

The wait for treatment

People's experiences in
Suffolk

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Trusted Insights

Contents

Navigate this report.

Content	Page number
Summary	4
Our thoughts (Wendy Herber, Independent Chair)	4
Summary of key learning points for system leaders	6
Introduction	8
Communication about the survey	10
Our sample	12
Our results	20
How waiting affects people's lives	20
Summary of free-text responses about the impact of waiting	32
Support while waiting	46
Support to make lifestyle changes	54
Communications	58
Patient choices	72



Summary

Our thoughts on people's experiences



Wendy Herber

Independent Chair, Healthwatch Suffolk

The issue of rising hospital waiting lists is so often in the news and is likely to affect all of us in some way. Much government and media attention is targeted at bringing the number of those waiting down, but in this report, we're focused on the lived experience of those currently waiting; seeking to understand more about what it is like to wait for care in Suffolk.



"Perhaps the biggest question raised by this report is **'who is responsible for coordinating and providing care that enables people to 'wait well'?'**"



This is our second report on waits for elective care. Our first report published in 2021/22 revealed the devastating impact of waiting on people's lives and made recommendations to health and care leaders about holistic management of those waiting, communication with patients, and inequalities. The first report also provided a useful baseline of evidence for both integrated care systems and local hospitals, and we suggested research should be repeated to see whether things have changed. In this report, we deliver on that promise.

There are some important differences in our approach this time. For example, we've changed our approach to some questions, and we've explored how waiting is experienced differently depending on the hospital department people are waiting for. We also remain focused on trying to explore how waiting can be more difficult for those with some specific conditions and vulnerabilities (such as having family caring responsibilities).

The evidence suggests that the impacts of waiting vary, and so support for those waiting needs to be tailored to conditions, life circumstances and the length of people's wait. A one-size-fits-all approach just won't adequately meet the needs of many people's unique

experiences. Just as we need personalised health and care, we need tailored support for times when that care just can't be delivered quickly.

Worryingly, this report also reveals 'an epidemic of pain' as people struggle to manage as they wait. This is especially true of certain conditions. It shows that delay in treatment is both creating new family carers supporting those living in daily pain, and simultaneously disabling those who already have caring responsibilities at home.

As our last report showed, waiting for elective care affects every part of people's lives. It shrinks people's worlds and, in some cases, isolates people from friends and families through fear and immobility – eroding key sources of support at a time when people need it most. It affects jobs and financial security, relationships, independence, and can seriously impact people's mental and physical wellbeing.

Perhaps the biggest question raised by this report is who is responsible for coordinating and providing care that enables people to 'wait well'? Is it the responsibility of the hospitals that triage and allocate treatment? Is it the responsibility of GP's to monitor the impact of waiting on people's social, mental and physical health, and provide links and support to mitigate that damage? Or is it assumed to fall to the patient themselves? And what do we do when people are too ill, isolated or vulnerable to find or ask for help?

Since our last report, 'waiting well' resources have been created by our local health and care system. Whilst recognising the benefits of this, and the efforts of those working in systems to address the needs of waiting patients, the findings of this report must drive us to ask whether that resource is enough to keep people as well as possible.

What more can be done to help people to protect their families, retain social and economic independence, and live with the negative impacts of their condition?

Developing the resources to treat people faster takes time. While we all wait, perhaps it's time to ask whether more needs to be done to tailor and proactively deliver support to those needing medical care, and to prevent people falling into crisis before they can be treated.



Are we in an epidemic of pain?

Millions of people remain on hospital waiting lists, often for lengthy periods of time. Pain is a symptom of many conditions requiring hospital treatment, and so it is perhaps not surprising that people should mention it so frequently in their comments.

Over time, pain can be a significant drain on emotional and physical energy. It can lead to an increasingly isolated life and, at its worst, leave people bed-bound or afraid to move.

People described their concerns about long-term use of medications to manage their pain and how they had struggled to find support.

We think information about pain management should be central to the local 'waiting well' offer. Information should be much easier to find, and it should be proactively offered to those living with conditions known to cause people pain.

Improving the wait for hospital care



Communication

1. Every contact with people waiting for care across systems is an opportunity to find out how they are managing or coping with their wait. It's also a chance to signpost them to information and support that can help.
2. Access to good communication, including clear, up-to-date, and consistent updates on waiting times, is extremely important. This is especially true when appointments are cancelled. This is the best way to reduce anxiety for those waiting and to avoid the build-up of frustration.

Where it is necessary to cancel procedures, services should aim to provide revised wait times and inform people (within reason) of the reasons why their appointment will no longer take place.
3. Language is very important. Terms such as 'urgent' and 'priority' are frequently used. However, they do not reflect the experiences of most patients and can be misleading as to the reality of people's waits for care.
4. Gynaecology patients were the least satisfied with communication from their hospitals and may benefit from a different approach to communication.



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3. Findings s could be k waiting tir referral, an rights whil for care.
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No way through...



It was clear that people had struggled to find updated information about their wait. Often, calls went unanswered or were not returned, or the contact information provided was incorrect.

"The different ways of finding where you are on the list is confusing and frustrating... The app gave a date to be contacted by, and a number to call if I wasn't contacted. The phone line was dead."



1. Findings s could be k about wait point of re about the are waitin communic to make s the choice all stages

Protection from the impacts

one-size-fits-all approach to supporting people while they wait for care is unlikely to meet diverse needs. Developing a 'waiting well' offer is essential to ensure support is relevant and effective for different groups.

We suggest that people are better informed about waiting times at the point of referral, and also about their options whilst they are waiting for care.

What is the impact of pain? Pain is a common experience for many people, but it's not always recognised as a health issue. This is inadequately addressed in the local 'waiting well' offer. Such information should be easy to find, and include clear advice on how to manage pain while waiting.

2. Waiting well information should be prioritised to address the real-life impacts people experience as a result of their wait, such as issues with pain, managing work, avoiding deconditioning and other similar issues.

4. Families and friends have an important role to support loved ones, and to keep them positively engaged in healthy behaviours while they wait. Information and advice for family members could be a feature of the 'waiting well' offer.

6. Are we activating patients to engage in healthy pre-conditioning? It's not enough to signpost or expect that people will be instantly motivated to take up the offer of support. Positive attitudes to health management can be developed through person-centred conversations with professionals across systems (e.g., 'Health Coaching').

Offering choices

We suggest that people are better informed about waiting times at the point of referral, and also about their options whilst they are waiting for care. Proactive interventions are needed to ensure people know of the choices they can make at the point of their wait.

Shrinking worlds

People's worlds shrink when they're waiting for care. Often, mobility is lost, money gets tighter, and relationships change. We must support people to navigate these changes to avoid impacts on other services.



Introduction

About this report

About Healthwatch Suffolk CIC

Healthwatch Suffolk CIC (HWS) is a social enterprise delivering insight to shape local NHS and social care.

We passionately believe that listening and responding to people's lived experiences is vital to create health and care services that work for everyone.

We collect and share lived experience to improve standards of health and social care in Suffolk, regionally and nationally. Our independent role is enshrined in law, supported by trusted data and embedded in local integrated care systems by established relationships with partners.

More information about who we are can be found at

www.healthwatchesuffolk.co.uk/about-us.

This research

This research is helping our local health and care systems, leaders and services to explore people's lived experiences of waiting for elective hospital treatment or care.

It has been delivered by Healthwatch Suffolk CIC in co-production with local hospital trusts (West Suffolk NHS Foundation Trust, James Paget University Hospitals NHS Foundation Trust, and the Suffolk and North Essex NHS Foundation Trust) to shape and influence the provision of elective care locally.

The progression of this research follows an initial endorsement of the approach by the Suffolk Health and Wellbeing Board at its meeting in November 2023.



Our trusted insights

We are a leader in co-production, research, engagement and service evaluation, delivering projects for the benefit of our communities. Our experienced team are adept at working in partnership to deliver the best possible outcomes for you, and our local communities.

Think we can help? Please contact research@healthwatchesuffolk.co.uk.

Many thousands of people are currently waiting for hospital treatment. Nationally, the waiting list for hospital treatment rose to a record 7.7 million in September 2023 and fell to around 7.5 million in December 2024. The 18-week referral to treatment target has not been met since 2016.

Our previous research (see right) showed how the issue of care backlogs requires a response that is wider than our acute hospitals can support alone (though they play a critical part in addressing specific aspects of people's experiences). We showed how waiting for care is critically affecting people's finances, education, jobs, relationships, mental health, caring roles, and many more aspects of their lives.

Acknowledging the significant progress across local systems to address patient experience, this research builds upon our previous insights. It has been an opportunity to explore how people feel about their wait for care now and encourage ongoing action to address the aspects of people's lives most affected by their wait for care.

A system-wide collaborative approach is the only way to bring about real impact from this research, with tangible benefits for patients, carers, hospitals, commissioners, our VCFSE sector and other system partners. However, such an approach requires a structured system-wide response to make sure any recommendations or key learning are shared widely and lead to specific action.

With thanks from us



Healthwatch Suffolk would like to thank each and every person that has contributed to this research, including respondents, leaders within our local acute hospitals, local GP Patient Participation Group leads and every person who contributed to the co-production of the project and research tools.

A first check-in on experience of hospital waits (2022)



In 2021/22 Healthwatch England launched a national campaign to seek information about people's experiences of waiting for hospital care. Healthwatch Suffolk opted to review the national survey template together with our local health and care systems, and a unique approach was adopted locally.

With important support from local hospitals, a response rate of just under 1,400 people was achieved. This compared to a national response rate of around 2,600 responses (from people in 119 local Healthwatch areas). It was a leading example of a local Healthwatch working collaboratively with services to engage people about their experiences.

The 2022 report was widely considered. It was a timely first opportunity to understand the ways that people's lives were being impacted by their wait for care (e.g., their mental health, employment, relationships, caring responsibilities, and much more).

The research highlighted improvements that could be made to help people feel more supported (e.g., regarding communication and awareness of other sources of support). It led to action in local health and care systems to improve patient experience.

Our previous report, and information about the impact of the work, can be found on the Healthwatch Suffolk (www.healthwatchesuffolk.co.uk/ourresearch/electivecare).

[Go to the 2022 research](#)

Communication of the survey

This research was supported by our local acute hospital providers to achieve the best possible response rate. However, a much higher response rate was achieved in the west and north of Suffolk. This was, in part, attributable to differences in the communication methods adopted by the Trusts to include people in the research.

The West Suffolk NHS Foundation Trust (WSFT) and James Paget University Hospitals NHS Foundation Trust (JPUH) were able to repeat the 2022 method of direct text messaging people waiting for elective care, whilst the East Suffolk and North Essex NHS Foundation Trust (ESNEFT) chose alternative methods. The details of this are shown in the table below.

	2024/25 survey			2021/22 survey		
	Texts sent	Responses	Rate	Texts sent	Responses	Rate
WSFT	5,735	924	16%	4,045	736	18%
JPUH	3,442	379	11%	1,490	407	27%
ESNEFT	0	78	–	3,000	236	8%

ESNEFT shared the survey in other ways, including by distributing hard copies of the survey, leaflets and posters in waiting areas and featuring a QR code on clinic check-in screens for a few weeks at the end of the data collection period. HWS staff were also invited to engage patients visiting the Ipswich Hospital site. The first of two visits was abandoned because there were no elective care patients to engage in the clinic. The second visit took place within the physiotherapy department and 17 people were engaged (six surveys were distributed).

In addition, content about the survey was posted to Trust websites, resulting in at least 175 sessions on the Healthwatch Suffolk (HWS) website. A total of 144 of these referrals came from the West Suffolk NHS Foundation Trust, which promoted the survey on its home page. Trusts also shared details of the survey on social media.

A digital communications pack was developed and Healthwatch Suffolk distributed the survey widely to stakeholders across local health and care systems. Some of the methods included:

- Distribution at events, meetings, and networks attended by HWS Engagement and Community Officers across the data collection period.
- Regular promotion across HWS communication methods (e.g., social media, newsletters, stakeholder communications and website content).
- Promoted social media posts to people in Ipswich and surrounding areas reached 22,807 accounts and achieved 383 link clicks in addition to organic reach across HWS platforms.

Explore more – demographics

A thorough breakdown of the demographics of people included in this research can be found from [page 12](#).



Our sample

Who took part?

Sample overview

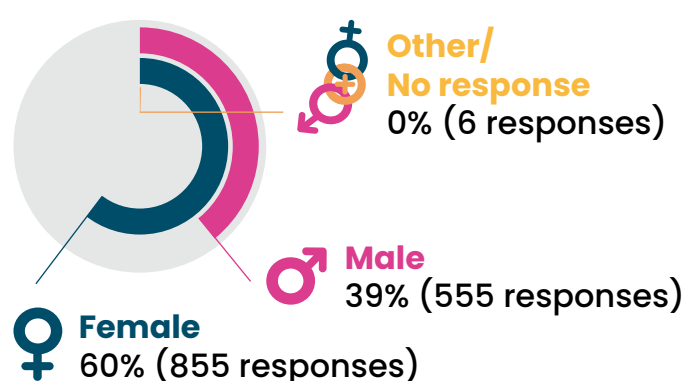
A total of 1,416 people responded to the 2024/25 survey. This closely matched the number of responses received to the 2022 survey, to which 1,382 people responded about 1,462 experiences of waiting for elective care.

Other similarities included:

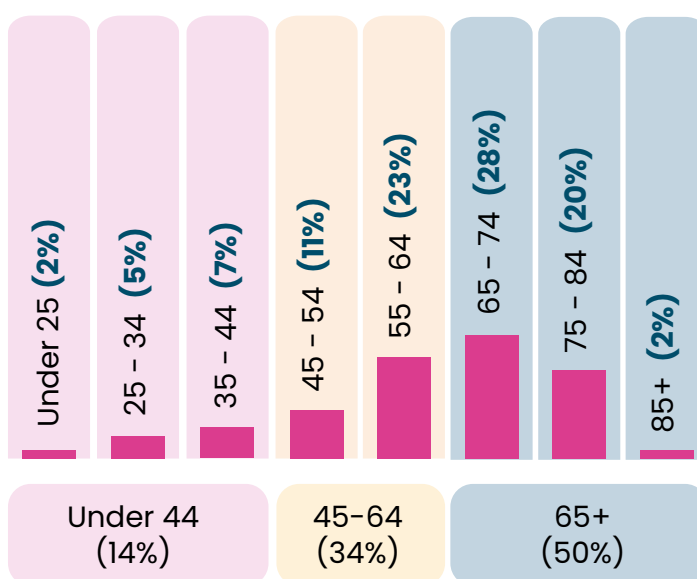
- A comparable gender distribution, with approximately 60% identifying as female and 40% as male.
- Broadly similar age profiles, with around a 50/50 split between those aged over 65 and those under the age of 65.
- Both cohorts were mostly 'White British' in ethnicity (94% and 86% respectively), with only 2% of respondents identifying with a non-white ethnic background.
- Approx 55% of respondents in each sample did not have any of the listed vulnerabilities (see page 14). Where vulnerabilities were reported, these were in the same proportions across both cohorts, with disability (20%) and mental health difficulty (11%) most commonly mentioned.

Please refer to the tables and charts for more information.

Graph one: The gender of respondents to the 2024 survey.



Graph two: The age profile of respondents to the 2024 survey.



Sample size (2024/25 and 2021/22 surveys)

In 2021/22, **1,382 people participated.**
In 2024/25, **1,416 people participated.**



Respondent age

Respondent age	2024/25		2021/22	
	Count	%	Count	%
Under 25	31	2%	35	3%
25-34	70	5%	62	4%
35-44	106	7%	123	9%
<44		14%		16%
45-54	159	11%	196	14%
55-64	328	23%	284	21%
45-64		34%		35%
65-74	401	28%	347	25%
75-84	288	20%	197	14%
85+	27	2%	20	1%
65+		50%		40%
Not answered	6	0%	118	9%

Table: The age profile of respondents to the 2024 and 2022 surveys.

Respondent ethnicity

Respondent ethnicity	2024/25		2021/22	
	Count	%	Count	%
White British	1,332	94%	1,195	86%
Any other white background	50	3%	35	3%
Not a white background	25	2%	27	2%
Not answered	9	1%	125	9%

Table: The ethnicity of respondents to the 2024 and 2022 surveys.

Respondent gender

Respondent gender	2024/25		2021/22	
	Count	%	Count	%
Male	555	39%	452	33%
Female	855	60%	807	58%
Other gender/Did not answer	6	0%	123	9%

Table: The gender of respondents to the 2024 and 2022 surveys.

