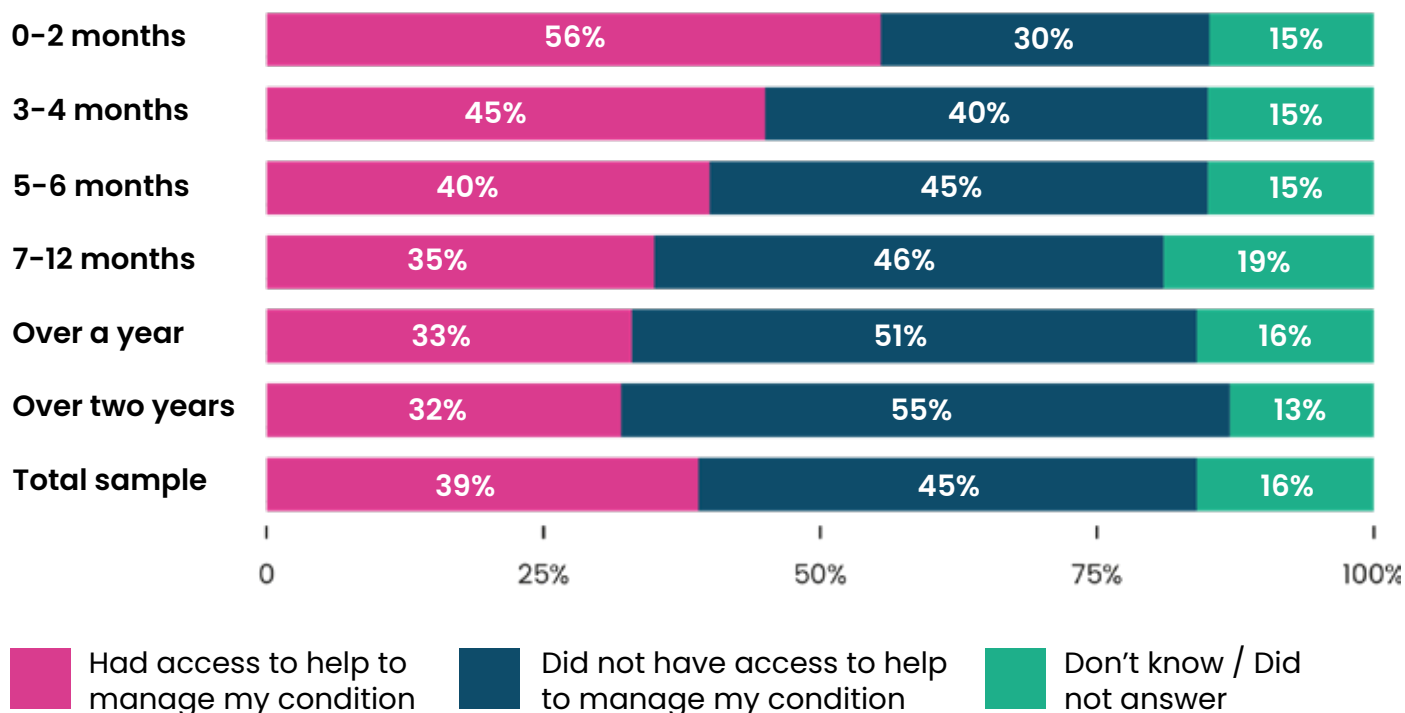
- people waiting for a first appointment, or a diagnostic procedure, were least likely to feel supported to manage their condition (26% and 23% respectively), whilst those who were waiting for 'some more treatment' were most likely to feel supported (48%);
- respondents who had been waiting over two years for treatment also felt less supported to manage their conditions than those who had been waiting a few months (32% compared to 56% for those who had been waiting zero to two months);
- forty-three per cent of men said they felt supported compared to 36% of female respondents;
- respondents with a vulnerability were less likely to say they felt supported to manage their condition – 30% of respondents with a diagnosed mental health problem, 31% of Carers, and 34% of people with a disability said they felt supported compared to 41% of those with no vulnerability;
- respondents living in the west of the county (Babergh, Mid Suffolk and West Suffolk) were more likely to report that they had been able to access support to manage their condition compared with people living in other areas;
- a high proportion of respondents living in Colchester also felt supported, however, the small sample size (39) means it is difficult to draw any reliable conclusions from this.



Support to manage symptoms

Forty percent (589) of respondents indicated that the hospital, or their GP, had helped them to manage symptoms whilst they had been waiting for treatment.

