

# **National Cancer Patient Experience Survey 2021**

## **National report (Qualitative)**

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# 1

# Introduction and methodology

## Introduction

The National Cancer Patient Experience Survey 2021 is the eleventh iteration of this survey, first undertaken in 2010. It has been designed to monitor national progress on experience of cancer care; to provide information to drive local quality improvements; to assist commissioners and providers of cancer care; and to inform the work of the various charities and stakeholder groups supporting cancer patients.

The questionnaire was reviewed in 2021 to reflect changes to cancer services and commitments to cancer care, as detailed in the NHS Long Term Plan ([www.longtermplan.nhs.uk/online-version/](http://www.longtermplan.nhs.uk/online-version/)).

The survey was overseen by a National Cancer Patient Experience Advisory Group. This group advises on the principles and objectives of the survey programme and supports questionnaire development.

The survey was commissioned and managed by NHS England (NHSE). The survey provider, Picker, is responsible for technical design, implementation and quantitative analysis of the survey. Detailed information about the survey methodology and reporting is available at [www.ncpes.co.uk](http://www.ncpes.co.uk).

The survey asked respondents a range of closed questions about their experience. They were also invited to provide qualitative, written feedback by being asked three open-ended questions at the end of the survey:

QA. Overall, how would you describe your care and treatment?

QB. Was there anything that could have been improved?

QC. Any other comments?

In addition to the quantitative analysis conducted by Picker, NHSE commissioned Explain Research to conduct a thematic analysis of the open-ended feedback. This thematic analysis sought to facilitate reflection and learning across services delivering cancer care for adults across England.

## **Eligibility**

The sample for the survey included all adult (aged 16 and over) NHS patients, with a confirmed primary diagnosis of cancer that had been discharged from an NHS trust in England after an inpatient episode or day case attendance for cancer related treatment in the months of April, May and June 2021.

## **Fieldwork**

The fieldwork for the survey was undertaken between October 2021 and February 2022.

## **Survey methods**

The survey used a mixed mode methodology. Questionnaires were sent by post, with two reminders where necessary, but also included an option to complete the questionnaire online.

A Freephone helpline and email were available for respondents to opt out, ask questions about the survey, enable them to complete their questionnaire over the phone and provide access to a translation and interpreting facility for those whose first language was not English.

# 2

## Understanding the results

In total, 59,352 people responded to the survey. The proportions completing the open-ended questions are as follows:

QA. Overall, how would you describe your care and treatment? (**84%** responded)

QB. Was there anything that could have been improved? (**62%** responded)

QC. Any other comments? (**44%** responded)

In early stages of analysis, when reviewing the comments provided for QC the vast majority were found to be a repetition of comments provided in response to QA and QB. Therefore, the focus of qualitative data analysis undertaken within this report was on responses to the first two open questions.

## Qualitative data cleaning

Certain information from the qualitative comments was redacted to protect the identity of survey respondents. The following information has been removed:

- Names of patients, staff, wards or units replaced with “(name)”
- Address information entered as “(address)”
- Specific dates replaced with “(date)”

Analysis confirmed that in a few instances, the survey was completed on behalf of respondents by family members or carers. These were deemed eligible for inclusion in the thematic analysis.

## Sampling

To ensure a thorough approach to sampling, a two-pronged technique was taken. This ensured that the sample included in the thematic analysis was representative and ensured qualitative rigour by applying the principle of data saturation.

In the first instance, a random sampling technique was undertaken to ensure that the sample included within the thematic analysis was representative of the survey population as a whole. It was calculated that to achieve a 95% confidence level with a margin of 3%, a sample size of at least 1,045 would be needed. To produce a representative sample of this nature, a random number generator was used to pick

1,501 respondents. For quality assurance purposes, proportions of the different demographics were tested between the sample and the overall population. All were found to be very similar and well within the probability bounds required. Further information about the sampling and how representativeness was ensured amongst the sub-group demographics can be found in the Appendix to this report (page 36).

