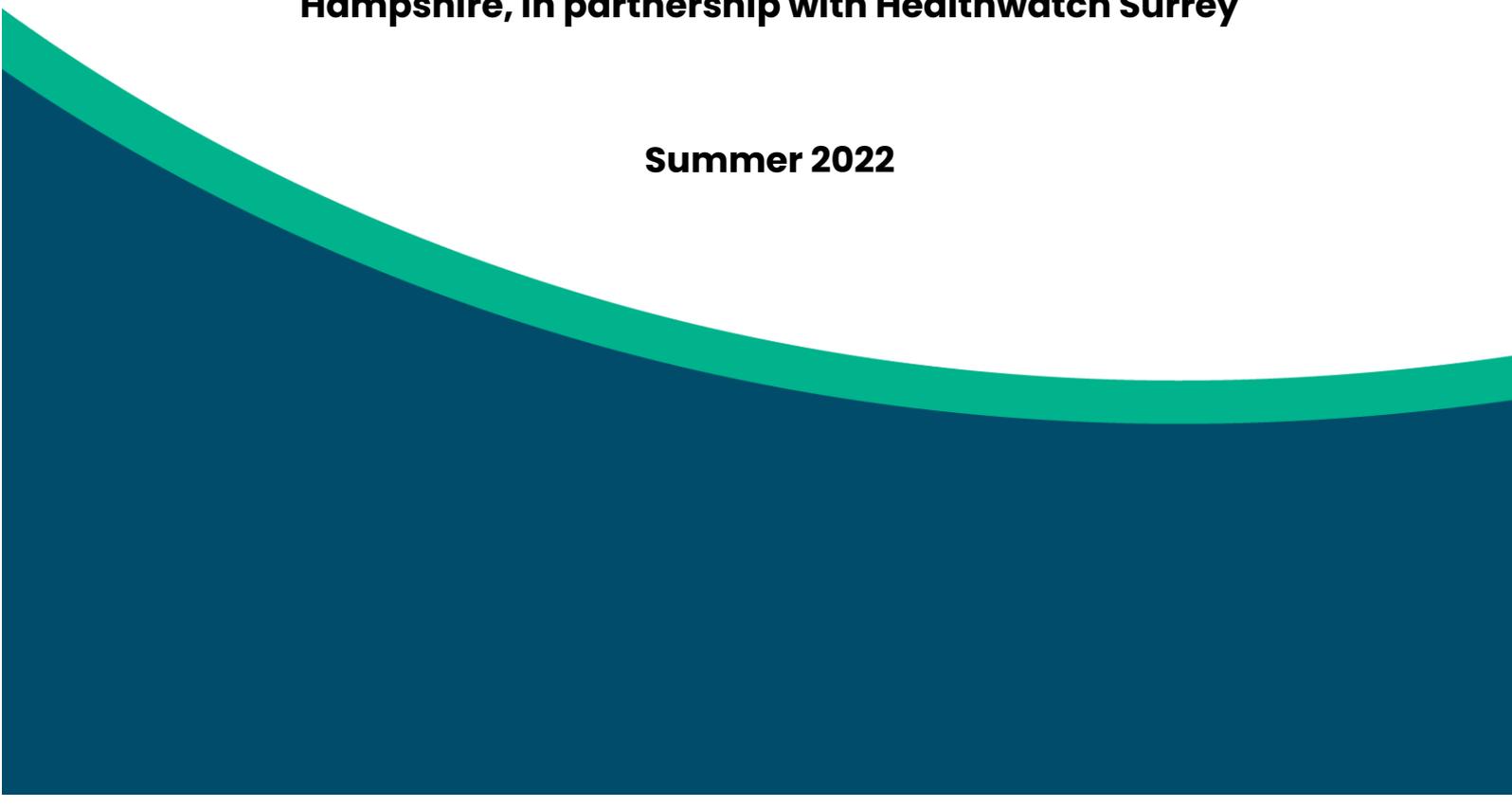


# Waiting for Hospital

## How people feel about waiting to access hospital care

**Healthwatch Slough, Healthwatch Bracknell Forest,  
Healthwatch Windsor, Ascot & Maidenhead and Healthwatch  
Hampshire, in partnership with Healthwatch Surrey**

**Summer 2022**



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## Context

The COVID-19 pandemic has resulted in many people having their operations, treatment and appointments cancelled or delayed.