Again, respondents who were waiting for a first appointment or a diagnostic procedure were least likely to feel supported (33% and 29%), and those who were waiting for 'something else' were the most likely to report that their GP or the hospital had helped them with symptoms (49%).



Graph 10: Responses to the question 'Do you feel you have access to the right help and information to manage your condition whilst you are waiting?', and their length of wait.

Other variations of note include that:

- women were more likely to say they had received support to manage their symptoms (41%) compared to men (38%);
- respondents with a disability were more likely to have been supported with managing symptoms (45%);
- respondents living in the west of Suffolk generally felt more supported;
- only 26% of respondents waiting for care at Colchester Hospital said they felt supported, compared to more than 40% at other hospitals - however, it should be noted that the sample size of patients waiting for care at Colchester was small (55).

	Percentage supported
Colchester Hospital	25%
Ipswich Hospital	46%
James Paget University Hospital	40%
West Suffolk Hospital	42%

Table 20: The percentage of respondents who said they had been helped by the hospital or their GP, and their hospital.

Support offered

Respondents were given a list of different types of support. They were asked to indicate whether they had been offered each one, and how helpful they had found it.

Overall, 82% (1,198) of respondents said they had been offered some form of support.

Respondents who said they had a disability were slightly more likely to say they had been offered support (89%/285) compared to those with other vulnerabilities such as a mental health diagnosis (84%/152) or being a Carer (81%/93).

Respondents reported that they were most likely to have been offered 'health-related' support, such as:

- information on treatment (53%/749);
- information on condition (47%/676);
- support from their GP (46%/649);
- support with pain relief (45%/624).

They were least likely to have been offered support related to:

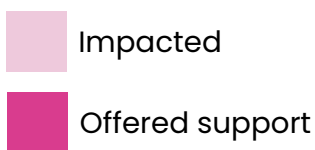
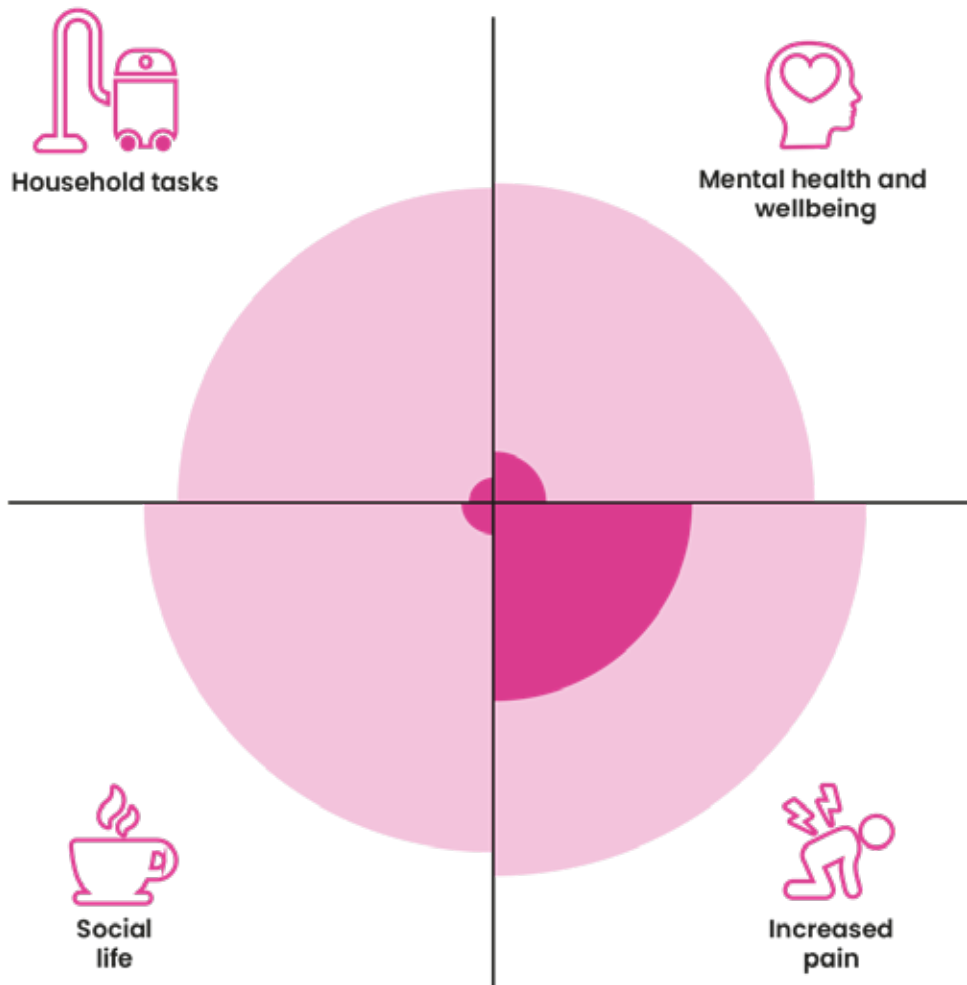
- community and charity organisations (6%/83);
- social care services (7%/103);
- social and emotional needs (9%/119);
- mental health (14%/196)