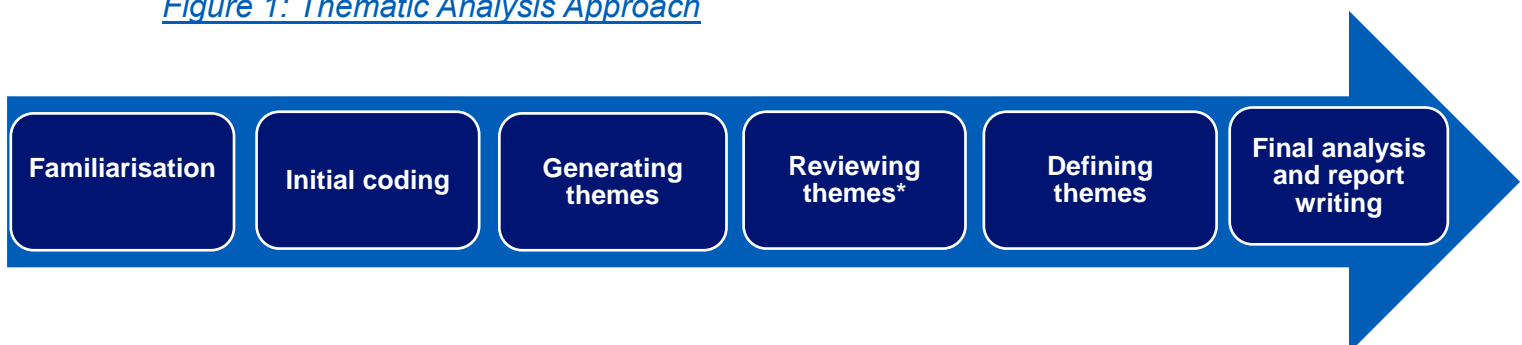
Finally, data saturation was used to ensure that the sample included in the thematic analysis encapsulated as fully as possible the range of experiences captured within the survey. Data saturation is the point at which no new themes emerge from the data. As the end of analysis approached no new ideas or concepts were emerging from comments, giving assurance that data saturation had been reached. Had this not been achieved, sampling would have continued as necessary.

## Qualitative analysis

Thematic analysis was undertaken to achieve a deep understanding of the findings from two open questions asked in the survey. This sought to facilitate reflection and learning across services delivering NHS cancer care for adults in England.

To analyse qualitative data, the standard six steps of thematic analysis were used to identify patterns of meaning within the data and explore commonality and contrast – see Figure 1. To enable thorough quality assurance, specialist qualitative analysis software was utilised to help organise the coding framework as it was developed.

*Figure 1: Thematic Analysis Approach*



*\*This included sub-group comparison*



The results of the thematic analysis have been reviewed and are shared in context of the relevant quantitative survey findings. This exploits the value of both the quantitative results, which tells us **the proportion** of respondents feeling a certain way, and the qualitative findings, which tells us **why** people feel that way. For example, where there is a high degree of agreement / positive experience evidenced in the survey data, the thematic findings offer an opportunity to understand why there was not 100% agreement / positive experience and therein, where the opportunities lie for reflection and learning.

## Sub-group comparisons

Sub-group comparisons were not the focus of the analysis. It is recommended that further focused sampling would allow for in-depth exploration of how experiences of cancer care may vary for different groups.

## Format of report

During the initial stages of familiarisation, it became clear that there were several overlapping themes identified amongst responses to QA and QB. The analysis was consequently structured by emergent theme, incorporating relevant responses to both questions.

## Context setting and wider considerations

### Interpreting results

Typically, positive comments are less detailed and therefore less actionable. In contrast, comments shared about areas for improvement or poorer experience of care are commonly more detailed and therefore provide more opportunity for actionable insight. Consequently, this report is focussed on the more detailed comments and allows us to explore the richest opportunities for learning.

## **Cancer specific insight**

When interpreting these results, it is helpful to note that some insights are not necessarily specific to the adult cancer patient audience. This has been noted where relevant.

## **COVID-19 pandemic**

It is important to note that the survey sampling period took place during an unprecedented year for the health and social care sector, with the continuation of the outbreak of the global COVID-19 pandemic. This had an impact on the NHS. For example, at various points throughout 2021 there were restrictions in place in terms of services available, visiting, access to facilities, hygiene protocols and many more aspects of care.

Where relevant the impact of the pandemic on experience has been noted in the findings. Largely the impact was in relation to wait times and communication for patients.

Additionally, a small number of comments which described the impact of visiting restrictions on emotional wellbeing were found whereby inpatients had no visitors and/or outpatients could not be accompanied.

# 3

# Headline findings

Thematic analysis has highlighted seven main themes as important experiences being shared by cancer patients.