The NHS had to postpone non-urgent elective care treatment when the pandemic hit, freeing up inpatient and critical care capacity. While this helped medical staff respond to the crisis, it has resulted in a huge backlog of people waiting for treatment.

The latest data shows that the number of people waiting for routine operations and procedures in England is at its highest level since 2007 – currently over 6 million.

The impact of delayed treatment can be huge, potentially leaving people in pain and affecting both their physical and mental health. It can even stop people working and performing day-to-day tasks, such as cleaning, shopping and caring for others.

It is essential that while people wait for treatment, they get support to manage their health and wellbeing in a way that is best for them. If someone needs hospital treatment, they should be receiving advice and information from the NHS about how to look after their health while they wait. (Ref: The NHS delivery plan for tackling the backlog<sup>1</sup>). They should be kept informed about the dates of their treatment and where they are on the waiting list.

The four Healthwatch across the Frimley ICS, in partnership with Healthwatch Surrey developed and undertook a survey (running for 8 weeks early March to late April) to provide insight to enable services to understand the local experience of waiting, to improve effective communication with those who are waiting, and reduce the potential for harm or deterioration while people are waiting.

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<sup>1</sup> <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2022/02/C1466-delivery-plan-for-tackling-the-covid-19-backlog-of-elective-care.pdf>

## Research Objectives

Understand the experience of waiting for hospital treatment

- Attitudes to waiting, and the impact of waiting
- Information and advice received while waiting
- Advice about health and care, and advice on waiting times
- People's sources for advice and guidance while waiting

## Method

Healthwatch Surrey ran the survey online and on paper, receiving a total of 182 validated responses.

The report detailing those responses is available separately.

This report details the responses gathered from the Healthwatch Windsor, Ascot and Maidenhead, Healthwatch Slough, Healthwatch Bracknell Forest and Healthwatch Hampshire (covering the North East Hampshire area of the ICS) areas. The survey was in online format only. Data covering the Surrey Heath area was gathered by Healthwatch Surrey but is included in this report. A total of 171 validated responses were received:

Healthwatch area	Number of responses received
Healthwatch Slough	74
Healthwatch Windsor/Ascot & Maidenhead	42
Healthwatch Bracknell Forest	35
Healthwatch North East Hants	10
Surrey heath (results from Healthwatch Surrey)	10

This report and that of Healthwatch Surrey have been produced in the same format to provide a consistent approach. We wish to acknowledge the work of Healthwatch Surrey in producing that format, which we have followed here (note much of the Context, Method, Scope etc will be duplicated in both reports with a few minor amendments where appropriate for local considerations).

## **Scope, risks and limitations**

The respondents in this survey were self-selected; the survey does not deliver a representative sample of people in the Frimley ICS area waiting for treatment, and it should not be used as a quantitative record of experience. Inevitably, we hear more from those with a bad experience to share than those whose experience was as expected or better than expected.

What the survey does do is shine a light on a range of experiences of waiting. There is a particular focus on opportunities to improve, but we also recognise good practice. Our aim is that our findings and recommendations are used as insight to enrich strategy and inspire opportunities to improve systems.

## Summary

### The experience of waiting

The focus of the survey was on information needed and received by those waiting for hospital treatment. Work by Healthwatch England and The King's Fund shines more light on the day-to-day realities of waiting for treatment<sup>2</sup>

We found:

- Any need to wait is worrying for many patients.
- Uncertainty about the length of wait is a major concern.
- Even those waiting less than 2 months felt generally negative.
- The longer the wait the more detrimental effect it has on people's health and/or wellbeing and mental health.