Where people had been offered 'health-specific' support (e.g. information about their condition, treatment and support from their GP, and support with pain relief), they generally judged this to have been helpful.

Considering the aspects of life that people reported were most affected by the delay (pain, social life, household tasks, as well as mental health and wellbeing), and the range of issues people were struggling with (e.g. cooking, cleaning, gardening, shopping, socialising, depression, anxiety, financial worries, isolation, and caring for others), it would appear there is a disparity between the support that people need and the support that people are being made aware of or offered.

Key findings included that:

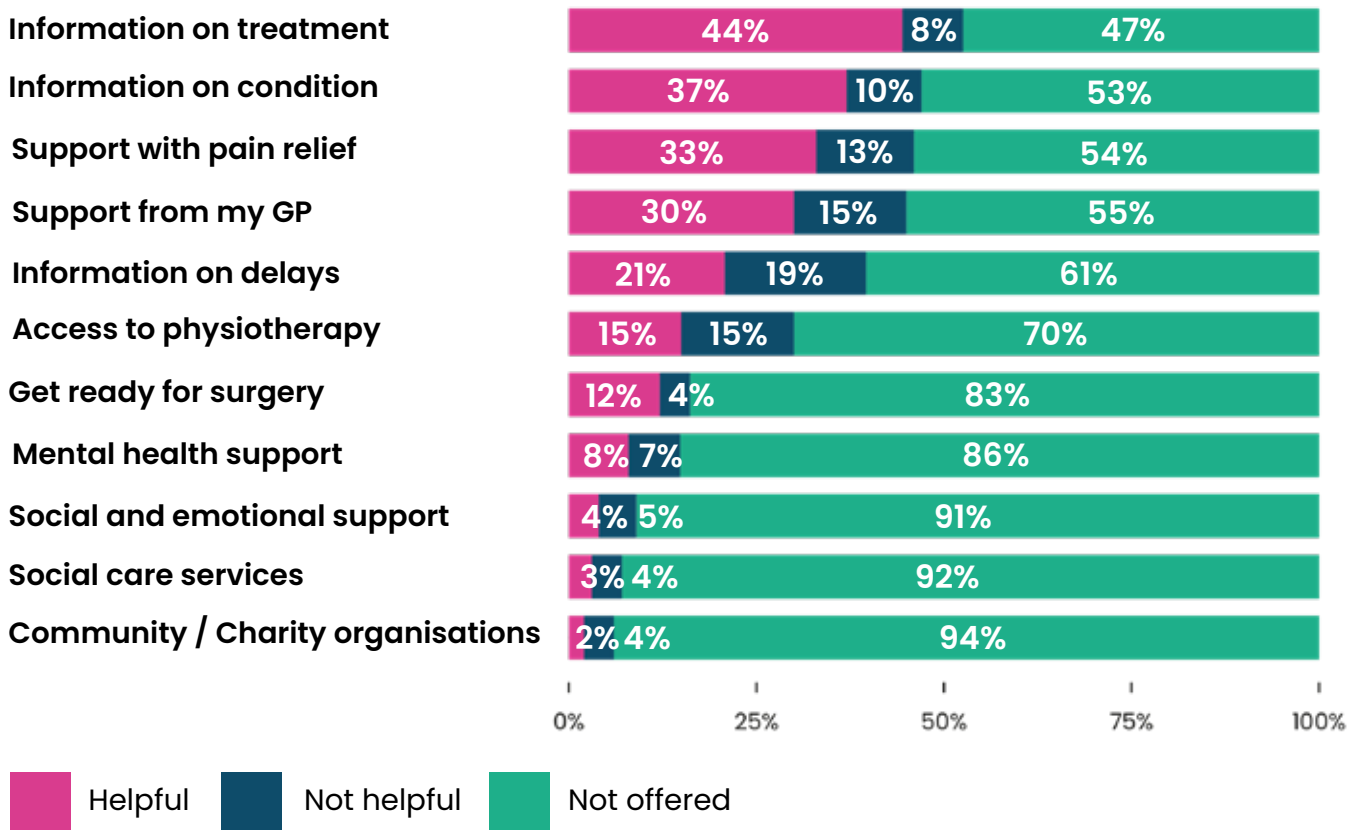
- only 16% (125) of people who said their mental health and wellbeing had been affected were offered mental health support;
- fifty-three per cent (489) of people who said they had experienced increased levels of pain said they were offered support with pain relief;
- only 9% (76) of people who said they were experiencing difficulties with socialising had been offered support from social and emotional services, and 6% (52) had been put in touch with a community or charity group;
- eight per cent (65) of people who were experiencing difficulty with household chores were offered additional help from social care services with day-to-day tasks, and only 6% (48) said they had been offered help from a community or charity group.