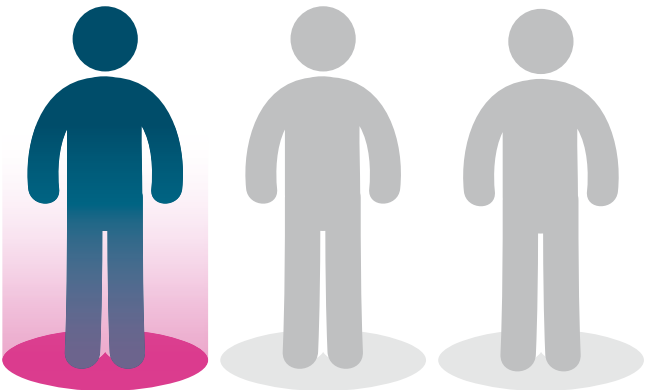
Respondent vulnerabilities

Vulnerabilities are factors known to indicate that someone may be at a disadvantage because of their personal circumstances.

	2024/25		2021/22	
	Count	%	Count	%
0	804	57%	754	55%
1	474	33%	377	27%
2+	82	6%	101	7%
Not answered	56	4%	150	11%

Table: The number of vulnerabilities in the survey selected by respondents in 2024/25 and 2021/22.

A third of respondents identified with at least one vulnerability.



	2024/25		2021/22	
	Count	%	Count	%
None	804	57%	754	56%
Disability	287	20%	288	21%
Mental health condition	151	11%	168	12%
Family carer	122	9%	108	8%
Sensory impairment	60	4%	-	-
Learning disability	25	2%	19	1%
Autistic spectrum	14	1%	15	1%
Dementia	3	0%	-	-
Not answered	56	4%	150	11%

Table: The vulnerabilities respondents identified with in the 2024 and 2022 surveys.

Notable sample differences

While there were several similarities between the two samples, it is worth highlighting some key differences.

- Hospital where people were waiting for care and treatment:** There was a higher proportion of people waiting for care and treatment at West Suffolk Foundation Trust (WSFT) in the 2024/25 sample, compared to the 2022 sample (65% vs. 50%). There was also a much lower percentage of patients waiting for treatment from East Suffolk and North Essex Foundation Trust (ESNEFT) (6% vs. 16%). This change is likely to be a direct

result of the different methods in which patients from each hospital were informed about, and engaged, in the project.

	2024/25		2021/22	
	Count	%	Count	%
West Suffolk Foundation Trust ¹	924	65%	736	50%
James Paget University Hospitals	379	27%	407	28%
ESNEFT ²	78	6%	236	16%
Other	–	–	60	4%
Did not know/Not answered/Not waiting	35	2%	23	2%

¹ - Includes three people waiting for treatment at Newmarket Hospital.

² - Includes 51 people waiting for treatment at Ipswich Hospital, 17 people waiting for treatment at Colchester Hospital (not Trauma/orthopaedics), and one person who was waiting for treatment at both Ipswich and Colchester (Dermatology and ENT).

Where possible, patients awaiting orthopaedic treatment at the East Suffolk and Essex Orthopaedic Centre have been coded to their originating hospital.

Table: The proportion of respondents waiting for care, and their provider of elective treatment or care (2024/25 and 2021/22 samples).

- **Department where people were waiting for care and treatment:** The 2024/25 survey asked respondents about the department they were waiting for treatment from. This was not asked in the 2021/22 survey and there is no equivalent information against which to compare results.

The data shows that over two-thirds (68%) of respondents were waiting for treatment from either trauma and orthopaedics, general surgery or gynaecology departments, with most waiting for trauma and orthopaedics. This was the same across all three hospitals, although there were some slight variations in the proportions of patients waiting for each department, for example:

- » A higher percentage of people were waiting for gynaecology and a smaller percentage of people were waiting for general surgery at ESNEFT than for either WSH or James Paget University Hospital (JPUH).
- » A smaller percentage of people were waiting for orthopaedic treatment at James Paget University Hospital compared to the other hospitals.
- » WSFT had the lowest percentage of gynaecology patients.
- » A broader range of patients were waiting for care at JPUH, with treatment needs spanning 15 different departments. In comparison, respondents at ESNEFT and WSH mentioned waiting for treatment from 13 departments.

More information is displayed in the table overleaf.



68% of respondents were waiting for trauma and orthopaedics, general surgery, or gynaecology. The sample is inclusive of people waiting for at least sixteen different acute hospital departments or specialisms.



40% were waiting for gynaecology.



18% were waiting for trauma or orthopaedics.



10% were waiting for general surgery.

	2024/25				
	Count	%	WSFT	JPUH	ESNEFT
Trauma and orthopaedics	571	40%	42%	35%	41%
General surgery	257	18%	19%	18%	10%
Gynaecology	136	10%	8%	12%	17%
Ear, nose and throat	94	7%	7%	8%	4%
Urology	68	5%	4%	7%	5%
Ophthalmology	66	5%	5%	5%	3%
Plastic surgery	55	4%	5%	3%	1%
Colorectal surgery	48	3%	4%	3%	3%
Dermatology	24	2%	2%	1%	6%
Pain management	19	1%	1%	1%	5%
Cardiothoracic	16	1%	0%	2%	1%
Vascular surgery	16	1%	2%	0%	0%
Multiple departments	12	1%	1%	1%	1%
Dental / Oral	11	1%	0%	2%	3%
Other	7	0%	0%	1%	0%
Neurology	6	0%	0%	1%	0%
None	2	0%	0%	0%	0%
Not answered	8	1%	1%	0%	0%

Table: The proportion of respondents waiting for care, their provider of elective treatment or care, and the department they were waiting for (2024/25 and 2021/22 samples).

- **Financial status:** The 2024/25 survey asked respondents to indicate which statement best described their financial status. This question was added to the survey as another indication that someone may be at a disadvantage because of their personal circumstances. Since this was not asked in 2022, there is no equivalent data to benchmark against.

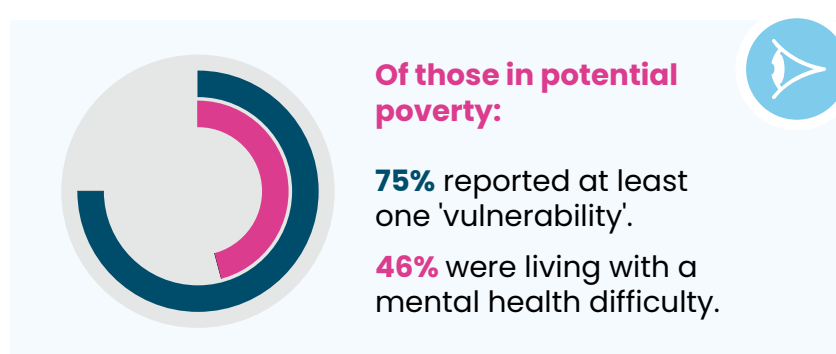
In total, 46% of respondents reported that they were financially secure, with enough money for basic necessities and some disposable income to spend or save as they wished. However, 31% of people said they only had money for basic necessities, and 6% indicated that they were living in poverty. This included that they sometimes ran out of money for bare essentials.



Table: The financial status of respondents.

	2024/25	
	Count	%
I have enough for basic necessities & disposable income (to spend/save as I wish)	657	46%
I have just enough for basic necessities and little else	441	31%
I don't have enough for basic necessities and sometimes run out of money	87	6%
I don't know / Prefer not to say	196	14%
Not answered	35	2%

Over three quarters (76%) of people who were living in potential poverty ('I sometimes run out of money') also reported one or more vulnerabilities and were much more likely to report mental health difficulties than those who were not experiencing financial challenges. See more detail in the table overleaf.



	2024/25		
	I have enough for basic necessities & disposable income	I have just enough for basic necessities and little else	I don't have enough for basic necessities and sometimes run out of money
Number of vulnerabilities			
0	66%	51%	22%
1	27%	40%	51%
2+	2%	7%	25%
Type of vulnerability			
Disability	15%	26%	31%
Family carer	7%	10%	17%
Mental health difficulty	6%	12%	46%
Sensory impairment	5%	3%	6%
Learning disability	0%	2%	10%
Autistic spectrum	0%	1%	5%
Dementia	0%	0%	0%

Table: The financial status of respondents and the proportions of people who identified with vulnerabilities featured in the survey.

- **Length of Wait:** There were clear differences in the amount of time people had been waiting for elective care, between the 2022 and 2024/25 samples. Specifically:
 - » Over a third of respondents in 2022 had been waiting for less than six months, compared to 20% of those responding to the 2024/25 survey.
 - » There was a higher proportion of people who had waited for more than a year in the 2022 cohort (40% vs. 33% in 2024/25).

Comparing the 2021/22 and 2024/25 data on length of wait at each hospital reveals:

- » The 2024/25 cohort of WSFT patients have been waiting less time than those who responded in 2021/22, with two-thirds of respondents (67%) having waited less than a year, compared to almost half (49%) in 2022.
- » The 2024/25 cohort of respondents waiting for care from JPUH had waited roughly the same amount of time as the 2022 sample. Approximately 60% had waited under a year and 38% had waited over a year.
- » There was a larger proportion of patients who had waited over a year for care from ESNEFT in 2024/25 than in the 2021/22 sample (38% in 2024/25 vs. 25% in 2021/22).

Our results

What people said about their experiences

How waiting affects people's lives

The 2024/25 survey asked respondents whether waiting for treatment had impacted the following five areas of their lives:

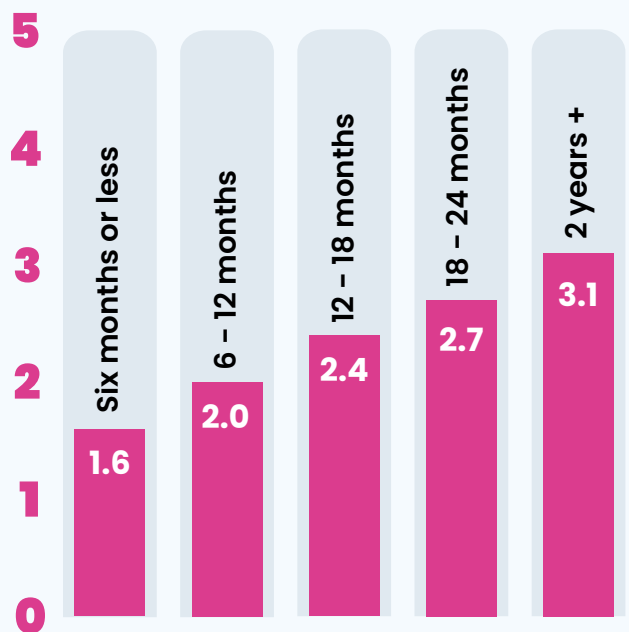
- Work/ volunteering
- Daily household tasks
- Caring for children or someone else
- Mental health and wellbeing
- Family and social life

Seventeen percent of people said waiting for care had not affected any of these aspects of their lives. Among those waiting the longest, a smaller proportion reported 'no impact', compared to those with shorter wait times. For example, 27% of people waiting less than six months said their lives had not been affected, whereas only 4% of those waiting more than two years reported the same.

People who had waited longest reported more impacts on their lives. In total, 40% (two in every five) of those who had waited more than 18 months said four or more areas of their lives had been impacted, compared to only 14% of those who had waited six months.

Please note: Relationships in our data may be apparent, but care is needed when interpreting these findings. We do not know for certain, that the number of impacts people experience have increased over time. Respondents who have waited over a year and who report impacts on their lives, may have experienced those same impacts when they had been waiting just six months. However, qualitative feedback reflects that several respondents felt their general physical and mental wellbeing had 'deteriorated' whilst they waited ([see from page 34](#)), which may account for the higher number of impacts reported by those who had waited longest.

Increasing impact?



People waiting longest reported higher numbers of current impacts affecting their lives (out of five featured in the survey).

Levels of impact on people's lives varied by the hospital department people were waiting for. More information and detail is shown in the table and graphics below. Some care is needed when interpreting these findings due to the small sample sizes for some hospital divisions.

The percentage of people reporting either three or four impacts on their lives varied by hospital department or speciality.



People waiting for multiple departments, pain management, orthopaedics and gynaecology were amongst the **most likely to report three or four impacts on their lives.**



People waiting for ophthalmology, urology, plastic surgery or dermatology were amongst the **least likely to report three or four impacts on their lives.**

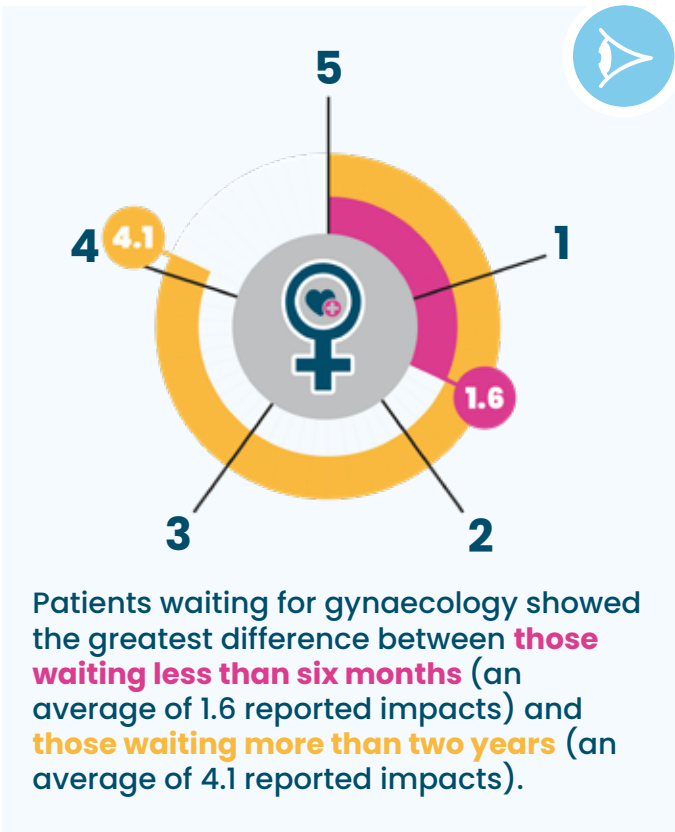
	No.	Number of impacts					
		0	1	2	3	4+	Ave
Multiple departments	12	8%	17%	8%	33%	33%	2.7
Pain management	19	5%	11%	26%	26%	31%	2.7
Gynaecology	136	12%	15%	22%	18%	33%	2.6
Trauma and orthopaedics	571	8%	20%	21%	25%	27%	2.5
Neurology	6	17%	33%	17%	0%	34%	2.2
General surgery	257	17%	32%	24%	13%	20%	1.9
Colorectal	48	29%	17%	43%	17%	21%	1.9
Ear, nose and throat	94	27%	23%	19%	14%	12%	1.6
Other	7	14%	29%	20%	14%	0%	1.6
Urology	68	19%	46%	0%	7%	9%	1.4
Ophthalmology	66	32%	32%	13%	5%	13%	1.3
Cardiothoracic	16	31%	44%	9%	19%	6%	1.3
Vascular surgery	16	50%	19%	17%	0%	19%	1.2
Plastic surgery	55	35%	49%	9%	2%	6%	1.0
Dermatology	24	46%	33%	17%	0%	4%	0.9
Dental	11	55%	18%	9%	18%	0%	0.9
Total sample	1,416	17%	25%	20%	17%	22%	2.1

Table: The average number of impacts people reported, and their hospital department.

As already highlighted, the length of wait for elective treatment can also affect the number of impacts people experience. Therefore, it is important to consider both length of wait and departments together when interpreting this data.

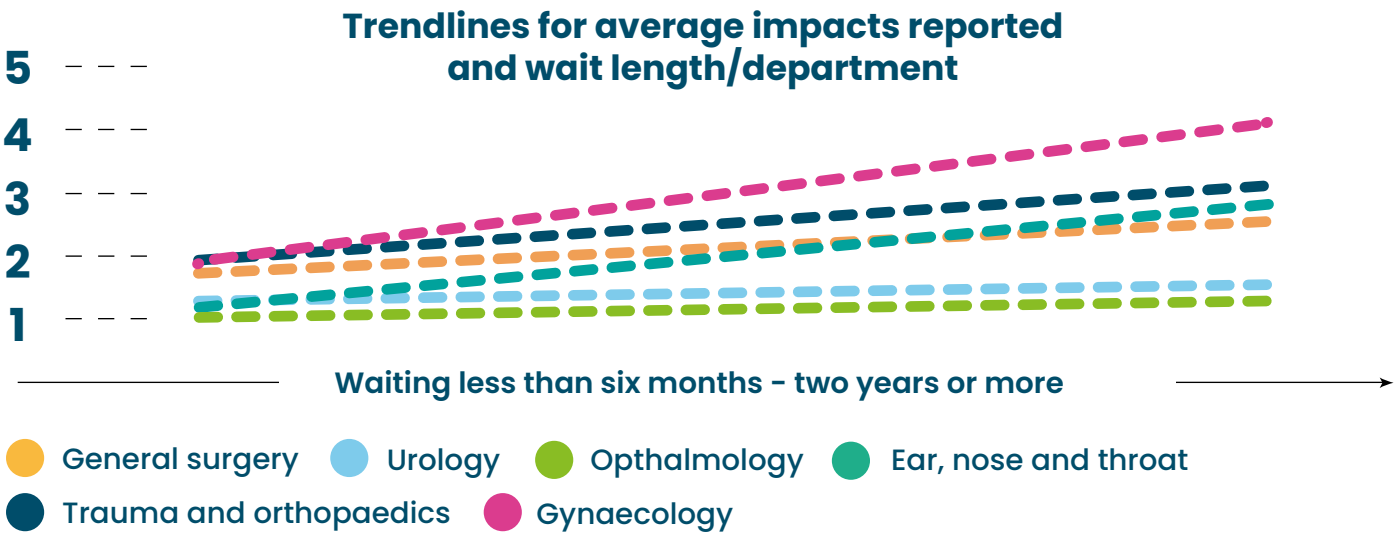
The table below shows the average number of impacts people said they experienced, together with the length of time they had been waiting and the departments they had waited for (top six departments only). The data indicates that:

- Regardless of department, those who had been waiting the longest reported the highest number of impacts on their lives.
- Trauma and orthopaedic patients who had waited less than six months reported an average of two impacts. This is higher than for patients waiting an equal amount of time for any other department.
- The greatest difference between those waiting under six months and those waiting over two years was evident amongst respondents waiting for gynaecology (1.6 impacts for those waiting less than six months, compared to 4.1 for those waiting more than two years).
- Similarly, the smallest difference in impacts was seen amongst patients waiting for general surgery (1.6 impacts at under six months, compared to 2.6 reported impacts for those waiting two years or more).