**Gratitude:**

An overwhelmingly strong theme was gratitude. Respondents discussed their care as excellent and highlighted many positive experiences with staff members being highlighted. Staff were praised for their kindness and compassion.



**Negative experiences with General Practice:**

Respondents often felt support from their GP did not meet their expectations. Concerns included that initial symptoms were not taken seriously resulting in delayed diagnosis; and there was a lack of proactive follow-up by the GP after diagnosis and/or treatment.



**Communication for patients:**

Respondents felt inadequately informed about aspects of their care and commented on lack of effective follow-up. They expressed a desire for face to face communication and emphasised the importance of a single point of contact.



**Co-ordination of cancer care:**

Communication between hospitals and departments was perceived as problematic by several respondents. This resulted in treatment delays which was distressing for respondents.



**Waiting times:**

Long wait times were mentioned in many different contexts. The most prominent example was waiting longer than anticipated for tests and treatment.



**Negative experiences with hospital staff:**

Reflecting the pivotal role of staff, when a negative interaction was experienced it stood out to respondents. There were isolated incidents of staff being unprofessional or inconsiderate, as well as a common feeling staff were 'too busy' and wards were 'understaffed' which impacted care.



**Wider hospital issues:**

Anticipated to impact patients widely, issues were cited with food quality and variety; parking access and costs; a lack of privacy; noise disturbance at night; décor needing an update; and beds being uncomfortable. Visiting restrictions linked to COVID-19 were also found to negatively impact experience.



# 4

# Thematic analysis findings

The following key themes emerged from the thematic analysis of the qualitative data gathered within the survey:

- Gratitude
- Negative experiences with General Practice
- Communication for patients
- The co-ordination of cancer care
- Waiting times
- Negative experiences with hospital staff
- Wider hospital issues

This section of the report contains the detail of each theme as well as a range of quotations which are used to substantiate and exemplify the experience of respondents using their own words.

As noted above, where possible the themes are presented in the context of the most relevant quantitative survey data. This allows for results to be considered more holistically, and therefore provides a greater opportunity for learning.

## Gratitude

### *What does the quantitative survey data tell us?*

- Respondents were asked to rate their overall care on a scale of 0 (very poor) to 10 (very good). The average rating of care given by respondents was 8.9 (Q59).
- 89.2% of respondents felt that they were always treated with respect and dignity while they were in the hospital (Q37).

An overwhelmingly strong theme was that of gratitude. The majority of respondents voiced thankfulness for the cancer care they had received. A high number of respondents articulated their care as excellent, with others describing it as progressive, efficient, brilliant and outstanding.

- *“I consider myself very fortunate to have had such excellent, highly professional & caring staff to look after me during these very difficult times. My surgeon and specialist nurse were very good and approachable. As of course were all the staff involved. My thanks to them all. Long live the N.H.S.”*
- *“I received outstanding care and treatment. I have a long-standing cardiac condition for which I have had open heart surgery in the past. My cancer surgeon ensured he had all the relevant information to ensure my safety during surgery.”*
- *“Excellent all around.”*
- *“Treatment and care couldn't have been better. All staff have been very caring, informative and genuinely concerned. All possible tests have been completed...”*
- *“My care and treatment were excellent, and I was well looked after throughout. The nurses and staff were very helpful.”*
- *“Very professional.”*
- *“I have had excellent care and treatment since my diagnosis.”*
- *“Most certainly brilliant.”*
- *“Excellent, progressive & mostly informative.”*
- *“Very good care at all hospital appointments and procedures. Cancer was dealt with within one month of diagnosis very effectively.”*
- *“The care and treatment I have received these past two years from the start of my diagnosis until now has been nothing short of outstanding. I cannot thank the NHS staff who cared for me*

*enough. My treatment started at the very beginning of the pandemic, and I was worried that my treatment may have had to be suspended but no - although changes had to be made and I went through it without support of family at the hospital. I never missed a round of chemo or radiotherapy.”*

- *“My care and treatment were excellent from start to finish.”*

As well as a large amount of gratitude towards overall care, respondents also frequently mentioned positive experiences with staff members. Personal attributes, for example kindness and compassion, were highlighted by respondents. They also discussed the ability of staff to ensure that they felt safe and relaxed.