Our findings indicate that there is a disparity between the ways that people's lives have been impacted by their wait for hospital care, and the types of support that have been offered to help people to cope whilst they are waiting.

This included that, for example, just **16% of people who said their mental health and wellbeing had been affected** recalled being offered mental health support.

Graph 11: The percentage of respondents offered support across a range of support types, and whether they found that type of support helpful or not.



Analysis of the data by vulnerabilities shows that respondents who had a disability were more likely to have been offered support with ‘health’ issues (e.g., treatment, condition, pain relief or physiotherapy) than those who were Carers, or who had a mental health diagnosis. Respondents who said they had a diagnosed mental health difficulty were more likely to have been offered support in the form of mental health services, social and emotional support.

See more detail in table 21 overleaf.

	Mental health	Carer	Disability	Total
Information on treatment	48%	42%	55%	53%
Information on condition	44%	43%	49%	47%
Support from GP	53%	50%	53%	46%
Support with pain relief	43%	47%	55%	45%
Information on delays	35%	28%	44%	40%
Access to physiotherapy	29%	35%	38%	30%
Ready for surgery	17%	13%	18%	16%
Mental health support	30%	10%	20%	14%
Social and emotional support	14%	7%	13%	9%
Community or charity organisation	10%	5%	8%	6%
Social care	10%	7%	9%	7%

Table 21: The percentage of respondents who said they had been provided with various types of support, and whether they identified with the 'mental health', 'Carer' and 'disability' 'vulnerabilities' in the survey.

Our findings highlight the wide-reaching impacts that can result if people are not provided with adequate support, or the right support whilst waiting for care.

Lofty Heights

Lofty Heights has a partnership agreement with Healthwatch Suffolk. It specialises in helping people to live safely in their own homes. In this section, you can read about some of the ways waits for hospital care have impacted its services, and the people it supports.



Lofty Heights is a not-for-profit social enterprise specialising in helping vulnerable people live safely in their own homes. They do this through the provision of sorting, clearing and decluttering services. In addition, their Homeward Bound service works with NHS and hospital discharge teams to make adjustments needed to people's homes to ensure they can be discharged safely or continue to receive care at home.

You can learn more about Lofty Heights on its website: www.lofty-heights.org

Over the year, Lofty Heights report that they have seen a marked increase in the number of people requiring their services, and an increase in the complexity of need and level of support people require. While this increase is not wholly attributable to the impact of elective care waiting lists, the experiences Lofty Heights has shared highlighted the issues people are facing, and the need for appropriate support to be identified and provided early, to ensure the best possible outcomes for people's health and wellbeing.

Some of the issues include:

- An increase in the number of people requiring decluttering services to deal with carpet litter, and kitchen clutter, that has built up due to deteriorating mobility.
- Examples of patients who have been discharged from hospital to homes with significant trip hazards caused by build up of clutter. One extreme example saw a patient, discharged from hospital following a simple procedure, trip over the clutter in the hallway resulting in an emergency admission for a more significant procedure, plus infection in the original wound site.

- Observing that people are de-prioritising services, such as regular house cleaning and garden maintenance, as the cost of living crisis grows. Poorly maintained properties have significant implications for the recovery of patients from either planned or unplanned hospital treatment due to increased trip hazards, and unhygienic conditions.
- More people having to take up an informal caring role whilst supporting relatives who are waiting for elective care.

We asked Lofty Heights about what could help, and this is what they recommended:

- **Better discharge planning for those on the elective care pathway, as well as those on emergency and urgent care pathways.**

Central to the Discharge to Assess (D2A) process, is the need for early assessment of the services that are required to ensure patients can safely be discharged home or to another community setting. However, D2A is generally only applied to patients who have had an unplanned admission.