### Information, advice and support

- A majority of people felt they had NOT been given information and/or support by either their hospital or GP to help them manage their condition whilst waiting (note – given the wide range of conditions and wait times it's not possible to know what information or support respondents should have been given).
- A majority of people had NOT been given details of someone to contact if their condition had got worse whilst waiting for treatment.
- 57% of people stated they had NOT been given advice or information to help with their health while waiting.

### Information about waiting times

- 59% of people said they had NOT been given information on how long their wait might be.

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<sup>2</sup> <https://www.healthwatch.co.uk/news/2021-09-27/people-living-poorest-areas-waiting-longer-hospital-treatment>

## Recommendations

We recognise and understand the current pressures on the NHS and acknowledge that providers are already doing their utmost to minimise waiting times for patients. We also appreciate that the current situation is not going to be resolved quickly.

With this in mind, and based on the feedback received, we therefore make only 2 recommendations. Both relate to how people should be actively supported to manage their condition to reduce anxiety and stress whilst waiting for treatment.

1. Review how patients can be provided with the information/advice/contacts and signposting they need to stay well, manage their condition and prevent avoidable deterioration while waiting for treatment, whether this comes from the hospital or via primary care.
  - a. Automated services such as texts, emails should be considered.
  
2. In order to improve trust and communication, and to reduce anxiety and stress, patients should be regularly informed (ideally every 12 weeks minimum) when their appointment is due or likely to be due. Reasons for delays should be made transparent.

## Demographics

(Of those that responded to these questions)

Survey completed on behalf of	
Self	83%
Another adult	8%
A child under 18	9%

Gender	
Female	53%
Male	43%
Other	4%

Age (of respondent or person survey completed on behalf of)	
Under 18	7%
18-44	23%
45-64	34%
65+	35%
Prefer not to say	1%

Ethnicity	
White British	59%
All other/prefer not to say	23%
Asian/Asian British: Pakistani	12%
White Other	6%

Respondents who are	
Unpaid carer	9%
Have a disability or long term health condition	35%

<b>Type of appointment waiting/waited for</b>	
Outpatients	38%
Diagnostics	16%
Day Surgery	16%
Operation with overnight stay	14%
Ongoing treatment	11%
Other	5%

<b>Hospital (for both still waiting and already received care)</b>	
Wexham Park	45%
Frimley Park	22%
Heatherwood	14%
Other	9%
Royal Berkshire	7%
Basingstoke & North Hants	3%

<b>Percentage still waiting or already received care (treatment, appointment or test)</b>	
Care received since Jan 2021	35%
Currently waiting for care	65%

## Main Findings

60 respondents stated they had received treatment since Jan 2021, 111 were still waiting at the time of completing the survey.

### The experience of waiting

(Results of those that responded to these questions)

#### Length of wait

	Received care since Jan 2021	Currently waiting
0-2 months	27%	18%
3-4 months	13%	11%
5-6 months	12%	17%
7-12 months	17%	25%
1-2 years	9%	11%
Over 2 years	4%	9%
Don't Know	18%	9%

**When asked “How do you feel about the length of time you’ve had to wait?” the following shows the percentage of those who expressed negative feelings.**

<b>Waiting Times</b>	<b>0-2 mths.</b>	<b>3-4 mths.</b>	<b>5-6 mths.</b>	<b>7-12 mths.</b>	<b>1-2 yrs.</b>	<b>Over 2 yrs.</b>
Respondents who had received care since Jan 2021	37%	66%	61%	84%	90%	100%
Respondents currently waiting	46%	68%	96%	68%	84%	100%

Some examples of feedback:

“Scared and frightened I’m in heart failure and worry about this blockage. I’m lucky as I am being seen by cardiac nurse, but I was diagnosed with heart disease last July 2021 and it’s taken so long for every step to take place. I have never seen a cardiologist only ever a nurse”. (Still waiting 3-4 months for outpatients’ cardiology).

"Very frustrated. My husband is in so much pain and to see him like this makes me cry" (Still waiting 1-2 years for knee surgery).

“Excellent. I was referred under the two week wait and I had an appointment, and on a Saturday too!, 8 days after the smear test that found the polyp”. (Waited 1-2 months for cervical outpatient – treatment received).