	No.	Number of impacts (months waiting)						Difference
		Ave	<6	6-12	12-18	18-24	24+	
Gynaecology	136	2.6	1.6	2.3	4	3	4.1	3.5
Trauma and orthopaedics	571	2.5	2	2	2.5	3	3.1	1.1
General surgery	257	1.9	1.6	1.9	2.4	2.2	2.6	1.0
Ear, nose and throat	94	1.6	1.5	1.4	1.6	2.3	3.2	1.7
Urology	68	1.4	0.8	1.8	1.2	2.3	1	1.5
Ophthalmology	66	1.3	0.9	1.3	1.6	0	2	1.1

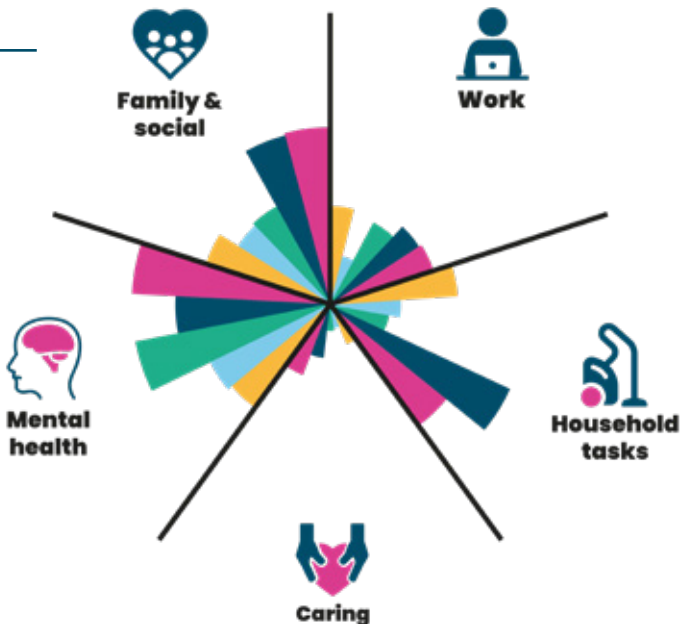
Table: The average number of impacts people reported together with the department they were waiting for (top six) and the length of time they had been waiting for elective treatment.



In addition to the number of impacts, there was also a difference in the types of impacts respondents reported.

- Patients waiting for trauma and orthopaedics were most likely (73%) to have had difficulties managing everyday household tasks.
- Almost three quarters (73%) of gynaecology and ear, nose, and throat patients said waiting had impacted their mental health.
- Two thirds of gynaecology (65%) and orthopaedic (64%) patients said their family or social life had been impacted.

See the chart (right) and table below for more detail.



The percentage of people who selected each type of impact varied by the department people were waiting for.

	No.	Work	Household	Caring	Mental Health	Family
Trauma and orthopaedics	571	39%	73%	20%	57%	64%
General Surgery	257	36%	47%	16%	47%	48%
Gynaecology	136	40%	55%	28%	73%	65%
Ear, nose and throat	94	34%	22%	10%	73%	41%
Urology	68	18%	26%	9%	49%	40%
Total sample	1,416	33%	53%	17%	55%	52%

Table: The percentage of people who selected various impacts, and the department they were waiting for.

Examples of comments about impact left by respondents waiting for different hospital departments



Orthopaedics



"It has affected me mentally & physically. Much difficulty in walking anywhere, putting items of clothing on, shoes and socks. Frightened I'm going to fall over, which I have done as my hip has given away. Not enjoying swimming anymore as I get problems afterwards with pain. My life and lifestyle has come to a halt."
(West Suffolk Hospital, Trauma and Orthopaedics)

"Due to increasing levels of pain, which has greatly affected my mobility, I no longer have an active social life. I have all my shopping delivered and have become increasingly isolated. Having spent a number of years as my late husband's carer, my lack of mobility made my caring duties more difficult when he needed me most."
(West Suffolk Hospital, Trauma and Orthopaedics)

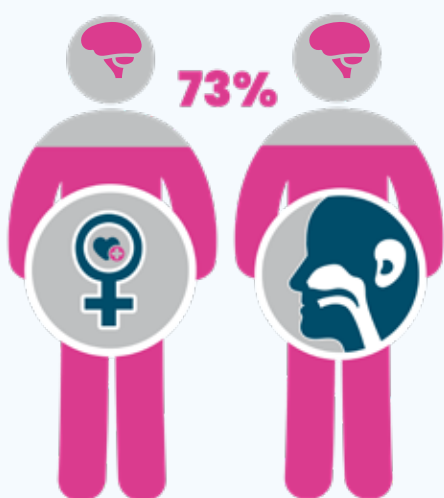
"This injury has caused me to be in pain every day. It also stops me from doing my machine operating role at work. I struggle even picking up my baby, which has an emotional effect on my mental health as I feel it's massively affecting my connection with him." (West Suffolk Hospital, Trauma and Orthopaedics)

General Surgery



"It's been a hectic and unpleasant waiting period as my hernia is continuously deteriorating and making my work life difficult. I cannot be employed as I am a warehouse operative and I cannot do heavy jobs. Therefore, I have not been able to earn enough money to take care of my family." (West Suffolk Hospital, General Surgery)

"Constant pain and discomfort, restricted diet, lack of sleep regularly due to symptoms, low mood as direct result of symptoms." (ESNEFT, General Surgery)



Almost three quarters of people waiting for gynaecology and ear, nose, and throat elective treatment said their mental health had been impacted by their wait for care.



"The problem I have with waiting so long is it has got worse. It affects my everyday routine and my kids and my grandson. **It has affected my mental health.**" (James Paget University Hospital, Gynaecology)



"I am living with moderate pain all the time and have had a number of flare ups of severe pain, during which time I am out of action. We have a large family, and when I am in severe pain or attending hospital my husband has to take time off work to look after the family – he is self-employed so this is extremely detrimental financially."
(West Suffolk Hospital, General Surgery)

Gynaecology



"I am regularly in severe pain and cannot function to work or do anything else on those days. I need to take strong painkillers, and the fatigue is bad. The distension in my belly is hugely uncomfortable and stops me taking part in exercise regularly or wearing normal clothes. I constantly have to wear sanitary towels as the bleeding can be at any time. This also negativity affects my sex life. When the bleeding is flooding, I can't leave the house. I have had no support for this other than medication and there is no financial support for when I can't work."
(ESNEFT, Gynaecology)

"Still experiencing all my symptoms with adenomyosis and endometriosis, which at times is very debilitating. This has major impact on my life at times physically and mentally. When pain is very bad it affects my daily tasks, every day routines, social, family life etc., as I spend a lot of time becoming introverted as I don't want to go out or can't participate in things as in so much pain. At times my life is basically in bed, sofa or constantly on painkillers. As I've expressed these conditions are up and down and no day is the same."
(James Paget University Hospital, Gynaecology)

ENT



"The past 10 months have been very difficult to cope with as I feel unwell and it has been an uphill struggle to get prioritised on the list for surgery. I work full time and have continued to work despite feeling ill, but the impact means I have no life outside work because I have no energy and the other symptoms mean I am exhausted at the weekend and in the evenings, so just rest to make sure I have the ability to get through the week at work again. I have lost 1.5 stone in weight and my mental health is not very positive.'
(West Suffolk Hospital, Ear, Nose & Throat)

"I'm awaiting surgery for ear and sinus issues. However, with having to call in sick to work so often due to uncontrolled symptoms (which can only be corrected with surgery) I was forced to cut my hours from 37 to 30. This has had a massive financial implication as my earnings have dropped by nearly £6k. This has caused me further financial difficulties, debt, stress and other health issues too."
(James Paget University Hospital, Ear, Nose & Throat)

"I am not currently able to work due to both my physical health condition and my mental health so finances are tight. As the ENT problem involves speaking, it is rather limited at times, I slur my words, don't speak as often and even in the public space such as in cafés and restaurants it's difficult to."
(West Suffolk Hospital, Ear, Nose & Throat)

Urology



"Numerous UTI infections, lack of self confidence, sexual relationship, depression." (ESNEFT, Urology)

"The wait is having an enormous effect on my mental health, causing lack of confidence and esteem. No self confidence left. My condition is considerably uncomfortable - No consideration given." (West Suffolk Hospital, Urology)

"The biggest problem for me is that on most nights I have to get out of bed roughly every two hours. I have found this difficult to cope with and look forward to a good night's sleep." (James Paget University Hospital, Urology)

People with more vulnerabilities reported more impacts on their lives.

- Among respondents with no vulnerabilities, one in five people (20%) said waiting for care had not impacted their lives, compared to 11% for those with one vulnerability, and only 7% for those with two or more vulnerabilities.
- Almost half (48%) of respondents with two or more vulnerabilities said waiting for care had affected at least four aspects of their lives.



	Total		Number of vulnerabilities		
			0	1	2+
Sample size	1,416		804	474	82
	Count	%	%	%	%
Number of impacts					
0	235	17%	20%	11%	7%
1	352	25%	28%	23%	13%
2	278	20%	20%	19%	20%
3	245	17%	16%	20%	12%
4	199	14%	12%	17%	28%
5	107	8%	5%	11%	20%
Average impacts	2.1		1.9	2.4	3.0

Table: The percentage of people experiencing impacts featured in the survey (comparing the number of self-reported 'vulnerabilities' and the number of impacts selected in the survey).

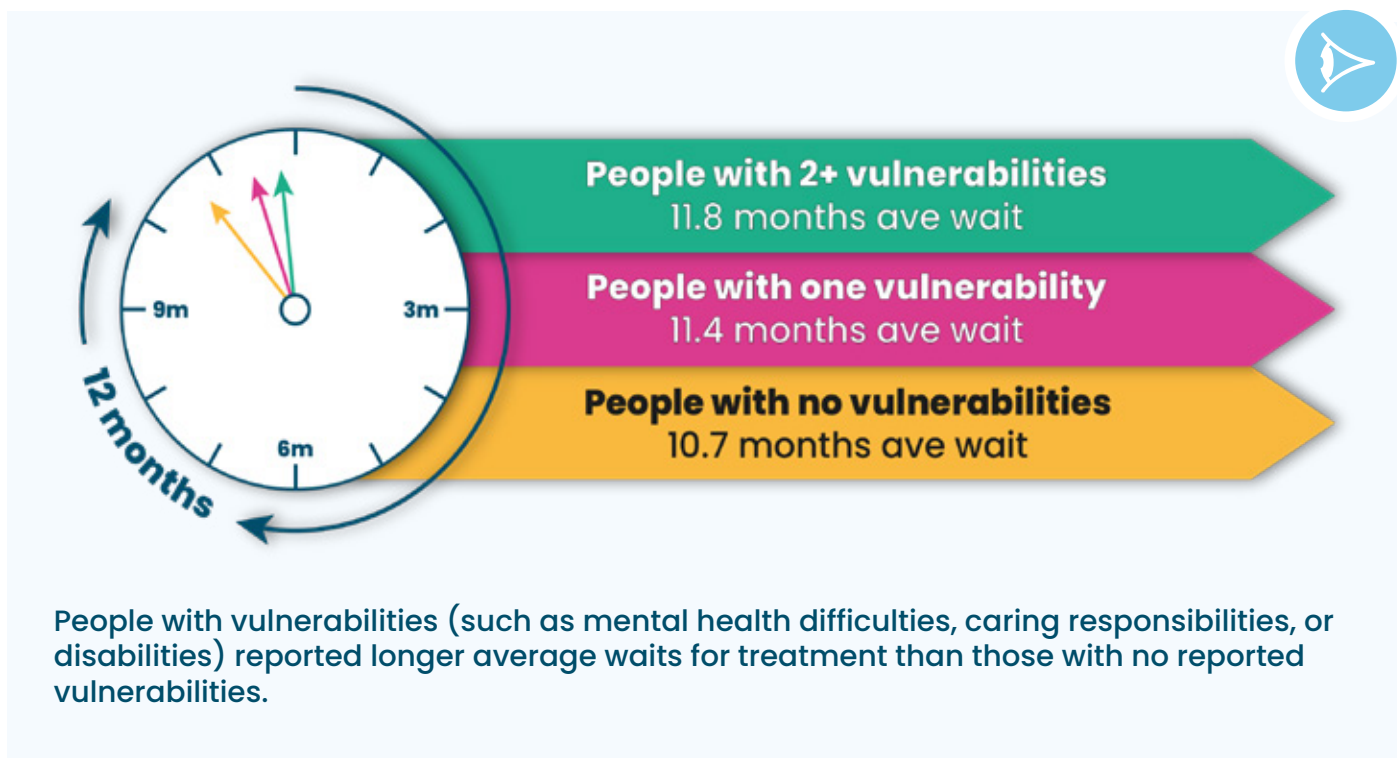
Again, it is important to consider how long people have waited when analysing this data, because this may also affect the number of impacts people experience.

The graphic below shows that, in this sample, individuals with two or more vulnerabilities tend to have experienced longer wait times (average 11.8 months) compared to those with one vulnerability (11.4 months) or no vulnerability (10.7 months). This aligns with national findings on inequalities in wait times for planned care.

The 2023 Kings Fund report '[Tackling health inequalities on NHS waiting lists: Learning from local case studies](#)' highlighted that:

"There are structural, economic and social factors that can lead to differences in the length of time people with the same clinical needs wait for treatment, and differences in the impact waiting has on their daily lives. For example, the NHS can be difficult to navigate and appointments difficult to attend; people reach the waiting list in different health states and deteriorate at different rates; and individual circumstances affect whether someone can do things like work or fulfil caring responsibilities while they wait."

Further targeted work would be required to fully explore the factors underlying the inequalities evidenced within this data set.



People with vulnerabilities experience different types of impacts.

- Analysis of the percentage of people who reported impacts while waiting for care revealed that individuals with a diagnosed mental health condition, learning disability, or those living in potential poverty had above-average scores on all five aspects of life.
- Over half of carers said that waiting for treatment had affected their ability to care for someone else.
- Female respondents were more likely to report impacts in all areas, compared to men.
- Respondents from a non-white ethnic background were more likely to say they had experienced difficulties with their mental health while they wait, than people from white ethnic backgrounds. They were also more likely to say that their ability to work had been affected too.

Below are some examples of comments about impacts, left by respondents who reported one or more vulnerability.



Carers

"I have a prolapse bladder and have been fitted with a pessary... I am a caregiver for my disabled husband. He needs help with all aspects of day-to-day life. My GP told me no lifting, stretching or straining and to take things easy. I told him, 'Take things easy? That doesn't happen in my world!!'. Whenever I take him out, I'm the one struggling to get his walker in and out of the car."
(West Suffolk Hospital, Gynaecology)

"I am a carer for my husband plus I work full time... I am in constant pain, my mobility has declined considerably, my ability to drive is affected and thus my work is impacted. My ability to care for husband and our home decreased significantly."
(ESNEFT, Trauma and Orthopaedics)

"[It's affected] my ability as a carer for my husband. My ability to pay for domestic help. My ability to pay for carers to help my husband shower,

dress etc. each morning. My ability to pay for help is only because we received attendance and carers allowance. Otherwise, it would be have been impossible."
(West Suffolk Hospital, Trauma and Orthopaedics)

Mental Health difficulty (MH)

"Fuels my depression. I hate waiting and my hernia is slowing me down."
(ESNEFT, General Surgery)

"I also suffer from chronic depression and anxiety; this is increased by the pain being worse."
(James Paget University Hospital, Trauma and Orthopaedics)

"Another impact has been my mental health resulting in needing to increase my antidepressants as well as having CBT. I also have two children, which it has impacted especially as my daughter has autism and complex needs."
(West Suffolk Hospital, Gynaecology)

Sensory Impairment (SI)

"I am in constant discomfort I am hard of hearing and this wait is impacting on my ability to communicate



"Waiting for a new hip. Full time carer to a disabled son and another son who has just had heart surgery. Pain level is unbearable by middle of the day. Disabled son has cerebral palsy and autism , and he is a big 19-year-old. My daughter has had to step up and help around her job and family as I can't drive to shop, can't weight bear my son anymore.