- *“The team looking after me are wonderfully hard working, compassionate, professional and thoughtful...”*
- *“I can’t fault the team of nurses / healthcare at (name) for my treatment I have received so far, they made me feel so relaxed and at ease.”*
- *“Excellent; a very caring, committed, and dedicated team which removed much of the potential stress. I always felt that I could ask for more information if I needed it.”*
- *“My care and treatment were excellent, and I was well looked after throughout. The nurses and staff were very helpful.”*
- *“Excellent treatment from oncology & professionals.”*
- *“My care and treatment have been of the highest quality. The consultants / doctors / nurses have always treated me with the utmost kindness and respect and always were very pleasant.”*
- *“Hospital staff were fantastic, second to none. Thank you.”*
- *“Overall, it was a good experience. I had the best surgeon and the super friendly staff to look after me.”*
- *“I found the consultants, medical staff, and helpers all excellent and very caring. Thank you all.”*
- *“An excellent hospital with caring staff.”*
- *“Very professional, mostly carried out with care and empathy. The surgeon and his team were outstanding!!”*



## Negative experiences with General Practice

### *What does the quantitative survey data tell us?*

- 64.1% of respondents who had contacted their GP practice said that the referral for diagnosis was explained in a way they could completely understand (Q3).
- Respondents were asked if they got the right amount of support from staff at their GP practice while they were having cancer treatment. Of those that said their GP practice was involved in their cancer treatment, 43.7% said this was definitely the case (Q51)
- 18.0% of all respondents said they had a review of their cancer care by a member of staff at their GP practice (Q52).

There were several comments shared in relation to general practice. These tended to focus on diagnosis, with respondents feeling that their GP had not listened to their concerns or had misdiagnosed them. It was highlighted that although GPs were made aware of symptoms and concerns these had not been taken seriously and consequently for some respondents, they felt that referrals to relevant specialists were unduly delayed.

- *“The GP practice could have taken the possibility that I might have cancer seriously from the start and if referred to (name) sooner I could have been diagnosed up to six months earlier. They should have conducted more tests and been quicker making referrals.”*
- *“When one goes to the GPs with lumps...they should be biopsied/investigated as soon as possible and taken seriously. I would have been treated for cancer 7 months earlier if my lump in my armpit had been biopsied the first time I went to GP's.”*
- *“Yes, care received from GP practice in initial contact and diagnosis was extremely poor. Multiple visits over many years missed my condition every time and approximately 2 years later I was diagnosed when I presented at A&E.”*

Additionally, expectations for proactive follow-up by GPs following cancer diagnosis and/or treatment was evident, and several respondents described feelings of being ‘abandoned’ with this expectation unmet. Difficulty with access to GP appointments was also shared by several respondents.

- *“The care & support from my GP surgery was non-existent. It would have been nice to have had a courtesy call following my operation to see how I was and if I needed anything. As it was, I need extra pain relief & treatment for sickness. Very disappointed with care from GP.”*
- *“At least a call from the GP to ask if you need any support.”*
- *“Unable ever to see your G.P.”*
- *“If I can improve anything that is G.P. Practice. It’s very hard to get G.P appointment now. The care you get from G.P. is gone downhill.”*
- *“Local doctor aftercare was non-existent. Could be down to new covid procedures.”*
- *“I have had no contact from my G.P practice, I think it’s important that my G.P makes contact to offer further support.”*

## Communication for patients

A strong theme emerging from analysis concerned how cancer patients are communicated with. This theme has several different facets: the requirement for more information; follow up support; the importance of a single point of contact; and preferred methods of communication.

### The requirement for more information

#### *What does the quantitative survey data tell us?*

- 82.2% of respondents said their treatment options were completely explained to them in a way they could understand before their cancer treatment started (Q20).
- 71.7% said that before their treatment started, they definitely had a discussion with a member of the team looking after them about their needs or concerns (Q24).
- 62.5% said they were given enough information about the possibility of the cancer coming back or spreading, such as what to look out for and what to do if they had concerns (Q55).

Many respondents highlighted a need to be more informed about aspects of their cancer care. They felt that the rationale for treatment decisions was not always properly explained, nor was information about potential side-effects, and how to monitor themselves for signs of recurrence.