**When asked “Has the length of the wait had any effect on you, good or bad?” the following shows the percentage of those who stated the wait had a detrimental effect on their health and/or wellbeing.**

<b>Waiting Times</b>	<b>0-2 mths.</b>	<b>3-4 mths.</b>	<b>5-6 mths.</b>	<b>7-12 mths.</b>	<b>1-2 yrs.</b>	<b>Over 2 yrs.</b>
Respondents who had received care since Jan 2021	40%	53%	61%	84%	90%	100%
Respondents currently waiting	11%	31%	8%	13%	18%	43%

Some examples of feedback:

“Mental health has deteriorated. Worry all the time, can't sleep”. (Waited 1-2 years for blood cancer diagnostic procedure -treatment received).

“Yes, my mental health was very much affected. The ability to complete even simple daily tasks along with being unable to have 100% confidence to continue to provide full-time care for my brother” (Waited 1-2 years for cataract day surgery- treatment received).

“In chronic pain and just fed up with being kept in the dark on when the procedure will happen” (still waiting 7-12 months for lumber prolapse operation).

**When asked about any changes to appointments (both for people who have received treatment and those still waiting):**

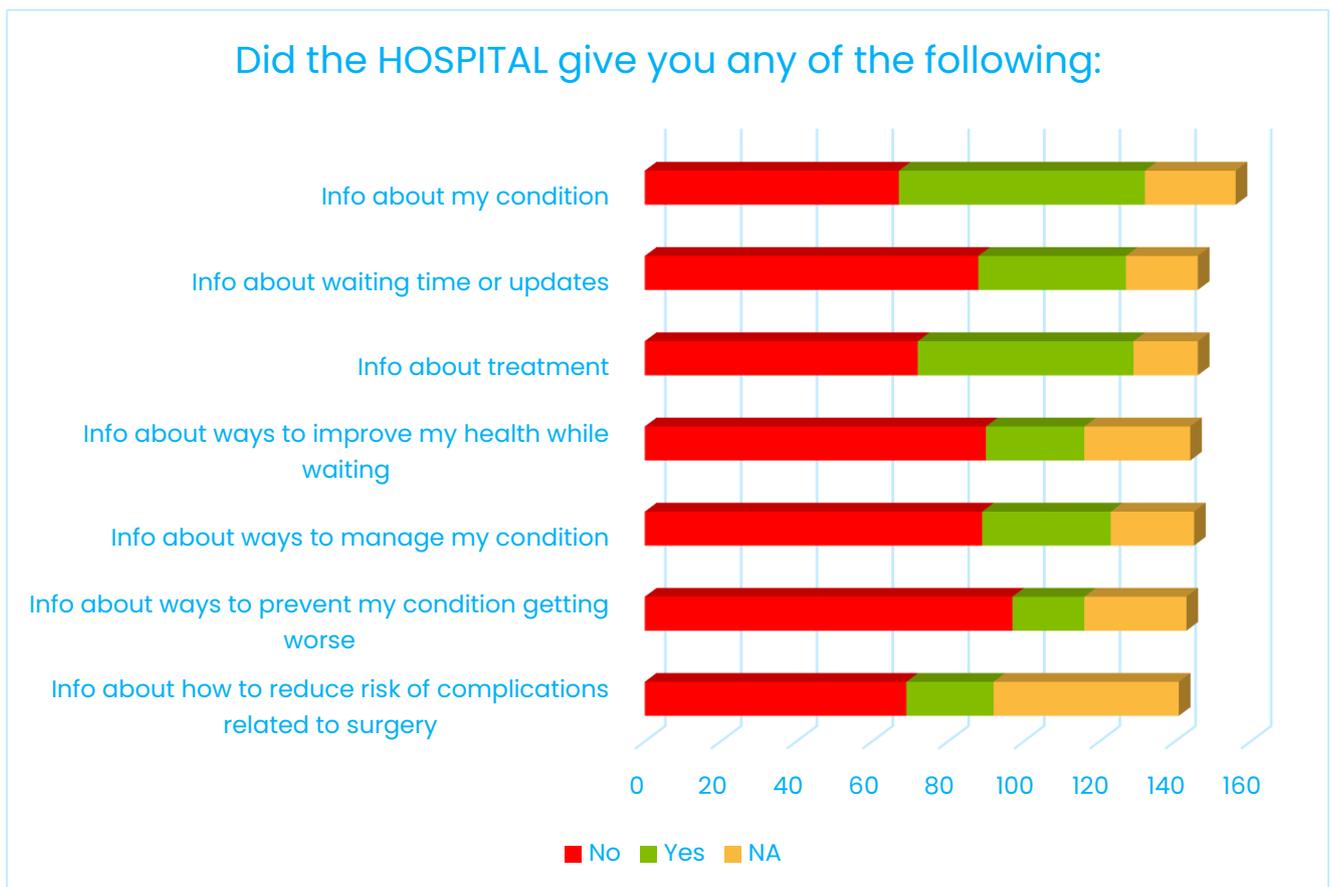
- 23% told us their appointment had been changed by the NHS
  - Of those, 45%% had been changed once
- 32% had been changed twice
- 15% had been changed several times
- 8% did not provide a response