"In constant tears."

(West Suffolk Hospital, Department unknown)



effectively. My right ear is constantly running, and my hearing is awful. I am 80 years old, and this is making me feel very sad and alienated."

(James Paget University Hospital, Ear, Nose & Throat)

"I'm really struggling to see to the point where I can't even see the television. It's not good, and very worrying. I can't read letters, or hardly anything. The cost of travel has impacted my ability to access my mental health services too, as I now rely on taxis."

(West Suffolk Hospital, Ophthalmology)

Autism (ASD)

"The longer it takes, the worse I have become, the longer recovery will be. My quality of life has fallen significantly as has my ability to work and look after myself and my home... It has got to the point of feeling 'what's the point?' As I am existing and not living..... It is frustrating and demoralising. I feel useless and a burden."

(West Suffolk Hospital, Ear, Nose & Throat)

"Poor health can feel like it consumes me sometimes. I feel like I either am constantly talking about it or not talking about it at all. I have found expressing my experiences through

art helps (I work as a creative also). It's a way of processing it and juggling the complex emotions."
(ESNEFT, Gynaecology)

Learning Disability (LD)

"I have been unable to work for 8 months with no support. I am in constant agony unable to do everyday tasks (bend down and lift anything)."

(West Suffolk Hospital, General Surgery)

"I have suffered an overall decline in my health and now have a heavy reliance on medication such as Oramorph. This medication makes me feel sick and I still suffer pain. I have had two admissions into ED dept at QEH kings Lynn, still no further on. This has put a huge strain on my mental health."

(West Suffolk Hospital, Urology)

"My small business will not survive much longer. I am in pain 24/7. No one can seem to give me any answers about appointments. I cannot dress myself or drive anymore."

(ESNEFT, Pain Management)

Disability

"Waiting for a second hand operation

which was about 18 months wait and now on another 18 month wait to have the second joint done. It's difficult as I'm a wheelchair user too so impacting daily life, work and personal care etc. Hand physio have tried to help with splints and support which I'm grateful for."

(ESNEFT, Trauma and Orthopaedics)

"It has affected other health issues, having to use a walking stick has exacerbated the cervical stenosis I suffer from and the collapsing lumbar discs. To help this, I use two sticks or a Zimmer frame. This makes me feel old and failing. I have constant pain from my arthritic hip, my neck and my back these two are being made worse due to the long wait for new hip."

(James Paget University Hospital, Trauma and Orthopaedics)

"It's getting really hard as waiting for hip replacement surgery so now can't walk I don't go out just sit in the chair all day, I just about get to the toilet using a Zimmer frame I'm afraid that if I'm left a lot longer I won't be able to do that either as I'm in so much pain it worries me, I can't shower even with a stool as I can't step in and out I'm just hoping I hear something very soon I suffer with depression and this isn't

helping as I have no quality of life."
(James Paget University Hospital, Trauma and Orthopaedics)

Poverty

"Unable to lead a normal life, being disabled anyway is hard, but not being able to do more than 30 minutes without feeling exhausted and drained, and by midday wanting to sleep. With my heart rate varying between 170 and 51 beats a minute every day tires me, I haven't seen my family since this started as I don't feel capable of travelling too far. The stress is not helping my mental state. Also now, due to benefit changes, I'm worrying about paying my bills."
- (James Paget University Hospital, Cardiothoracic)

"This has had an impact on my mental health, my physical health and my personal wellbeing. I now can't work due to the state of my health. Been advised not to also. So financially this has hit my entire family."
(James Paget University Hospital, General Surgery)



"It's getting really hard as waiting for hip replacement surgery. So, now can't walk. I don't go out, I just sit in the chair all day. I just about get to the toilet using a zimmer frame. I'm afraid that, if I'm left a lot longer, I won't be able to do that either as I'm in so much pain it worries me. I can't shower, even with a stool, as I can't step in and out.

"I'm just hoping I hear something very soon I suffer with depression and this isn't helping as I have no quality of life."

(James Paget University Hospital, Trauma and Orthopaedics)





Key Learning – impact on lives

- People waiting for different types of treatment reported varying levels and kinds of impacts on their lives. For example, those awaiting orthopaedic care were more likely to struggle with household chores, while those waiting for gynaecology treatment more often reported effects on their mental health.
- People with different vulnerabilities reported varying levels and kinds of impacts on their lives.
- Over half of family carers said that waiting for treatment had affected their ability to care for someone else.
- Regardless of what type of treatment people were waiting for, those who had waited longest reported higher levels (numbers) of impacts. Those who said that their lives had not been impacted by the wait for care were more likely to have been waiting less than six months.
- People with more vulnerabilities tended to have experienced longer waiting times.

Considerations for system leaders:

A one-size-fits-all approach to supporting people while they wait for elective care is unlikely to meet the diverse needs of patients. Developing tailored 'waiting well' information is essential to ensure support is relevant and effective for different patient groups. People's situations and circumstances, including their need for information, advice and support about 'waiting well' may also change over time. Careful consideration should therefore be given to both the content of the information and the most effective timing and methods for delivering it to patients.

Further work is required to fully explore the inequalities in waiting times for people with different types and levels of vulnerabilities.

Summary of free-text responses on impact of waiting

In addition to the quantitative question, respondents were invited to share their experiences of waiting for care and how it had impacted them in a free-text box. A total of 1,144 people provided comments.

These insights add depth and context to the quantitative data described above, illustrating the complexity and diversity of individual experiences. They also highlight the interconnected nature of the impacts people experienced. For example, this included how pain can restrict mobility, which can affect ability to work and financial stability, increasing stress on individuals and their families.

Pain (394 mentions)

A third (34%) of all respondents who left a comment in the open ended text field wrote about the pain or discomfort they experienced whilst waiting for elective care. Experiences ranged from 'general discomfort and inconvenience' through to those who described their pain as 'excruciating', 'debilitating' and 'unmanageable'.

Some experienced occasional pain, while others spoke of being in constant or persistent pain and several respondents reported that their levels of pain had either increased or that they were experiencing pain more frequently.

Pain was often identified as the primary cause of other impacts on people's lives, affecting their ability to work, socialise, and move around. Furthermore, living with constant pain had a significant impact on some people's mental health and wellbeing, as well as disrupting their ability to get quality sleep.

"Inability to stay mobile, sleepless nights. In constant pain." - (ESNEFT, Trauma and Orthopaedics)

"Having to take time off work due to pain." - (James Paget University Hospital, General Surgery)

"The worst thing is coping with the pain which is affecting my mobility." - (West Suffolk Hospital, Trauma and Orthopaedics)

"Frustrating, excruciating pain, life debilitating, very bad on my mental health." - (West Suffolk Hospital, Trauma and Orthopaedics)

"The worst thing is coping with the pain..."



An epidemic of pain?

A third of people described how pain was having an impact on their lives. For some, the pain has been debilitating and unmanageable. Many described how their pain had increased over time.

"The pain disturbs my sleep." - (James Paget University Hospital, Trauma and Orthopaedics)

"I am in constant pain and struggling to continue with daily activities, some days are a bit better, but generally not good. My mental health has been affected as I struggle to do anything social." - (James Paget University Hospital, Gynaecology)

Many relied on pain relief to manage their symptoms, with some reporting an increasing dependence on medication to enable them to cope with daily life. Some respondents however reported pain medication to be less effective over time, while others highlighted side effects of prolonged use of pain killers. This included constipation, nausea and weight gain. Concern was expressed by some about the long-term health impacts of constant use of pain relief.

"Increased pain requiring more pain killers, I am concerned if there are any long-term effects from pain killers." - (West Suffolk Hospital, Trauma and Orthopaedics)

"Having to take pills that make it hard to work and not feel good. Pain makes you feel rubbish hard to stay positive." - (West Suffolk Hospital, Pain Management)

"I have suffered an overall decline in my health and now have a heavy reliance on medication, such as Oramorph. This medication makes me feel sick and I still suffer pain." - (West Suffolk Hospital, Urology)



56

"I spend around 16-18 days a month now in the worst pain, sometimes bed-bound. I'm sent to the A&E and not treated well due to 'all tests clear', yet I'm in agony and feel my insides are bursting... I had to leave my job, and now do my best to work for myself - but many days I cannot do that. I've been told the wait for surgery is 73 weeks!! I'm isolated and alone, with no real answers.

"I have teenage children, and they have to help me. This isn't fair on them. I cannot go out with friends. I worry about leaving home, I cannot open my bowels comfortably any more due to pain, and I get pain during urinating, my period and ovulation, along with episodes of urinating blood which has hospitalised me (with still no answers). **The thought of waiting another 18 months is heartbreaking.**"



Shrinking worlds? Hundreds of people said their wait for care was leading to poorer health and reduced mobility.



Deterioration in physical health (135 mentions)

In addition to comments about managing pain, 135 respondents reported an overall deterioration in their physical health whilst waiting for elective care.

While some comments simply mentioned a general reduction in physical health (e.g., 'I have gotten a lot more poorly!', or 'Mobility and fitness have deteriorated'), others highlighted that the specific condition for which they were waiting for hospital treatment had deteriorated (e.g., 'The lump just gets bigger and the pain comes and goes', 'I am now in more need for surgery as my prolapse has got worse', or 'Eyesight getting worse in left eye with headaches').

Some respondents reported that waiting for elective care had also led to additional impacts on their physical health. For example, changes in posture to compensate for a bad knee or hip placing extra strain on the unaffected leg.

Respondents expressed concerns about the longer-term effects of waiting for care on their overall health including:

- Inability to maintain a healthy lifestyle through regular exercise, which could hinder recovery and affect healthy aging;



"My condition is slowly worsening having an impact on my other knee which now need surgery."

(West Suffolk Hospital, Trauma and Orthopaedics)



- The risk of their condition deteriorating so far that more invasive or emergency surgery would be necessary;
- The possibility of their condition progressing to an irreversible stage or reaching a point where surgery would no longer be an option.



"I think because I have waited so long in such a lot of pain that even when the operation is done I will be struggling to get back to normal as it has affected my hips, legs and back having to wait this long is so counterproductive."

(West Suffolk Hospital, Trauma and Orthopaedics)

Examples of quotes about 'deterioration of physical health' include:

"Because of the nature of the operation I am waiting for, I remain uncomfortable and unable to do any physical exercise, resulting in weight gain and therefore potentially further health issues." - (West Suffolk Hospital, Gynaecology)

"My principal concern is that my eyes will presumably continue to deteriorate waiting for laser surgery. Hopefully, any deterioration will not be irreversible."
- (James Paget University Hospital, Ophthalmology)



"When this lump was first found it was the size of my little finger nail. It is now quite large and growing. This will mean more invasive surgery. I am not sleeping properly and have been thinking about trying to remove this myself and then go to A & E to have it stitched back up. This is severely impacting my mental health." - (James Paget University Hospital, Urology)

"Heart condition has deteriorated and it has affected the kidney function." - (Hospital unknown, Cardiothoracic)

"I'm waiting for a knee and shoulder replacement surgery, but also I have sciatic pain... I can't walk my dog as far or as frequently as I would like. I am concerned that I will lose my muscle strength that I am trying to maintain to support my damaged joints, as the waiting seems endless..." - (West Suffolk Hospital, Trauma and Orthopaedics)

"Just anxious really as letter says urgent treatment for suspected BCC not knowing how long is acceptable to wait without causing more damage or irreversible damage to health."
- (West Suffolk Hospital, Plastic Surgery)

"The delaying of surgery has meant my hip is now worse. I am now looking at an 18 month wait for surgery. I am now obese as I cannot exercise, and now also pre diabetic. I wonder if I'd had hip replacement earlier if this situation could have been avoided?" - (James Paget University Hospital, Trauma and Orthopaedics)

Mobility (158 mentions)

A total of 158 people specifically reported increased difficulties with mobility, while waiting for care. As highlighted in the section above, for many, this has led to physical deconditioning and raised concerns about the long-term effects on their overall health and their ability to recover from surgery.

"My mobility has decreased and I am concerned that by the time I have received a new knee, I shall find recovery difficult." - (West Suffolk Hospital, General Surgery)

"I am worse every day. Mobility down to 20 metres, constant pain, poor sleep, cardiovascular is weak as I can't exercise, depression, anger, pointlessness to life." - (West Suffolk Hospital, Trauma and Orthopaedics)

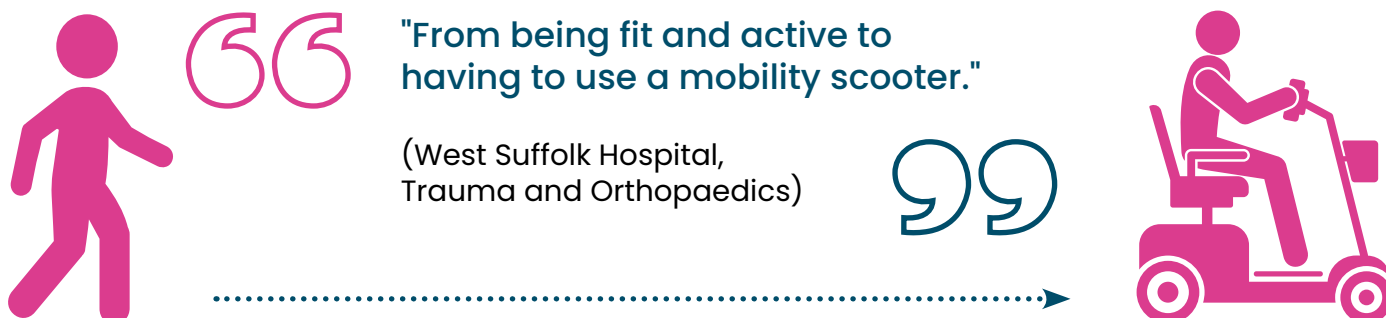
"At the start I was pretty fit, walking less than in previous years but still able to do four or five miles. I was a member of a cycle club (30m in a morning), a kayaker, and danced four evenings a week. Now I can manage half a mile with a stick, I cycle alone, manage to a limited extent in the kayak with a great deal of help, and only just manage to stagger round a dance floor leaning on a partner. Most of this deterioration has been in the last 6 months and I'm terrified of what state I'll be in in another nine months - the earliest possible date for a half knee replacement. My fitness has slipped so much, and I did do all the physio courses available and still do all exercises at home daily." - (West Suffolk Hospital, Trauma and Orthopaedics)

Respondents highlighted that a reduction in mobility often led to increased dependence on others, particularly close family members, to assist with daily household chores (such as gardening, cleaning, shopping, driving) and, in some cases, personal care tasks (washing, dressing, toileting) as well. For some this had placed additional strains on relationships with family members.

"My mobility has got a lot worse. Relying on more care from my wife." - (West Suffolk Hospital, Trauma and Orthopaedics)

"I appreciate I'm lucky in comparison to some, but it seems such a waste, especially as I'm 80 next year. It's friends helping me now - I used to be able to do for them!" - (West Suffolk Hospital, Trauma and Orthopaedics)

"I've been confined to the house as I can't walk from one room to the other. I have a trolley, but I'm still in a lot of pain. I can't shower as the pain is excruciating, and I find it very lonely."





"I am in constant discomfort I am hard of hearing and this wait is impacting on my ability to communicate effectively. My right ear is constantly running and my hearing is awful.

"I am 80 years old and this is making me feel very sad and alienated. Please help me."

(James Paget University Hospital, Ear, Nose & Throat)



"I have neighbours who come in now and again to offer help, so I'm not completely isolated. But I don't like to ask too much." - (West Suffolk Hospital, Trauma and Orthopaedics)

"Constant pain. Unable to walk without walking stick and only around the house or garden. Depressed and use of medication and painkillers has effects generally to my body. Severe psoriasis owing to stress. No contact with GP or WSH unless requested by them to attend. Have seen GP twice during this time and consultant once. Time span for surgery still unknown. Huge impact on my hitherto healthy lifestyle. Also on health of my wife who during this period had breast cancer surgery, but has had to care for me also. Cannot drive or indeed do anything other than sit and read. Coping in this situation is very difficult. I am 72 and find myself in tears at times. Have considered just giving up." - (West Suffolk Hospital, Trauma and Orthopaedics)

"I am waiting for a hip replacement, my mobility is very reduced. I struggle to dress myself and to have a shower, or do the cleaning etc. If I drop anything, I cannot pick it up, so my son has to help and do a lot for me!" - (West Suffolk Hospital, Trauma and Orthopaedics)

Several respondents noted that mobility difficulties left them feeling isolated, excluded from social activities, and, in some cases, housebound. For some, this had led to low mood, lack of energy, lack of motivation and depression.