The feedback Lofty Heights has shared, and the evidence from the survey findings, indicate that there may be many people waiting for planned care, who are struggling with general household tasks and who may need extra support to ensure that they can return to an environment that is both safe and supports their recovery when they are ready for discharge.

- **Earlier discharge planning for all.**

A guiding principle of D2A models is the need for rapid, effective assessments that ensure services can be mobilised to aid safe discharge.

This means that planning for discharge needs to start as soon after admission as possible, to ensure appropriate services are available and joined up. Feedback from Lofty Heights indicates that discharge planning is not always happening soon enough for patients on the urgent/emergency care pathway, and is virtually non-existent for those receiving planned care.

There is a need to engage services that can support discharge as early as possible. For those receiving elective care, this could start before admission.

- **Good, timely information sharing across the system.**

For example, Lofty Heights shared that notes made by the ambulance service about the patients property are not consistently shared with hospital wards, and are therefore not available to all the agencies involved in the discharge planning for the patient.

Recommendations

Read our recommendations for how people's experiences of waiting for hospital care could be improved by our local health and social care systems.



The following series of recommendations have been determined from our analysis of what people said could have been better about their care and support whilst waiting for hospital care. They have been co-created with NHS leaders responsible for addressing the backlog of care, to ensure that they can be implemented and used to shape the future of support for Suffolk residents.

Information and communication

People waiting the longest for treatment are also those most likely to report that they have not received information, or communication, about their care or condition. Hospitals, and communication teams across the NHS should factor this finding into their planning, ensuring that people waiting the longest times have received good information about their wait, as well as the support available to them from other services.

In general, there needs to be a much-improved process of communication across the span of time people are waiting, with defined opportunities to update people transparently about their wait, to check in on their condition and to remind people about the fullest extent of support available to them whilst they are waiting. Communication should be regular, honest, and easy for people to interpret and understand. Importantly, there is a need for people to receive transparent information about how their wait is being determined to help manage patient expectation.

Critically, communication with patients must be accessible to avoid inequality and/or exclusion. Services must ensure that their communications meet the requirements of the NHS Accessible Information Standard (AIS).

That is to say that people must receive information about their wait in a format they can understand. Not getting this right can have serious, and lasting, consequences for people's health, and can mean that important communication is missed. More information about the AIS, and people's rights is available from www.healthwatchesuffolk.co.uk/your-care-your-way/knowthefiverights/.

It is also clear that many people feel their mental health has been affected by hospital waits, and yet most feel they have not been offered information about how they could access help. Much greater collaboration between hospitals, commissioners, and VCSE organisations is needed at alliance and Integrated Neighbourhood Team levels to ensure people are made aware of the mental health support available to them whilst they are waiting.

Qualitative responses highlight that people would like an increased frequency of communication, including updates on their wait and better information about alternative local support. Many felt this would help to reduce levels of anxiety. It may also help to prevent patients from needing to chase for responses, and potentially free up telephone lines/contact methods for those who need more urgent responses from services.

A number of respondents were positive about communications from the hospitals regarding their wait and/or procedure. However, most respondents highlighted improvements that could be made. Specifically, this included:

- **Better, or increased, information about wait time** – Many respondents highlighted how

a lack of information about their expected wait time was increasing their stress, and affecting their ability to plan key aspects of their lives (e.g., work arrangements, holidays, family events etc).

- **Position on the waiting list** – Many people felt it would be useful to understand more about how their wait was being prioritised. People often had no perspective on how their needs were being reviewed by the trusts, or where they were currently positioned on the ‘waiting list’. Better, and more transparent/open communication is needed about this.
- **Consistency of information** – Communication and information from hospitals is often not aligned with the things people are told by the professionals involved in their care, and conflicting information is sometimes received from different departments within the hospital (leading to additional delays for people).

Staff need to be cautious about raising unrealistic expectations. If they do not know how long the wait might be, staff should advise people about the communications patients should expect to receive, and that this may include estimated wait times. Professionals need to be aware of how miscommunication can have a significant impact on people’s lives, and should have sufficient knowledge about the process of communication regarding elective care waits to be able to advise patients accordingly.