Only two people told us they had changed their own appointment: both due to worries about Covid.

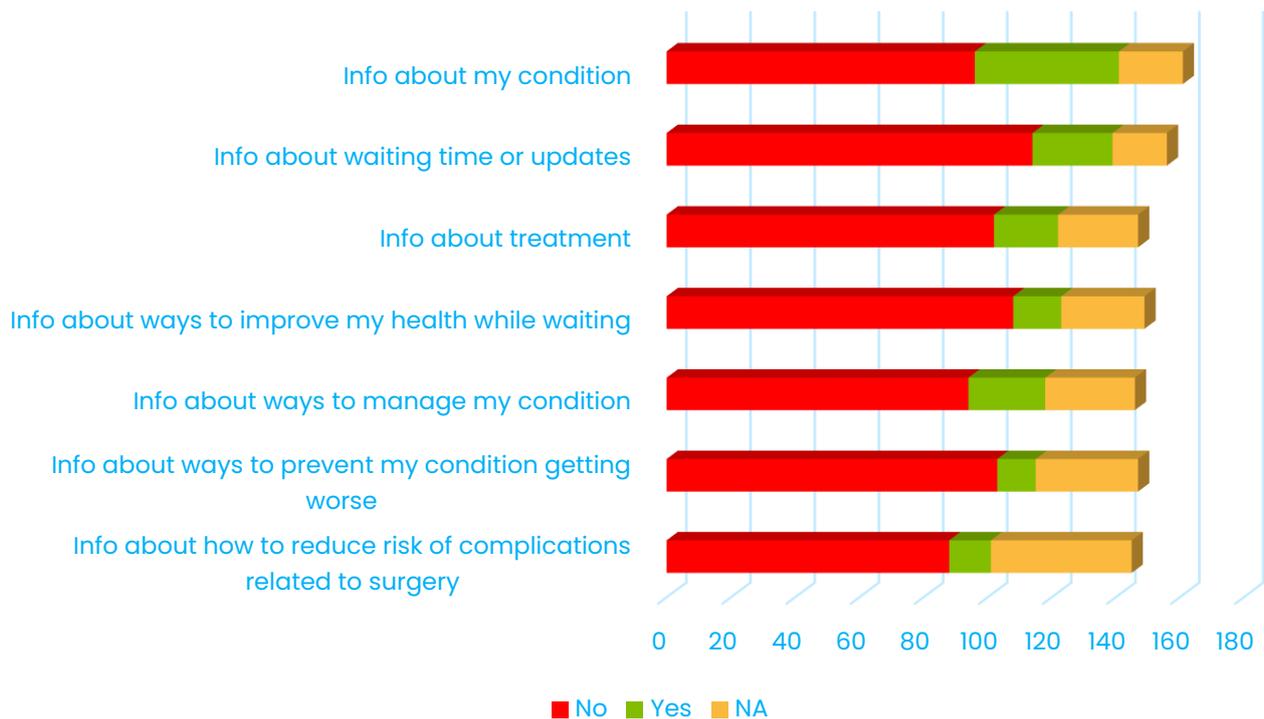
**Healthcare Advice and Support While Waiting**