"I have become housebound and not able to stand or walk for any length of time." - (James Paget University Hospital, Colorectal Surgery)

"I have become immobile, have had to change my job so that I can work from home, and I have become excluded from social and family activities as I am unable to participate." - (West Suffolk Hospital, Trauma and Orthopaedics)

"Really it's mostly the increasing pain and the decreasing mobility. I socialise less because I find it difficult to get about." - (West Suffolk Hospital, Trauma and Orthopaedics)

"I am in constant pain, my mobility has declined considerably, my ability to drive is affected and thus my work is impacted. My ability to care for husband and our home decreased significantly. My wellbeing has declined and I now take antidepressants." - (ESNEFT, Trauma and Orthopaedics)

Mental Health (195 mentions) and sleep (66 mentions)

The impact of long-term pain and illness on mental health has long been recognised, along with the crucial role of quality sleep in maintaining wellbeing and resilience.

Respondents reported that waiting for elective care had a range of impacts on their mental health and wellbeing including:

- increased levels of anxiety due to worries about deteriorating health;
- low mood, depression and social withdrawal due to reduced mobility and chronic pain;
- stress from not knowing when the procedure will take place;
- lack of energy and motivation due to health limitations;
- loss of confidence and self-worth, as a result of having to rely on others;
- disrupted sleep.

Examples of feedback like this included:

"It is affecting my mental health as I don't want the condition to deteriorate while I'm waiting." – (West Suffolk Hospital, Gynaecology)

"My life is on hold as I don't get out much. Constantly waiting to hear creates anxiety. The impact of waiting for so long has curtailed several of my normal activities and hobbies (e.g., reading and water colour painting), including driving, and has therefore contributed to me feeling isolated and sometimes quite low." – (West Suffolk Hospital, Trauma and Orthopaedics)

"My mobility has reduced considerably and my mental health has been adversely affected. I have had to increase my pain medication, and my temper has increased. I have trouble sleeping, going to bed later and waking during the night due to the pain." – (West Suffolk Hospital, Trauma and Orthopaedics)

In some cases, the impact on mental health was further exacerbated when respondents were informed their need for treatment was 'urgent', only to be left waiting for months, with little communication from the hospital to update on the situation.

"Just anxious really as letter says urgent treatment for suspected BCC not knowing how long is acceptable to wait without causing more damage or irreversible damage to health." – (West Suffolk Hospital, Plastic Surgery)

"After being admitted to hospital for treatment, it was agreed I would be put on the urgent list for surgery. I have now been on this list for three months and had four dates for surgery cancelled... The impact of this repeated build up and disappointment is given no consideration at all... One of the effects of my condition is low mood, and the impact of this situation has led to a deterioration in my mental health to depression and anxiety, which is having a significant impact on my performance at work and my home life." – (West Suffolk Hospital, Ear, Nose & Throat)

Some respondents reported more severe mental health impacts, including experiencing panic attacks, breakdowns and suicidal thoughts.

"It's been a very long time waiting for the CT scan and now waiting for the operation my problem is getting worse can't sleep having panic attacks." - (West Suffolk Hospital, Colorectal Surgery)

"Affected my quality of sleep, as breathing at night is an issue. This has had a knock on effect at work as I had a minor breakdown, and decided to step down. Feel drained at times, as poor quality sleep is having an effect on my day to day mood." - (West Suffolk Hospital, Ear, Nose & Throat)

"More complex surgery needed. Loss of finances. Loss of job. Severe depression. Suicidal thoughts." - (ESNEFT, Gynaecology)



"Cannot drive or indeed do anything other than sit and read."

"Coping in this situation is very difficult. I am 72 and find myself in tears at times. Have considered just giving up."



Work (170 mentions)

A total of 170 people described how their ability to work or undertake volunteering had been affected whilst they wait for elective care. Some had received support from their employer and were able to make reasonable adjustments to their workload, working conditions and hours. Others had not been so fortunate and had found their employer (and colleagues) to be less sympathetic or supportive of their situation.

A few respondents had given up work entirely. This was not always from personal choice. One respondent felt that his sickness/absence record would impact on his longer-term job prospects.

"I've had to have time off work. My employer has got occupational health involved and offered to get other help." - (West Suffolk Hospital, Gynaecology)

"My workplace has adapted my work around what I am able to do within reason." - (James Paget University Hospital, Trauma and Orthopaedics)

"I miss work, which doesn't help my employment. I do worry that my manager, who is understanding at the moment, will eventually get fed up with me ringing in sick all the time." - (James Paget University Hospital, General Surgery)

"I am waiting for gall bladder removal. I am having regular flare ups of extreme pain due to pancreatitis, which is causing me to take time off work. I only receive statutory sick pay and have been put on disciplinary action due to the amount of time I am having to take off." - (ESNEFT, Colorectal Surgery)

"I have been waiting over two years for surgery. I have been threatened with my job to be put onto medical investigation due to having time off." - (ESNEFT, Gynaecology)

"I work as a dispenser at a doctors surgery. I'm really struggling as a lot of the day is on my feet, work I feel are not very understanding, but financially I have to work." - (West Suffolk Hospital, Trauma and Orthopaedics)

"Work have not been supportive as I have only done nine weeks work in the last year." - (West Suffolk Hospital, Colorectal Surgery)

"I have had to reduce my hours at work in order to cope with the pain. I am unable to carry out some of my normal duties and adjustments have had to be made by my employer, which has caused issues with colleagues." - (West Suffolk Hospital, Trauma and Orthopaedics)

"The company that I worked for after six months let me go because I was no further forward for an operation." - (West Suffolk Hospital, Trauma and Orthopaedics)

"I've been retired medically, as my company has no other jobs for me. I've always worked and I'm not at retirement age. It has upset me." - (West Suffolk Hospital, Gynaecology)

"It also definitely contributed to my being made redundant in July as I wasn't able to be as efficient as previously." - (West Suffolk Hospital, Trauma and Orthopaedics)

Many people described how their wait for care was affecting them at work with consequences for their wellbeing, financial status and more.

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"I do a physical job, and am becoming increasingly disabled. Pain relief initially helped me maintain my effectiveness at work, but is now increasingly restricting the tasks I can perform. Financially - I am still in employment, though have missed out on a considerable amount of overtime work that I would usually have performed, but I am no longer physically capable of doing the work required for that overtime."



Finance (58 mentions)

Ability to work inevitably has an impact on financial stability and income. In total, 58 people reported that their overall finances had been affected while they waited for care and treatment. While most comments mentioned the reduction or loss of income that had resulted from a change in employment, a few respondents highlighted additional costs that living with a long term health condition can incur. Examples of additional costs included:

- purchase of health products such as sanitary or incontinence wear;
- costs for employing home help (cleaners, gardeners, dog walkers etc.) or personal carers;
- purchase of daily living equipment such as walking aids, chair raisers, hand rails, mobility scooters etc.;
- increased costs of travel insurance;
- paying for health treatments e.g., physiotherapy, pain injections etc.

Examples of comments related to this included:

"I have become severely incontinent whilst waiting. Also it costs a great deal in sanitary products which I cannot really afford. Because of this problem I can't visit my friends attend meetings or go on holiday. I have no idea when this problem will end or even if it will." - (West Suffolk Hospital, Gynaecology)

"My ability as a carer for my husband. My ability to pay for domestic help. My ability to pay for carers to help my husband shower, dress etc. each morning. My ability to pay for help is only because we received attendance & carers allowance. Otherwise it would be have been impossible." - (West Suffolk Hospital, Trauma and Orthopaedics)

"As I travel a great deal for work and have been waiting for a colonoscopy with possible surgery included in the procedure, I have been unable to get travel insurance especially to



Some faced financial challenges because of their wait for care.



"Am out of work at the moment as my work won't let me back until after my surgery. Asking my family to help with my bills."

go to America. This is impacted massively on my life and it also meant we couldn't even go on holiday without carrying massive extra costs." - (James Paget Hospital, General Surgery)

"I am having to pay out for incontinence pads which I need to wear all the time." - (West Suffolk Hospital, Gynaecology)

"Not able to get out in the garden walk my dogs or drive my car. I have to rely on neighbours and friend to go to appointments get shopping walk my dogs and I have an added expense of the dog walking and also a cleaner." - (West Suffolk Hospital, Trauma and Orthopaedics)

"...I have cocodamol prescribed by my GP, but even so, it is becoming more painful to walk and exercise. I have fallen many times, causing me to purchase a rollator to enable me to walk with confidence. In addition, I have also found it necessary to purchase a new armchair with a higher seat to enabled me to stand more easily. I now have a blue badge for disabled parking due to my restricted ability to get about." - (James Paget University Hospital, Trauma and Orthopaedics)

Limited impact/resigned to wait (90 mentions)

Amongst these comments, 47 people reported that waiting had not had a significant effect on them and a further 43 people expressed acceptance or resignation about their wait.

Within comments attributed to this theme, there was a high proportion of people who had only been waiting six months. For example, 19 people (40%) who said waiting had not had any impact had been waiting for less than six months, and 15 people (34%) who were resigned to waiting had been waiting for less than six months.

Key sub-themes within these responses included:

- **Retired and unaffected:** Several respondents mentioned that as they were retired, waiting did not impact their finances, employment, or caregiving responsibilities;
- **Effective pain management was important to people's ability to cope:** While some respondents experienced occasional or manageable pain, others relied on medication or doctor support to help them cope. Those without significant pain found waiting more bearable but remained aware that their condition could worsen;
- **Long waits were regarded as inevitable:** Comments from some respondents indicated they accepted or were resigned to the situation, acknowledging systemic issues rather than blaming hospitals or doctors for the long waits;
- **Awareness of low priority status:** Several respondents acknowledged that their surgery was non-urgent, and expressed patience and empathy for others with more critical needs;
- **Regular clinical monitoring or review provided reassurance for some:** Being regularly assessed and kept informed helped some respondents manage the wait more easily;
- **Management of expectations:** Several respondents said they were prepared for long waits having been informed of expected waiting times at initial consultations or through communications from the hospital.

Examples of comments like this included:

"I am retired so finances, employment or caring responsibilities are not affected." - (West Suffolk Hospital, Trauma and Orthopaedics)

"Waiting on surgery that's not extremely urgent but is required. Pain comes and goes but is manageable. Happy to wait." - (West Suffolk Hospital, Trauma and Orthopaedics)

"I expected it, I was helped by doctor giving me some medication to help me while I am waiting. I was told that I would expect a wait and was clear." - (James Paget University Hospital, Gynaecology)

"I am not in any pain and it has not affected my everyday living. So not a big hardship." - (West Suffolk Hospital, Ophthalmology)

"Waiting is not really affecting my life. I am still able to do everything I want, and I am not in any pain. I just carry on." - (West Suffolk Hospital, Dermatology)

"There are some days where the pain is unbearable. But there is nothing you can do except wait as I am in the same boat as others." - (West Suffolk Hospital, Trauma and Orthopaedics)

"I understand that this isn't an emergency surgery therefore as annoying as this is for me it's not as important for me to wait, others who need this first as priority should always come before less urgent." - (West Suffolk Hospital, Ear, Nose & Throat)

"I have been seen by professionals & kept informed about my up-coming operation. It has been put back by just under a month which I am happy to wait." - (West Suffolk Hospital, General Surgery)



Support while waiting

The open-ended question about peoples experiences whilst waiting for treatment (and the impact of waiting) also encouraged people to comment on the support they had received. It further asked them to reflect on the support they felt could help them to cope better while waiting.

While many respondents mentioned that the use of pain relief had helped them to cope, thereby supporting or sustaining them through the long wait, only 243 people explicitly mentioned 'support' in their feedback.

Over a quarter of these respondents (66/27%) used the opportunity to state that they had not received or been offered any support. A further four people did not feel they needed any support at this time.

Support from friends and family

Among the remaining comments, 67 people (28%) highlighted that friends and family had been their main source of support, providing a mix of financial, practical, and emotional assistance. These comments highlight that waiting for care does not only affect the patient, but can be a whole family issue, impacting the health, wellbeing, finances and daily lives of other family members too. Some respondents noted that this had placed an additional strain on the relationships they have with their friends and relatives.

Examples of comments about the support family and friends have provided and the impact this has on families are shown below.

"Friends support has enabled me to stay sane when sometimes I just would like to give up."
- (West Suffolk Hospital, Trauma and Orthopaedics)

"My mobility is extremely compromised. At present time housebound. Dependent on others for shopping, walking my dog, personal hygiene, all achieved with the help of good friends."
- (James Paget University Hospital, Trauma and Orthopaedics)

"I am out of work at the moment as my work won't let me back until after my surgery. Asking my family to help with my bills." - (James Paget University Hospital, Trauma and Orthopaedics)

Impact on family

"Not very good, put pressure on marriage, can't book time away, can't enjoy time with my children, causes anxiety, depression, can't train and struggle with fitness." - (Hospital Unknown, Trauma and Orthopaedics)



"A friend has taken holiday from work to care for me, so this is now impacting her too..."

Waiting for care does not only affect those waiting for treatment, but it can also affect people's wider family and their other relationships.

"The waiting is awful. Every day means living off pain killers to get through my daily life. Constant pain is debilitating and very wearing. It has much impact on my family, which makes me sad." - (West Suffolk Hospital, Trauma and Orthopaedics)

".....The waiting for the operation is frustrating and depressing, it is also affecting my son who has mental health problems because he is worrying about me!" - (West Suffolk Hospital, Trauma and Orthopaedics)

"Very hard. I have many symptoms of endometriosis. I spend around 16-18 days a month now in the worst pain, sometimes bed-bound..... I'm isolated and alone, with no real answers, my symptoms are progressing and getting worse and more frequent. I have two teenage children, and they have to help me, this isn't fair on them." - (ESNEFT, Gynaecology)

".....Time span for surgery still unknown. Huge impact on my hitherto healthy lifestyle. Also, on health of my wife who, during this period, had breast cancer surgery but has had to care for me also. Cannot drive or indeed do anything other than sit and read. Coping in this situation is very difficult..." - (West Suffolk Hospital, Trauma and Orthopaedics)

Not everyone however had close family to support them. The following comments highlight the difficulties some people faced coping alone. This was particularly difficult for those who have experienced bereavement during their wait, who have not only faced the grief of losing a partner but also the loss of their support system.

"Just trying to cope with everyday tasks, as I live on my own. Increasingly more tasks I am unable to cope." - (West Suffolk Hospital, Trauma and Orthopaedics)

Some felt their wait for care was affecting their relationships (e.g., putting pressure on marriages)



"The wait means that I am living with discomfort and the embarrassment/inconvenience of not being able to fully control my bladder.

"It means that my ability to engage with some of the more active areas of my life and my marriage are negatively impacted."



"My husband died in May. I was his carer and hence unable to ask for surgery to replace one of my badly affected shoulders. He was able to help me dress, etc. Since then it has been such a struggle to do many everyday things." - (West Suffolk Hospital, Trauma and Orthopaedics)

"I live alone as my husband died last year. I live in a rural location with no services and no bus. I am dependent on driving and fear that I may be unable to as my cataracts progress without surgery." - (West Suffolk Hospital, Ophthalmology)

"I'm waiting for a hip operation - I've seen the surgeon twice, but they're quite reluctant as this is my third hip replacement. I have no direct family, so recovery is a potential issue." - (West Suffolk Hospital, Trauma and Orthopaedics)

Other forms of support

Other forms of support mentioned by respondents included:

- A total of 41 people mentioned they had accessed physiotherapy and/or exercise classes/groups. In some cases respondents had been referred by their GP or the hospital, others had sourced classes for themselves. Scepticism was voiced by some that physiotherapy was simply a mechanism used by health services to delay access to surgery. In contrast several other respondents commented positively about the benefits of physiotherapy and exercise in helping them to maintain overall strength and mobility while they wait.

"Swim on referral session have helped maintain movement." - (West Suffolk Hospital, General Surgery)

"Regular physiotherapy appointments to give me exercises to undertake to improve strength and mobility as much as possible to aid in rehabilitation afterwards." - (West Suffolk Hospital, Trauma and Orthopaedics)

"I have completed a six week arthritis course through Suffolk physios which has been fairly helpful." - (West Suffolk Hospital, Trauma and Orthopaedics)

"I pay privately to see a sports physio once every 2-3 weeks to help keep me moving. I pay to go to a gym 4 times a week to keep my muscles strong and to keep my mobility. I don't receive any help or support." - (West Suffolk Hospital, Trauma and Orthopaedics)



"I've self-referred to active living program at the leisure centre but only found out about this for myself. It would be good if the department could give more information about managing with arthritic knees."