Specifically, respondents suggested the following as examples of areas in which more information would be useful:

Detailed  
information on  
cancer type

Information on  
type of  
treatment

Information on  
side effects of  
treatment

Dos and don'ts  
after surgery

- *"The after effects towards my body of the Radiotherapy."*
- *"Perhaps, a little more information during the hospital stay regarding the treatment given."*

- *“Perhaps explain the radiotherapy procedure more as when the machine powered up it was sitting a long time at the wrong side of my body, and I thought wrong side was being done. If it had been explained machine then passes over your body to other side, I would have been more relaxed, but staff were lovely.”*
- *“I have a rare form of cancer and wasn't provided anywhere near enough information on this or any direction where to find it. I had to do the research myself.”*
- *“Better information following surgery on exactly what I should or should not do regarding exercise, and when I could start to exercise more. Also, I was not told what to signs to look out for if the cancer returned or spread.”*
- *“More information about side effects, especially of radiotherapy.”*
- *“More explanation of my illness & any future care that would help me.”*
- *“More information about hormone treatment side effects and danger of lymphedema. Had to request appointment for lymphedema clinic.”*

## Follow up support

### *What does the quantitative survey data tell us?*

- Respondents were asked whether once their cancer treatment had finished, they could get emotional support at home from community or voluntary services. 31.8% of respondents that needed care and support said this was definitely the case (Q53).
- 55.4% said their family or someone else close to them were given all the information they needed to help care for them at home (Q49).

Respondents also commented on the lack of support and communication they received after their discharge from inpatient care and treatment. They felt that they were not followed up effectively, with appointments either lacking entirely or being infrequent. As with the requirement for more information, this finding varied by age of respondent.

- *“My follow up treatment plan has been vague, and I have had to push appointments etc.”*
- *“Follow up to have been a little sooner.”*
- *“After care. No one has contacted me about next appointment which I find very unsettling.”*

- *“The one thing I was disappointed with was I never was given a 6 weeks follow up appointment after my radiotherapy ended despite several calls to the team. I finished on the (date) and my follow up is on the (date). I must admit I did feel a bit “abandoned.”*
- *“Communication after discharged (outpatients).”*

## The importance of a single point of contact

### *What does the quantitative survey data tell us?*

- 91.9% said they had a main contact person within the team looking after them who would support them through treatment, with 81.5% saying that this person was a specialist nurse (Q17).
- 85.0% said it was ‘very’ or ‘quite easy’ to contact their main contact person (Q18).

The analysis revealed the importance of having a single point of contact during treatment. Those respondents that did not receive this care felt they would have benefited from it, reporting difficulty in contacting a professional with any questions or concerns. They felt a main contact could have helped them understand and navigate their treatment experiences.

- *“Getting through to people by phone has often been difficult; either there has been no answer, or an answer phone to leave a message.”*
- *“Seeing the same consultant each visit or telephone consultation.”*
- *“Having 1 point of contact in the beginning would have been much better as it was confusing to know who to speak with, I felt a bit being sent from pillar to post, obviously when worrying about my condition. It would have helped if it was better co-ordinated.”*
- *“A specific contact / individual assigned to me.”*
- *“Generally poor & not very helpful. Never seemed to talk to the same consultant twice. I was told I had been placed with a particular consultant and to this date I have never spoken to her.”*
- *“The best improvement you could make would be to add a permanent nurse contact for the entirety of my care. Someone I could call at any time to discuss any concerns or questions.”*

## Preferred method of communication

An emergent theme amongst respondents concerned the methods of communication they experienced during their cancer care. Some felt that face-to-face consultation should have been the primary method of communication rather than telephone communication. Whilst they understood that this was a result of COVID-19 restrictions, it was expressed that calls and video appointments took away the ability to understand body language and made it more difficult to express concerns.

- *“Very good, I’m sure the covid situation has affected the care. For instance, many follow-up appointments were by telephone rather than face to face so any ‘body language’ communication was lost.”*
- *“My cancer care has been excellent. The only thing that is a shame is most aftercare appointments are being done over the phone and I really think people need to be seen in person. This is because of covid which I understand.”*
- *“Face to face appointments rather than telephone or video calls.”*
- *“Given that it was during Covid lockdown, care was mostly done by phone, even checking the wound was by video link. It was ok but I didn’t feel I was able to share my thoughts adequately.”*

It was highlighted that receiving a diagnosis over the phone was an inappropriate way to hear such potentially distressing news. This approach left respondents feeling unsupported and, for some, resulted in additional distress.