(Results of those that responded to these questions)

**When asked if they had received information from the hospital or GP:**



### Did the GP give you any of the following:

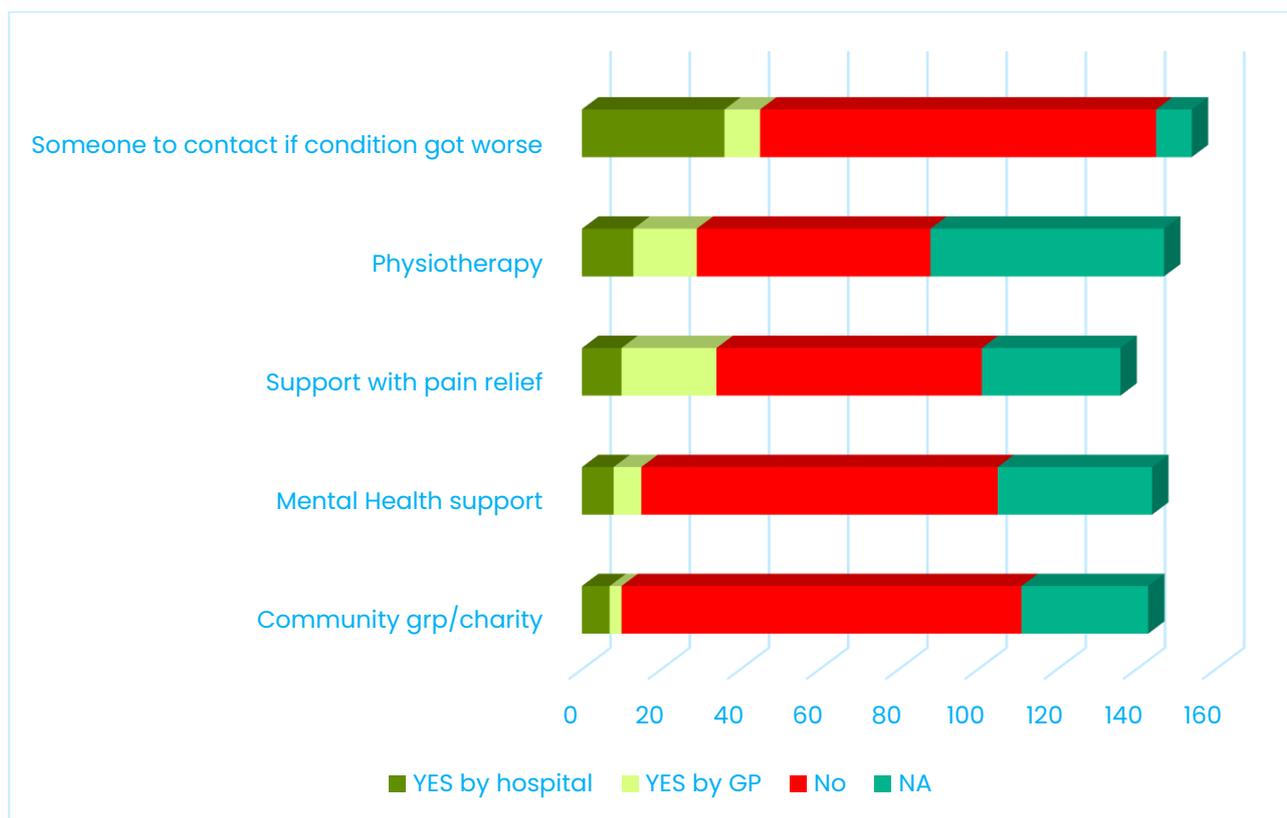


### When asked “How helpful did you find the information/support you received?”:

	From the hospital (%)	From the GP (%)
Not at all or did not answer	60%	70%
Not Very	8%	6%
Neither/NA	11%	9%
A little	10%	6%
Very	11%	9%

Note: Given the wide range of conditions and wait times it’s impossible to know what information or support people should have been given.