(West Suffolk Foundation Trust, Trauma and Orthopaedics)



"Physio appointments just put off referral to hospital and the exercises were uncomfortable or sometimes painful." – (James Paget University Hospital, Trauma and Orthopaedics)

"Whilst my GP has referred me for surgery, I am being bounced around the system physio and orthotics being two examples. Neither have gone anywhere near solving my problems of chronic pain, balance and walking issues. It appears that the hospital is manipulating their waiting lists by using physio as a distraction." – (ESNEFT, Trauma and Orthopaedics)



"Occupational therapists have been really helpful getting me aids to help me around the house and getting a wet room put in."

(ESNEFT, Trauma and Orthopaedics)



"Referred again to physiotherapy which of course I cannot do. Very debilitating and frustrating because I cannot do much from the waist down." – (ESNEFT, Trauma and Orthopaedics)

"I keep walking the dog every day and did have a GP referral for aqua aerobics. The membership has come to an end. My GP has referred me again but I've heard nothing from my local centre." – (West Suffolk Hospital, General Surgery)

- Thirty-four people mentioned accessing and using mobility and daily living equipment to help them while they waited. Again, some people had been supplied with specialist equipment, while others had sourced and paid for equipment themselves. A few respondents had been assisted, by OT services, to make larger adaptations to their home. Four people had either applied for, or were considering applying for, a blue badge.

"Hand physio have tried to help with splints and support which I'm grateful for." – (ESNEFT, Trauma and Orthopaedics)

"Community Health have visited me and helped with advice on exercising and disabled aids around the house." – (West Suffolk Hospital, Trauma and Orthopaedics)

"Trapped indoors and cannot get out. Got two steps into the bungalow. One is just too high to get up. Use a frame to get around indoors. Had people come around to measure the steps but nothing has been done." – (West Suffolk Hospital, Trauma and Orthopaedics)

"Made alterations to house (ramps and an extra banister) – paid. Purchased bath and shower seats, and perching stools. Assessed by Occupational health and provided with sticks and trolley. Purchased mobility scooter." – (ESNEFT, Trauma and Orthopaedics)

- Nineteen people left general comments stating they felt 'well supported' during their

wait, or that healthcare professionals (including GPs) had been supportive.

"Support and engagement has been appropriate and proportionate." - (West Suffolk Hospital, Plastic Surgery)

"I have had very good communication from the hospital regarding the waiting list. I feel well supported." - (West Suffolk Hospital, General Surgery)

"My GP has been helpful." - (James Paget University Hospital, Trauma and Orthopaedics)

- Eight people had received support from specialist practitioners (for example, diabetic nurses, pelvic floor nurses or nutritionists etc.) or said their condition had been regularly monitored by a health team at their hospital. A further six people had accessed pain management services and three people had been referred to mental health and wellbeing services by their GP.

Regular monitoring

"Whilst waiting for surgery I have to attend clinic every six months." - (West Suffolk Hospital, Gynaecology)

"The hospital has been good at trying to manage my expectations and to reassure me with in between appointments." - (James Paget University Hospital, Other)

"[My consultant] has phoned me twice during the last six months to discuss/monitor my condition. I have found this reassuring." - (West Suffolk Hospital, Urology)

Support from Specialist health care professionals

"Been seeing a pelvic floor nurse, she's been really understanding but I need an operation; there's only so much she can do for me." - (James Paget University Hospital, Gynaecology)

"I have felt very stressed waiting. Also the hospital diabetes nurse has been helping me to lower my blood sugar as the surgeon will not operate while it is high." - (James Paget University Hospital, Ear, Nose & Throat)

"I have received practical help in the form of gynae physiotherapy and pessary fitting. The gynae practitioners I have met have been knowledgeable and very willing to give information about dealing with symptoms." - (West Suffolk Hospital, Gynaecology)

Pain Management classes

"Pain escape classes have been really helpful. Physio has been helpful and reassuring. Having to adjust how I live in line with my knee problem." - (James Paget University Hospital, Trauma and Orthopaedics)

"Have done a six weeks course at on exercises with a very good team from the Kirkley Mill tot help with the pain and now are still doing exercises. Keeping fit and

active does help but will be glad when knee replacement is done." - (James Paget University Hospital, Trauma and Orthopaedics)

"The group physio sessions for pain management and strengthening were very useful, but after that I feel I was just left to wait with no end in sight. And the waiting list times kept changing." - (West Suffolk Hospital, Trauma and Orthopaedics)

Mental health support

"I'm housebound, and depressed, and feeling isolated and helpless. Wellbeing is liaising with me." - (West Suffolk Hospital, General Surgery)

"My GP had to help me several times to escalate things. Mentally it's made me feel very unwell and I'm sure it's had an effect on my other illnesses. I've ended up having to get wellbeing support from my wellbeing coach at my GP office." - (James Paget University Hospital, Plastic Surgery)

"I am grateful that I had an NHS psychologist who specialised in treating people with chronic illnesses during my period of infertility. She helped immensely, however she wasn't replaced when she left the NHS." - (ESNEFT, Gynaecology)

- Only two people specifically mentioned 'Waiting Well' services within their feedback. Neither had been a satisfactory experience, with one ending abruptly due to lack of funding. The other service was not available, despite being widely advertised.

"Attended waiting well services physiotherapy, but it ended abruptly due to lack of funding. Nothing else available." - (West Suffolk Hospital, Trauma and Orthopaedics)

"I was hoping to attend a 'waiting well' course at a local leisure centre. But despite it being mentioned on various websites, it doesn't actually exist. I was booked onto a session and turned up to be told it hadn't run for a while. I have since got a doctors referral for GoodBoost sessions at Bury St Edmunds, which I have not yet started. I hope they will help with the pain in my osteoarthritic hip." - (West Suffolk Hospital, Trauma and Orthopaedics)

Other forms of support, which only a few respondents mentioned, included:

- Hospital transport (1)
- Suffolk One Live (1)
- Paid support e.g., cleaner, gardener, dog walker (4)
- Support around finances and benefits (3)
- Weight loss program (1)

What support would people like?

Some people considered the support they might need to wait well. Most who did stated that better communication and clearer information about waiting lists (including expected wait times) would help them to cope better.

Respondents felt that better information would:

- reduce anxiety and fears about being forgotten;
- provide clarity on their position on the list, and the numbers of others ahead of them;
- give assurance that progress was being made on the waiting list;
- ensure people were aware about changes to wait times, which would allow them to plan their lives.

Examples of quotes about better communication included:

"An occasional update from the hospital would help, so I could have some idea of how long I still have to wait." - (West Suffolk Hospital, Trauma and Orthopaedics)

"Many times I have felt complete frustration, annoyance and ignorance, particularly of timescales. I've felt expected to go along with the pretence of anything progressing, when in reality I've just been kicked down the road for another six months. I presume this is a method of controlling the size of the waiting list, but there's a dishonesty and patronism about it. When actually on a list and waiting, I've felt ignored and forgotten. Nobody bothers to find out how you are coping or more importantly give an update of where you are on the list." - (West Suffolk Hospital, Ophthalmology)

"Communication and updates on how long the waiting list would have been better, so you don't just feel like a number or forgotten." - (West Suffolk Hospital, Trauma and Orthopaedics)

"Awful communication, told I'm on a waiting list but not indication of how many others, no updates or changes on my waiting time. The anxiety it is causing me not knowing when I'm going to suddenly have time off is awful." - (West Suffolk Hospital, Gynaecology)

66

"I was given a date for surgery by phone and in writing. However, this changed and I was not informed. I discovered it yesterday by a courtesy call. As I have been off blood thinners for seven days thinking I was having surgery, the consultant advises that I can't be off them a further seven days. So, the revised surgery date was also cancelled. Today, I now have no date!"

(West Suffolk Foundation Trust, General Surgery)

99

"In terms of what would be helpful – it's very difficult because **all I want is timely treatment on the date it is booked, decent communication with supportive and sympathetic people, who understand what it is like feeling ill and needing medical intervention.**

"That seems to have been completely lost."



Support to make lifestyle changes

Respondents were asked if they had been advised to make any lifestyle changes before their operation (i.e. losing weight, getting more exercise, taking medication). A total of 1,406 people answered the question.

Twenty-four percent (339) had been asked to make lifestyle changes, 73% (1,028) were not asked, and 3% (39) did not know.

Weight loss (152 mentions)

Weight loss was the most commonly reported lifestyle change respondents had been asked to make, with a further 58 people being told to do more physical activity, and 46 asked to change their diet (e.g., low-fat diet, cutting out foods).

Within the qualitative responses:

- Thirty-seven respondents shared that they were successfully able to lose weight.
- Nine had received support to lose weight from their healthcare provider.
- Several respondents discussed the challenges they faced with weight loss, exercising and changing their diet. These challenges included:
 - » Fifty-nine people reported that exercising was physically difficult for them due to pain or lack of mobility.

"I was asked to watch my weight and keep as active as possible. This has been challenging, given the level of pain, and I now need crutches to walk to keep active." - (West Suffolk Hospital, Trauma and Orthopaedics)

"I can't exercise due to the discomfort and for me I need to exercise to lose weight." - (James Paget University Hospital, General Surgery)

- » Twenty-six people said they were not offered support with weight loss, or that this support was offered too late (i.e. a year into waiting or a week before surgery).

"No help has been offered to help to lose weight. Options should be offered to support me." - (West Suffolk Hospital, Gynaecology)

"Upon initial pre-op call was asked if I would like to make use of weight loss programme, feel like that's a bit late if you then have surgery the following week. Would feel it would have been more beneficial to have this service offered when put on the wait list for surgery." - (ESNEFT, Gynaecology)

- » Eleven people reported specific challenges to losing weight, such as their age, medications or other medical conditions having an impact.

"Losing weight has been a problem because I've been on steroids and I've put on weight." - (James Paget University Hospital, Trauma and Orthopaedics)

"Due to high levels of cortisol, I will struggle to lose weight. I keep getting booked in with the health and wellbeing coach at my GP who put me on a keto diet,

which made me feel poorly. I was then diagnosed with diabetes and told that diet was dangerous for me." - (James Paget University Hospital, Ear, Nose & Throat)

- » Five people shared how fatigue or lack of time affected their ability to lose weight (i.e. being able to focus on this around other commitments).

"I was asked to try to lose weight. I managed to lose 10kg before I got pregnant. However when I was put on the waiting list a second time, I couldn't lose weight. It's only been two months, but I haven't lost anything – as a mum to a toddler things have been very different this time around. My symptoms keep me up at night and cause fatigue, and with a toddler around I can't sleep. So I rely much more on food for an energy boost. I wasn't offered any support. Information about any healthy meal services would be useful – often I don't have energy or capacity to cook. So, we have to rely on takeaways." - (ESNEFT, Gynaecology)

- » Four people described how mental health issues were a barrier to losing weight.

"I have attempted to lose weight, but found it very difficult due to my inability to exercise and the depression I have to overcome." - (West Suffolk Hospital, Trauma and Orthopaedics)

"A catch-22 situation when pain, immobility and depression from social exclusion means you are unable to lose weight." - (West Suffolk Hospital, Trauma and Orthopaedics)

- » Six people mentioned weight loss medications. No patients were able to access this through the NHS, and five reported that they had paid privately for this to support them losing weight. One individual reported needing to sell things in order to sustain this.

"You hear about weight loss jabs, but no one has followed-up with help and options." - (West Suffolk Hospital, Gynaecology)

"I have had to sell things to pay for this treatment and make things to sell. It's really not sustainable anymore, but trying to hang on until my operation." - (West Suffolk Hospital, Trauma and Orthopaedics)

Stopping or reducing smoking or vaping (25 mentions)

There were mixed views on whether patients got support with reducing or stopping smoking and vaping, with four people saying they were not supported and three reporting support from their GP and/or smoking helplines.

"I have been asked to stop smoking and lose weight. This has been difficult due to medications and no support." - (West Suffolk Hospital, General Surgery)

"Told had to stop smoking for operation have now stopped smoking got help from GP with low dose patches using CBD nicotine vapes which helped a lot gets very depressing at times." - (West Suffolk Hospital, Trauma and Orthopaedics)

Taking new medications (23 mentions)

A number of people said they had been asked to take particular medications while they waited. Challenges faced included individuals not wanting to take these medications (1) or facing bad side effects (1).

"I am taking medication prior to my operation. I am taking three pills a day, which I can do easily." – (James Paget University Hospital, Gynaecology)

"I was taking tablets everyday, which is something that I was totally against. I was told I would have to continue taking them until the operation in 18 months time." – (ESNEFT, Urology)

"I have had to take new medication to try and manage condition. This has side effects of nausea, dizziness, abdominal pain and headaches, which impact daily. No support with managing these have been offered." – (West Suffolk Hospital, Ear, Nose & Throat)

Other changes

- Fourteen people were given specific exercises (i.e. mobility) which they needed to do.

'Keep up with daily knee exercises.' – (West Suffolk Hospital, Trauma and Orthopaedics)

- Nine were told to stop or reduce their alcohol intake.

'I was told to cut out alcohol as it can slow down recovery.' – (James Paget University Hospital, Colorectal Surgery)

- Nine had to attend regular physiotherapy.

'The physiotherapist helped me to find alternative ways of completing the exercises without further impacting my mobility.' – (West Suffolk Hospital, Gynaecology)

Other lifestyle changes, which only a few patients reported, included drinking more water or a certain amount a day (4), avoiding sunlight or UV (2), having to come off or go on birth control (3), blood pressure monitoring (2), reducing blood sugar (3), avoiding caffeine (3), doing less physical activity (i.e., avoiding heavy weights, stretching or lifting) (3), stopping HRT therapy (1), stopping supplements (1), and taking Vitamin D (1).



Key learning – impacts and pre-conditioning support

- Waiting for care has a significant impact on people's lives, affecting their physical health, mental wellbeing, relationships, and ability to support themselves—both financially and otherwise.

- Many people are living with significant pain whilst they are waiting for hospital treatment. This has a major impact on other aspects of their lives, including their ability to work, socialise, care for others etc.
- Many respondents reported an increased dependence on family and friends for support while they wait.
- Communication was reported as key to people feeling well supported.

Considerations for system leaders

Reviewing the themes above may help assess how well current information and support offers reflect the real-life impacts reported by patients. It will also help to identify whether people are being effectively directed to the practical support (such as help with work issues, avoiding physical decline, accessing equipment for daily living, or finding occupational therapy and social care services) they need to help them during their wait for care and treatment.

There is scope to better support people in understanding how to manage their pain, either as an alternative or alongside traditional pain medication. This could include proactively sharing pain management toolkits and placing clear, accessible advice on pain at the heart of any 'waiting well' communications. It is paramount that information like this is easy for people to find, especially amongst groups of patients most likely to be affected by pain.

The crucial role family and friends play in supporting people while they wait for elective care should not be underestimated. In addition to practical support, friends and relatives offer valuable emotional support and comfort to those waiting for treatment. Consideration should be given to how social networks of support can be enhanced and better supported to help people manage. Information and advice for family members should be a feature of the 'waiting well' offer.

For those who lack support networks, or who may be socially isolated, it is important to consider how the positive influence of others may be replicated or encouraged. This might include proactive signposting to sources of emotional wellbeing support and grass-roots support networks.

Approaches should be explored for encouraging people to better engage with resources that help them maintain their wellbeing while awaiting treatment. For example, evidence has shown that positive attitudes to health management can be developed through person-centred conversations (such as health coaching). This encourages individuals to reflect on their own goals, strengths, capabilities and personal resources (e.g., support networks). Health staff should be provided with access to resources and opportunities to develop the skills necessary to having behavioural change conversations with patients.