- **Information about treatment and symptoms** – People have received insufficient information about what to expect regarding their illness/condition, or the treatment they are to receive from the hospital. People waiting for care should receive good information about how symptoms may progress/worsen, and what to do if they are concerned about this – how can they access support from other services? Who should they approach? People also highlighted that there had been an absence of information that would have aided them to make informed choices about their treatment (e.g., pain management).
- **Use of language** – People expressed that the language used in hospital communications, and by professionals, is often unhelpful in managing expectations. Use of words such as ‘urgent’ and ‘emergency’ within communications can raise patient expectation, leading to a wrong impression that they will be prioritised or seen much quicker than is actually possible. In fact, many people who received information like this, have subsequently waited many months, if not longer. Use of these terms can also elevate people’s stress levels, especially in the absence of clear information about treatment (see below).
- **Reassurance** – In the absence of information, or regular communications, people frequently expressed the need for reassurance that they were still on the list, and had not been missed or forgotten because of the backlog. Given the impact of waiting on people’s lives, it is entirely reasonable to expect that people should have an awareness of whether they are on the list. If communications should have been received, there is a need to review why people express this view – to what extent does the system measure and/or check whether communications are received/opened by patients?
- **Estimated dates** – It is accepted that there are many factors affecting the length of time people are required to wait for their treatment, and this can make prediction of wait times difficult. However, every effort should be made to honestly inform people about the length of time they may be expected to wait for their treatment.
- **Information following cancellation** – A small number of respondents (25) suggested

improvements after they had experienced the cancellation of a treatment/procedure. They included:

- » more notice that their procedure was going to be cancelled;
- » better information about why treatment had to be cancelled;
- » a date, or estimated timescale, for when their procedure would be rearranged.

Holistic support and integration

There is a considerable disparity between the types of support offered to people whilst they have been waiting, and the aspects of life most impacted by the wait for hospital care or procedures.

Health and care leaders must seriously consider how people's needs can be addressed in a holistic way, and new NHS structures under Integrated Care Systems should bring new opportunities to achieve this. This may include better provision of services available to support other factors, or limiting influences, known to affect people's mental or physical wellbeing. This includes (not an exhaustive list):

- poor mental health;
- caring responsibilities;
- difficulties with work and finances;
- the rising cost of living;
- pain and immobility;
- social isolation and relationships;
- difficulties with housework and maintenance.

Taking this action will help people to live well whilst they are waiting, and help with the avoidance of rapid deconditioning. We would like to see outcomes in local strategies centred around these wider determinants of people's health and wellbeing, and that will require lasting, meaningful and well-resourced connections with voluntary, community and social enterprise organisations that are well-placed to help the NHS to meet these needs.

Inequality

Our findings suggest that inequality may be leading to poorer outcomes and experiences for some groups, including people from multi-ethnic communities, people with disabilities, people with mental health concerns, and Carers. More research would be needed to understand these trends fully, and this should be an ambition for the systems.

Our findings have sufficient synergy with the results of other research to warrant the resourcing of further work to understand how the backlog of hospital care may be affecting vulnerable people, and communities. This interactive webinar from the NHS Confederation has showcased different approaches hospitals have taken to restoring services with health inequalities as a driver: www.nhsconfed.org/events/tackling-health-inequalities-when-reducing-elective-backlog-webinar

Data sharing and transparency

There is a need for wider transparent sharing of data relating to the demographic profile of people waiting for hospital care in Suffolk, in order that we can contextualise this report, and any future reports. This will help the system to be able to discuss important improvement work that may be needed regarding inequality. Healthwatch Suffolk (HWS) would ask to be directed to this data.

In general, the 'conversation' about elective care waiting requires much more transparency and openness. More information should be made available to HWS, and the wider public, about exactly how hospital waiting lists are managed. This will help people to understand more about why they may need to wait longer than others, and how their waiting time is determined.

Survey repetition – how can we be sure local plans are making a difference?

It is recommended that both Integrated Care Systems work together with Healthwatch Suffolk to repeat this survey. Hospital waiting lists are here to stay, and so it is important to check whether local plans to help people to stay well whilst they are waiting are making a difference.

A follow-up survey could be co-produced together with system leaders to compare results against this baseline of patient experience, and to ask new questions where knowledge gaps are identified. For example, a future survey may focus on understanding more about how issues, such as the cost of living crisis, are compounding the concerns of people who may be facing financial stress as a result of their wait for elective care.

Such a repeat of the survey would require the same commitment from local acute hospitals to share the survey directly with their patients, although greater consistency between the trusts regarding patient sampling would be required.

Additional recommendations from engagement with Lofty Heights

See information on pages 74 and 75 for more information about Lofty Heights, and its observations about those it supports waiting for hospital care..

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We will be making this report publicly available by publishing it on our website.

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