**When asked “have you been offered any of the following?”:**



**When asked if they had received help or support from elsewhere people told us (of those that answered):**

	% Respondents
No help or support offered	40%
I didn't need any other info/support	28%
Advice found online/apps	24%
Other (inc. private healthcare, friends/family and healthcare professionals such as District Nurses/Macmillan)	5%
Received help from voluntary org./charity	2%
Received support from social services	1%

A handful of people told us about information or support they found especially useful:

- Booklet from pre-op assessment on what to expect and how to prepare for going into hospital (patient with bladder cancer)
- Calls from specialist nurse (patient with cancer)
- Support from Macmillan Cancer Navigators

**When asked “Is there any information or support you would have liked to receive while waiting?”:**

- 38 people said they wanted an update on their appointment/waiting time
- 11 people wanted more information about how to manage their condition/pain management
- 5 people wanted more information about whether their condition was worsening
- People also asked for information about stress, home care, local support offers and what to expect from hospital procedures/treatment

## Waiting Times

(Results of those that responded to these questions)

**When asked “Do you think the hospital should contact you to update you on your waiting time and reassure you that you are still on the list?”:**

	% Respondents
Yes, about once a month	60%
Yes, about every 3 months	22%
Yes, about every 6 months	3%
No, I don't need the hospital to do this	15%

**When asked “how much do you agree or disagree with the following?”:**

	<b>Strongly Agree</b>	<b>Agree</b>	<b>Neither</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
I was given enough information by the NHS about the waiting time for my appointment / treatment	8%	13%	20%	28%	31%
The letters I received from the NHS about my appointment /treatment were clear and easy to understand	12%	34%	26%	13%	15%

149 people had not heard of “My Planned Care” and only 3 people had used it.

Being in good health when having treatment is believed to make a difference to how well the treatment goes. **When asked “Were you given any advice or information to help with your health while waiting? For example, advice on smoking, weight, alcohol, exercise?”:**

	<b>% Respondents</b>
No	57%
Not applicable	27%
Yes (comments all related to advice on exercise, diet, reducing smoking/alcohol and weight loss). Only 2 people said they had been given information about how to manage their conditions)	16%

**When asked “Would you be willing to be treated at another hospital if that meant you could be treated sooner?”:**

	<b>% Respondents</b>
Yes, to a local hospital	68%
Yes, to any UK hospital	14%
No	10%
Yes, but I would need help to travel	8%

**Is there anything else you would like to tell us?** – a range of comments received:

“Communication is key. When you have a number to call and they don’t answer it’s really upsetting when there is no other communication forthcoming”.

“Communication is the most important component between patient and clinical staff and there are no easily available avenues. Patients are often made to feel an inconvenience when enquiring about the appointments”.

“Complete lack of care, physical and mental from the staff. You are made to feel troublesome if you call for information or updates, that is if the call is answered or the voice message even responded to”.

“I am realistic that waiting times are very long but communication to acknowledge you are on the waiting list and approx.. number of months would make it easier to manage and plan. The unknown is frightening when you are in daily pain”.

“I appreciate there are long waiting list but I’m truly frightened I will die suddenly this is my heart we are talking about”.

“I now have a terminal Cancer which could have been caught earlier if I had seen my GP for an examination”.

“Simply an acknowledgment would ease the patient as we would know we are actually in a queue and have not been missed or forgotten about”.

“Without a diagnosis the wait creates further anxiety. My mental health is generally very good but this 6 month wait (with still no idea how much longer) does create anxiety. My

suspected condition is progressive and early intervention is crucial before permanent nerve damage can cause physical disability. I appreciate the enormous pressure on the NHS but a brief letter/email/call to acknowledge the referral and set out an expected waiting time would make a huge difference”.

“I cannot really fault the treatment I received from all connected with my treatment and aftercare. My experience has been positive and one appointment change to a follow up consultation did not create difficulties. I am amazed that everything kept to time considering other issues being dealt with by the NHS”.

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