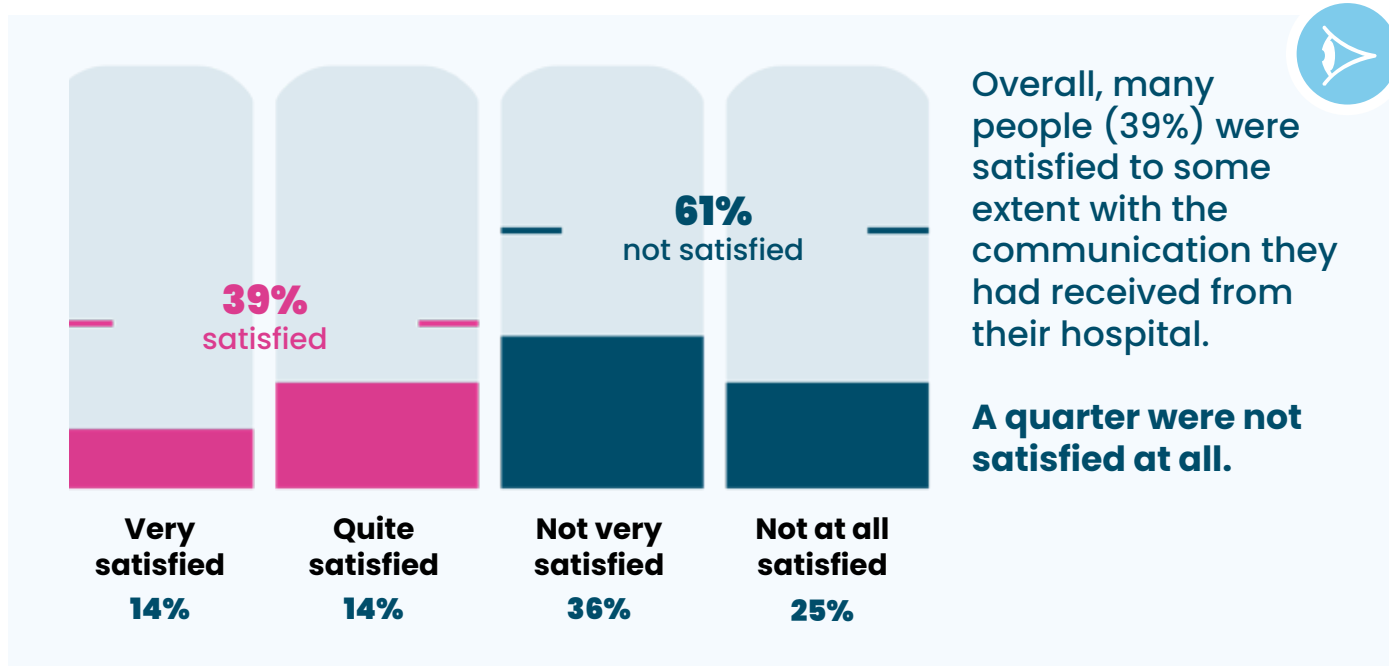
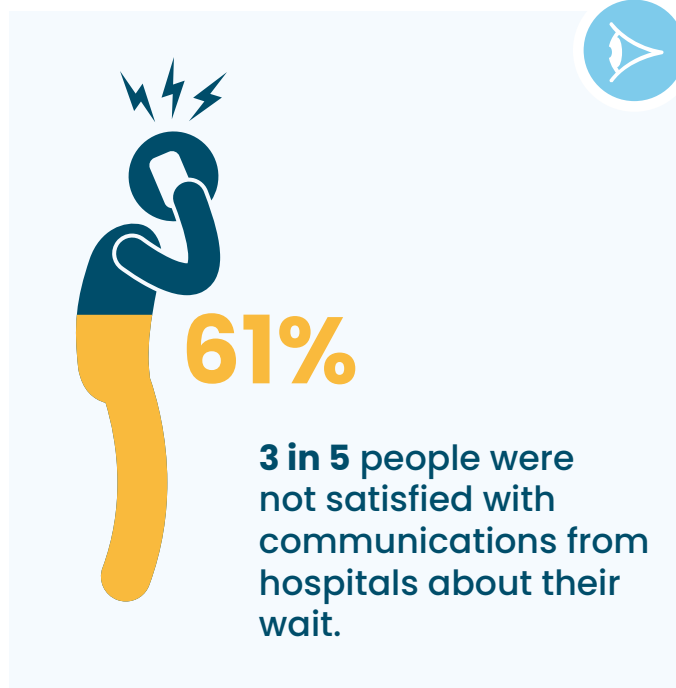
Communications

Satisfaction with communications

Respondents were asked how satisfied they were with the communication they had received from the hospital.

Across the whole sample, more respondents (three in five or 61%) said they were not satisfied with the communications they had received from their hospital, than said they were happy (39%). The graph below shows the detailed breakdown of responses across the sample.

Note: This report will not draw comparison as to the performance of each hospital because the sample sizes are not equitable.



"At the request of my GP, I have tried to speak to the consultants secretary to see where I am on the waiting list but having tried seven times on different days and got the answerphone, leaving a message every time. **No one from the hospital has returned my calls. So, I am completely out of options.**"

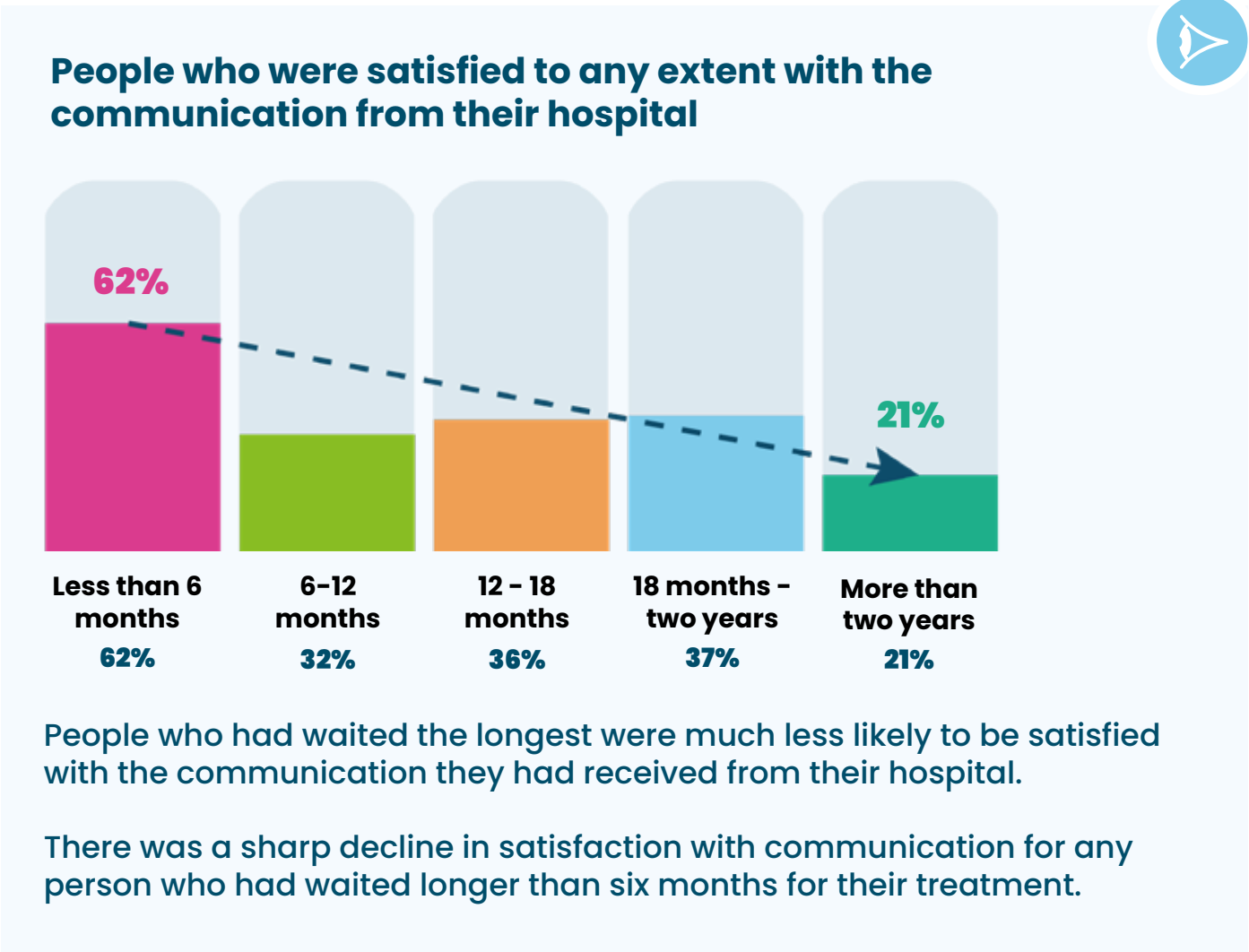
(James Paget University Hospital, Gynaecology)



Respondents who reported more impacts on their lives as a result of their wait for treatment were more likely to say they were not satisfied with the communications they had received.

In total, only a third of people who selected one impact or more were satisfied with communications from their hospital, compared to nearly two thirds of those reporting no impact from thier wait.

The graph below shows that a similar trend was also evident amongst those who had already waited more than six months for their treatment.



Analysis of satisfaction with communications by hospital department (top six only) highlights that people waiting for gynaecology treatment are generally less satisfied than those waiting for treatment from any other department. This trend was similar across all three hospital trusts.

See the table below for more detail.

	Sample	Satisfied
Gynaecology	135	22%
Trauma and orthopaedics	554	44%
General surgery	252	41%
Ear, Nose and Throat	94	38%
Urology	66	41%
Ophthalmology	65	33%

Table: The percentage of people who were satisfied (to any extent) with the communication from their hospital, and the department (top six) they were waiting for.

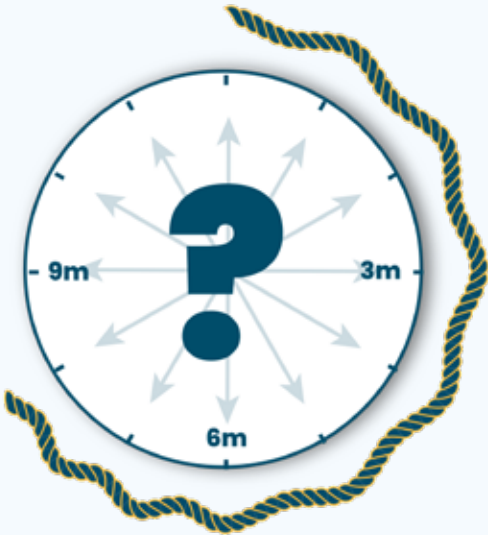
Knowledge of length of wait

The survey asked people if they knew how long they would need to wait for their elective treatment or care.

Approximately a third of respondents (32%) said they knew how long they would have to wait to receive hospital treatment, while the other two thirds (67%) did not.

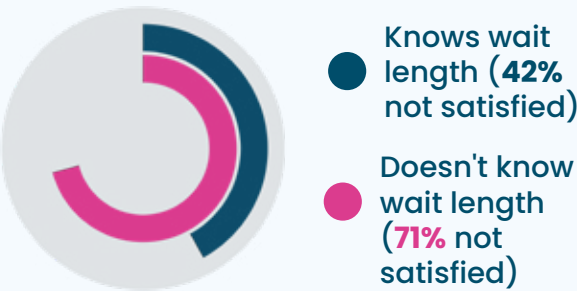
Respondents who said they knew how long they would have to wait were more likely to say they were satisfied with the communications they had received.

How long is a piece of string?



67% of people said they did not know how long their wait for care would be?

Dissatisfaction with communications



People who knew how long they would need to wait for treatment were less likely to be dissatisfied with communications they had received.



"During the summer, I emailed the gynae secretary and they could only tell me that they are currently offering dates to people who have been on the list 75+ weeks. However, they warned me that winter pressures could add to that time. The only contact I have had otherwise is a link to update my details and confirm that I want to remain on the waiting list."

(James Paget University Hospital, Gynaecology)



Qualitative responses about communication

In addition to the quantitative question, respondents were invited to share their experiences of the communication they had received from their hospital in a free text box.

A total of 1,104 people left a comment. These insights help provide context and depth to the satisfaction scores gathered in the quantitative questions outlined above.

Positive comments

Access to good communication can help people feel supported while they wait. In total, 144 respondents (13%) left positive comments about the communication and information they had received from the hospital.

While some respondents described communication as 'okay,' 'good,' 'excellent,' or said they were 'satisfied,' others praised it for being 'helpful,' 'informative,' 'comprehensive,' 'clear,' and 'honest.' Regular or prompt updates were also widely appreciated.

A further 23 respondents were not expecting any communication from the hospital. This was either because they had only recently joined the waiting list, because they were well within the expected wait time given for their surgery, or they simply did not feel it was necessary.

"I have had very good communication from the hospital regarding the waiting list. I feel well supported." - (West Suffolk Hospital, General Surgery)

"Phone call every few months." - (ESNEFT, Trauma and Orthopaedics)

"Good communications by text and phone." - (West Suffolk Hospital, Gynaecology)

"Very honest - it was all explained by the consultant." - (West Suffolk Hospital, Trauma and Orthopaedics)

"All communication has been good, swift and informative." - (West Suffolk Hospital, Trauma and Orthopaedics)

"Very comprehensive information supplied both on paper and digitally." - (West Suffolk Hospital, Urology)

"They always keep me aware of what's going on and my consultant is awesome."
– (ESNEFT, Trauma and Orthopaedics)

"JPH Orthopedic have been very good and always gets back to you." – (James Paget University Hospital, Trauma and Orthopaedics)

"Communication from hospital overall is good but the fact that the wait is so long is ridiculous," – (James Paget University Hospital, Gynaecology)



"Called to see when surgery was expected as holiday was due to be used, gave me a rough time line was very helpful and professional and very understanding, amazing support couldn't have been more helpful."

(West Suffolk Foundation Trust, Ear, Nose, & Throat)



Lack of communication

Hundreds of respondents reported little or no communication from their hospital following initial consultations (446 mentions). Although, some also mentioned occasional messages asking them to confirm if they still wanted their procedure (86 mentions). The lack of proactive contact led many (266 mentions) to reach out to the hospital themselves for updates, with mixed success:

- Several respondents said their calls went unanswered or that messages left on answering machines were not returned;
- Some respondents felt the attitudes of staff members, when they did eventually get through, were 'dismissive', 'lacked empathy', or made them feel a burden on the system;
- Others had found staff to be helpful and understanding of their situation, but that they were not always able to provide any additional information about wait times.

"There is a serious lack of communication. For every singular appointment, I have to call up to get any information. It seems this year it has gotten worse as they are reluctant to even give a ballpark of when you will next be seen. When they do, it always ends up considerably later than indicated. I feel like often times I only get appointments through luck and calling at the right time, with someone who wants to help." – (ESNEFT, Gynaecology)

"I phoned and was given a date which is now imminent." – (West Suffolk Hospital, Trauma and Orthopaedics)

"Communication is a bit shambolic. Also, one department I've been trying to phone



"I rang when the NHS app told me to, due to it being over the date, and was rudely told it'd be over a year like everyone else."

(James Paget University Hospital, Gynaecology)



is almost impossible, a bit like trying to get through to MI5 or GCHQ. Phone rings endlessly. No answer." - (James Paget University Hospital, Plastic Surgery)

"I have had no contact about the wait. I have tried contacting the consultants secretary but she does not answer her phone. I have then gone to general admissions who said they would email her to contact me, but to date I have not heard anything." - (James Paget University Hospital, Trauma and Orthopaedics)

"Have tried phoning the relevant department but am met with an answer machine instructing me to leave a message or go online, neither of which has brought any response." - (James Paget University Hospital, General Surgery)

"At the request of my GP I have tried to speak to the consultants secretary to see where I am on the waiting list, but having tried seven times on different days and got the answerphone leaving a message every time. No one from the hospital has returned my calls. So, I am completely out of options." - (James Paget University Hospital, Gynaecology)

"Hospital text messages have been good but when I tried to ring the hospital to get put through to the fracture and orthopaedics unit there was no answer then the line just went dead." - (West Suffolk Hospital, Trauma and Orthopaedics)

"Every time I make contact, I am made to feel a burden." - (West Suffolk Hospital, Trauma and Orthopaedics)

"Consultants secretary has been polite and friendly through out." - (ESNEFT, Trauma and Orthopaedics)

"On the occasions I have called admissions, the department has been helpful and advised according to the situation that is affecting timescales." - (West Suffolk Hospital, Trauma and Orthopaedics)

"I found secretary's to be really not helpful at all. Then I rang again, as couldn't believe I could be spoken to in that manner. I got the most pleasant lady I could wish for. She realised I needed the treatment as soon as possible, spoke to the surgeon and got back to me in 30 mins." - (James Paget University Hospital, General Surgery)

"The staff member who answered the phone was extremely dismissive, unwelcoming and non personable." - (James Paget University Hospital, Ear, Nose & Throat)

Being updated

More than two hundred (210 mentions) respondents said they had been given an indication of a likely wait time for their procedure (either verbally in clinic, via a letter, or when patients had contacted the department by phone). However, information they received ranged from being quite vague (e.g., 'a long time', 'a few months') to fairly specific (e.g., '12 weeks', 'by Christmas'). Few respondents had received an update on waiting times after their initial consultation.

"I have asked twice for any idea (even a ball-park time-frame) of when my operation might be and have been told they do not know. I asked would it be a month, six months or

a year and they could not say. It is frustrating that there is absolutely no idea. It would help me so much to have even a rough idea as I plan out my commitments." - (James Paget University Hospital, Gynaecology)

"Told it will be a long wait." - (James Paget University Hospital, Dental/Oral)

"Called about five or six months ago and just told it will be next year." - (West Suffolk Hospital, Plastic Surgery)

"At my consultation, I was advised that it would be months before my surgery can take place. I am not sure how many months is meant by the terminology months." - (James Paget University Hospital, Colorectal Surgery)

66

"The NHS app says average wait for Ipswich Hospital is 25 weeks and based on clinical need!!!! Since I'm not being monitored or spoken to, I have no idea how the hospital knows what my clinical needs are." -

(ESNEFT, Trauma & Orthopaedics)

99

Digital updates

Fifty-nine people mentioned that they had consulted the NHS app, or a hospital website, for details of waiting times. However, some reflected that information was often missing, inaccurate, or out of date. Inconsistencies in information and communication were not just confined to the NHS app. Respondents also highlighted discrepancies in the information they

No way through

It was clear many people had struggled to find updated information about their wait for appointments. Often, calls went unanswered or were not returned, or the contact information provided was incorrect.



"The different ways of finding where you are on the list is confusing and frustrating. The list is not available online anymore... If you phone, your call is not returned. Three calls to the appointments department gave different times, and two of them were referring to the wrong appointment. The app shows no appointment progress and doesn't update regularly. The app gave a date to be contacted by, and a number to call if I wasn't contacted. The phone line was dead."

- (ESNEFT, Trauma and Orthopaedics)





"I haven't heard from the hospital but on the NHS app it said it was an 18-week wait approximately. But I phoned today, and was told that was incorrect and in fact the wait is 18 months, not weeks. **This was very upsetting and confusing.**"

(West Suffolk Foundation Trust, Gynaecology)



had been given verbally or in writing. Overall, the lack of clear, consistent communication left some patients feeling frustrated, forgotten, and uncertain about their progress towards surgery.

"I only have my NHS app to check, and that's not updated regularly." – (West Suffolk Hospital, Gynaecology)

"Original wait time on website 18 weeks. Surgeon commented this had now doubled. Latest admissions information when contacted is now up to 65 weeks possibly. A lot of vagueness, but at least I know..." – (ESNEFT, General Surgery)

"Told to look at the NHS app but then advised the information is incorrect and is an average time for all treatments not my specific requirements." – (West Suffolk Hospital, Trauma and Orthopaedics)

"According to my NHS app the average waiting time for a cardiology appointment at JPUH would be circa 23 weeks after the referral date. I think I'm up to about 40 weeks now." – (James Paget University Hospital, Cardiothoracic)

"I use the NHS App, which I think is great when it works, or the information has been uploaded there. A lot of medical information missing from the app." – (James Paget University Hospital, Ear, Nose & Throat)

"I have phoned several times to chase up the appointment only to be told it could be months before I have the Appointment for the injections, yet I have the appointment for the review." – (West Suffolk Hospital, Trauma and Orthopaedics)

"We attended the pre-op to be told surgery had been cancelled, letters then arrived confirming and cancelling further ops, very confusing." – (West Suffolk Hospital, Ear, Nose & Throat)

"I had a general letter that recognised and apologised that I had been waiting a while for surgery, reassuring me that I am on the list. It stated that I would get another letter after three months if I hadn't had my surgery. I haven't had this." – (ESNEFT, Trauma and Orthopaedics)

"I feel the on line information is completely untrue. Saying that a hip operation is about 24 weeks wait is just a blatant lie." – (West Suffolk Hospital, Trauma and Orthopaedics)

Communication about cancellations

Thirty-three respondents expressed frustration with the communication they had received when appointments/procedures had been cancelled. Common concerns included:

- Lack of notice that an appointment or procedure was being cancelled, resulting in some patients making unnecessary pre-op preparations (e.g., changing their medication or fasting) or travel to the hospital;
- Lack of information about the reasons why an appointment or procedure had been cancelled;
- Not being given a new date or a revised wait time for the procedure, following a cancellation.

"I have had to call twice after the operation was cancelled. I did not hear anymore and was disappointed as I was all ready for the operation." – (West Suffolk Hospital, Plastic Surgery)

"Hospital has been good at management of expectations, up until admissions, then wasn't informed correctly of cancellation of date of operation." – (James Paget University Hospital, Other)

"I arrived at West Suffolk Hospital, 20 miles away, for my appointment to find it had been cancelled with no notice. Not at all happy with that." – (West Suffolk Hospital, Trauma and Orthopaedics)



"Most frustrating was my last cancellation. Took a phone call two weeks before surgery asking if I still wanted to go ahead. They went through specific instructions about drinking water, medications etc. on the day. All was good, hopes raised and felt positive. Then, 30 minutes later, I got another phone call saying I was cancelled and no other date could be offered at that time."

(West Suffolk Hospital, General Surgery)



"My operation was cancelled, and I was not made aware of it. The process has now started again, and I still don't have any real information about why it was cancelled."
- (West Suffolk Hospital, Gynaecology)

"I didn't hear anything for 13 months and then get a phone call saying I'm being booked in, only a couple of days later I get another saying it's being cancelled again. I've had my pre-op, and the surgeon was available and two days later I'm told he will no longer be available." - (James Paget University Hospital, General Surgery)

"I was phoned for the first time earlier this year and booked in. I scheduled to have someone take me to the hospital and stay with me that night etc. Arranged it all, to get a phone call hours later to say they can't do it, with no reason given. I then waited more months until I spoke to my consultant who told me they won't operate on me because of my weight. Other than that, I've had nothing. No communication at all. I am really dissatisfied." - (James Paget University Hospital, Gynaecology)

Pre-operation assessments and false hope

Some respondents reflected that communication about pre-op assessments or post-op education sessions gave them false expectations that they would be called for surgery imminently. Some noted that pre-op assessments had occurred so far in advance that it needed to be repeated once they had a confirmed date for their surgery. Respondents described how this had inconvenienced them and had been an unnecessary duplication of time and money for the NHS.

Use of terms like 'urgent' or 'priority' also led patients to expect prompt treatment, which heightened anxiety when those expectations were not met.

"I had my pre-op assessment in June, which will have run out now. I took a day off to do it and will need another. I rang to check, as I believed the operation would be over the summer, to be told I wasn't on the list. Heard nothing since." - (West Suffolk Hospital, Gynaecology)

"My operation has now been cancelled twice, the first time I was made to feel that I was a pest and shouldn't be calling the admission team to find out a new date, and that they will call me. The second time, I had a phone call the very next day with a date for surgery and then informed that my pre-assessment had run out and needed to be done again." - (West Suffolk Hospital, Trauma and Orthopaedics)

"I have received notification of an education day that I must, and intend to, attend. However, I received two identical letters, one of which attached a questionnaire that required detailed information regarding after care for the surgery. As this confused me into thinking a date was available for my surgery, I went to the hospital to request clarification. I was informed no date has yet been set." - (West Suffolk Hospital, Trauma and Orthopaedics)

"Was told 18 months wait. Then had an education group appointment and a phone physiotherapist appointment to sort any equipment needed for after op, which was delivered. This got hopes up it might be sooner, but then nothing. Did ring secretary and left a message asking for a rough idea when it might be but got no response back. Assumed she gets lots of calls like that, so have just left it to wait and see." - (James Paget University Hospital, Trauma and Orthopaedics)

"I had a pre-op assessment in June. I was told the operation should be done within 12 weeks. Well that hasn't happened. I rang appointments, to be told I wasn't anywhere near the top of the list, and they couldn't understand why I had the pre-op." - (West Suffolk Hospital, Trauma and Orthopaedics)

"Understand the strain on NHS and how hard the workers work, but was told my operation was urgent - but it certainly hasn't been urgent." - (West Suffolk Hospital, Trauma and Orthopaedics)

"I was told I was on priority list, but have been told still nine to 12 months from first diagnosis. This is extremely worrying and stressful." - (West Suffolk Hospital, Plastic Surgery)

"The hospital doesn't communicate with me unless I call them to ask when I might be taken in for surgery. Each time I do speak to them, my expected wait for my URGENT procedure is extended by at least 3 months and although I know it is not the waiting lists staff fault, they offer no empathy and are in fact quite rude. Not good enough." - (West Suffolk Hospital, Trauma and Orthopaedics)



False hope?

People sometimes described how the language used in elective care management gave a false impression of the extent of their likely wait, and this led to frustration.



"Communication after AI assessment stated I urgently needed to be seen by a human in dermatology. Appointment made for March 2025, eight months in the future. I phoned up to query urgency criteria and was actually told, 'This is normal, what do you expect?'. I expect to be given a reasoned argument why an eight month wait is suitable for an urgent appointment for what is a cancer."

(West Suffolk Hospital, Dermatology)



99

"I was getting anxious that my direct inguinal hernia was getting larger and causing more problems. I phoned the secretary at the JPUH to find out when I could expect to have my hernia repair op... **Advised me to see my GP who could contact general surgery to update them on my hernias condition. I saw a doctor and heard that my hernia op [will be re-scheduled] after pre-assessment. Thankfully this reduces my waiting time to just under a year from 15 months."**



Key learning – communications

- Most respondents (61%) were not satisfied with the communications they had received whilst they waited.
- People who experienced more impacts on their lives, those who had waited the longest, and those who did not know how long they would have to wait were more likely to say they were not satisfied with the communications they had received.
- People waiting for treatment from Gynaecology were less satisfied with the communications they had received compared to people waiting for treatment from other departments.
- Patients contacting the hospital for updates reported that calls often went unanswered or no-one responded to the messages they left.
- While many people had consulted the NHS app or hospital website for updates, they often found the information to be inaccurate or out of date.
- People expressed particular frustration about the lack of communication when appointments were cancelled.

Considerations for system leaders

Access to good communication, including clear and consistent updates on waiting times, may help patients feel more informed and supported during their wait for care. The need for good communication is particularly important when cancellations occur. Giving people revised wait times, or telling them the reasons why their appointment has been cancelled can help to reduce uncertainty and frustration.

Gynaecology patients were the least satisfied with communication while waiting for treatment. This trend was consistent across all three hospital trusts, suggesting they may need a different approach to communication compared to patients in other specialties. Further work is required to understand the specific needs of this patient group.

Reviewing and improving the NHS app and website to ensure wait time information is up to date, accessible, relevant, and easy to understand will provide patients with some reassurance about progress on waiting lists, including any changes to expected wait times. It should also help to reduce the volume of calls to the hospital for updates.

A review of call handling systems and processes could help to improve the overall experience for patients when contacting their hospital.

Consideration should be given to the language used around waiting lists. Terms like 'urgent' and 'priority' are unhelpful, and they raised people's expectations about wait times. Scheduling of pre-op assessments and post-operative education sessions could also be reviewed to ensure people do not need to repeat them following a lengthy wait and to prevent false hope.

Finally, every contact with patients (whether face to face, over the phone or in writing) should be used as an opportunity to find out how people are managing and to signpost them to information and support that might help them to cope while waiting.

Patient choices

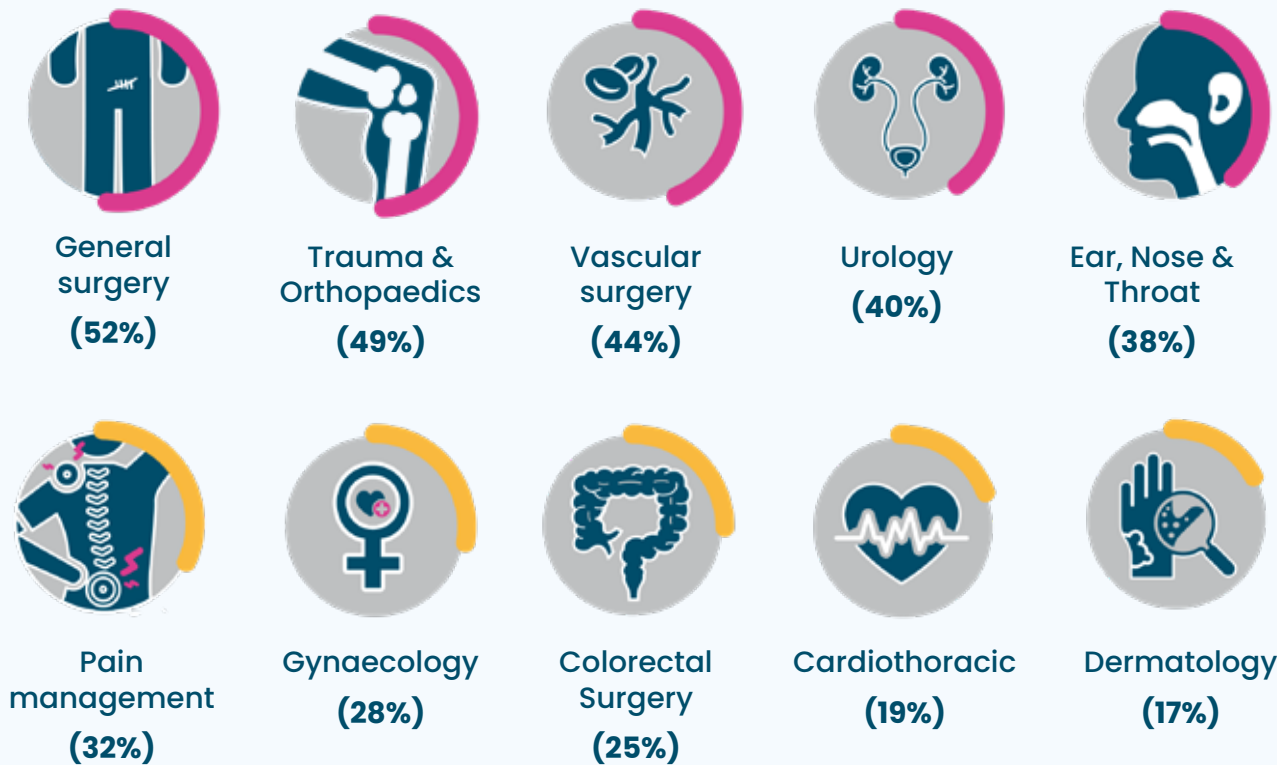
At the point of referral, a GP or other healthcare professional should inform people of the choices they have regarding elective hospital care. That includes discussion about the waiting times to expect from various providers. People may also have the right to choose a different hospital for their procedure if they have been waiting for more than nine months.

We wanted to explore people's understanding of their rights and choices. The survey asked:

- At the time of your referral, were you informed about the waiting times for the hospitals available for your procedure?
- Did you know that if you have waited more than nine months, you may be eligible to have your surgery sooner at a different hospital?

Being informed at referral

The graphic shows the percentage of those who said they had been informed about the waiting times at hospitals when they were referred for a selection of departments.



Note: The numbers of people responding about their wait for these departments varied from 16 – 571. More detail is shown in the table overleaf.

Information at referral

Less than half of respondents said they were informed about the waiting times for the hospitals available for their procedure at the time of referral.

Patients waiting for general surgery were the most likely to say they had discussed wait times at hospitals before referral. Almost half of trauma and orthopaedic patients had discussed wait times. In comparison, only 28% of Gynaecology patients had considered wait times prior to their referral for elective hospital care.

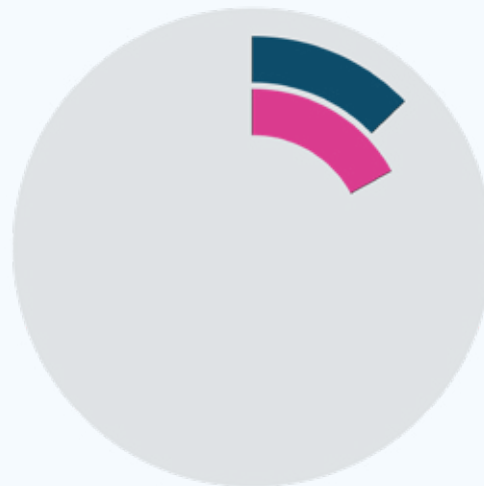
	Sample	Yes	No
General surgery	257	52%	45%
Trauma and orthopaedics	571	49%	44%
Vascular surgery	16	44%	44%
Urology	68	40%	54%
Ear, nose and throat	94	38%	57%
Plastic surgery	55	36%	51%
Ophthalmology	66	35%	56%
Multiple departments	12	33%	58%
Neurology	6	33%	67%
Pain management	19	32%	63%
Other	7	29%	57%
Gynaecology	136	28%	67%
Colorectal Surgery	48	25%	65%
Cardiothoracic	16	19%	81%
Dermatology	24	17%	71%
Dental	11	0%	73%
Total sample	1,416	42%	51%

Table: Respondents answers to 'At the time of your referral, were you informed about the waiting times for the hospitals available for your procedure?'

Eligibility for a transfer of care

- Only 13% of all respondents said they were aware of their right to change hospital, if they had been waiting more than nine months. Analysis of responses by length of time people had been waiting showed little variation, although a slightly higher proportion (17%) of people who had been waiting more than two years were aware they could possibly change their hospital provider to wait less time.
- Respondents waiting for orthopaedic care were most likely to say they were aware of their right to change hospital.

The right to choose



- Whole sample (13%)
- People who have waited more than two years (17%)

Only 13% of respondents were aware they could potentially choose a different provider after 40 weeks if it meant they might be able to wait less time.

Key learning – patient choices



- Less than half of people had discussed waiting times for their procedure at different hospitals prior to referral being made.
- Few (13%) respondents were aware of their right to change hospital after they had been waiting nine months for treatment.

Consideration for system leaders

There is a need for more proactive communication with patients about their rights and choices regarding elective care. This includes more information about waiting times for procedures at the point of initial referral, as well as right to transfer care after a prolonged wait for treatment.

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