- *“After going for a routine scan for back ache it would have been nice not to of got a phone call from my GP who just informed me that I had prostate cancer and then hung up. This would have been better as a face to face as I was then left in the dark until the cancer team contacted me which was worrying.”*
- *“I would have preferred being told I had cancer face to face rather than in a telephone call.”*
- *“I was told I had cancer on the phone I feel it would have been more appropriate to have been told face to face.”*
- *“Telling people over the phone that they have cancer but bringing them in to be told they are all clear...”*
- *“The way I was told over the phone I had cancer and to go out and enjoy my life was extremely distressing.”*

## The co-ordination of cancer care

Communication and information sharing between different hospitals and departments was perceived to be problematic by several respondents. When a respondent was under the care of multiple different departments, it was felt that poor information sharing resulted in a delay to treatment and caused unnecessary anxiety.

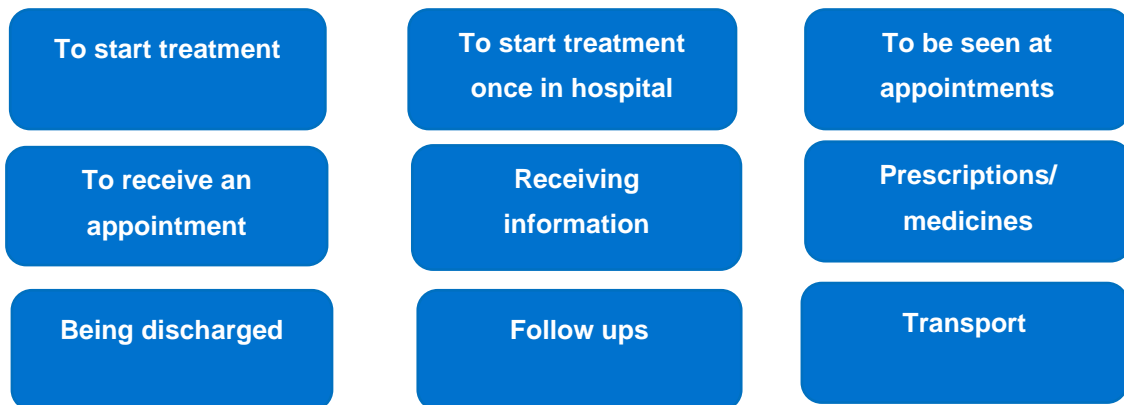
- *“Communication between teams at hospital could have been improved, but cancer specialist nurses always managed to sort things out.”*
- *“On a couple of occasions there was a breakdown of information handling between departments (albeit it was mainly electronic) and if I personally hadn't been as pro-active and passing information it could have delayed some progress in my treatment.”*
- *“My operation was at (name), after being released after 6 days I had to call an ambulance as I got an infection, because I live in (name) but my doctors are in (name), I was taken to the (name). The (name) were very slow in gaining the information from (name), the staff telling me that one was computerised, and the other was not!! The connection / communication between the two hospitals could have been a lot better.”*
- *“Sharing information regarding my treatment between departments would be helpful.”*
- *“Communication between depts could be better. I have heart failure, amyloidosis, and kidney problems. It sometimes feels like all the concerned parties are not aware of all the information.”*
- *“I feel that communication between departments at the hospital is poor and communication with me is also poor - cancer is hard enough but not knowing because the team fails to communicate with you is distressing.”*
- *“Where a cancer is being handled by more than one Department, e.g., Plastic Surgery and Oncology, the liaison can be a problem at times, and the patient can feel that he has been “signed off” by the one, without subsequent recourse to it with on-going issues e.g., lymphoedema following surgery.”*

## Waiting times

### What does the quantitative survey data tell us?

- When asked how they felt about the length of the time they had to wait for their test results, 81.9% felt the length of time was about right (Q7).
- 79.1% of respondents felt the length of waiting time at the clinic or day unit for cancer treatment was about right (Q43).

Long wait times were mentioned by many respondents across a variety of examples:



The length of time taken to start treatment was the most common issue highlighted by respondents. Importantly, some understood this wait to be associated with poorer prognosis.

- *“It did feel to me that it was a long time before I actually got to treatment, especially when my cancer had spread so rapidly with a poor prognosis.”*
- *“There was a 3/4-month delay in starting treatment. A matter of concern if my cancer was time sensitive.”*
- *“Cysts were first spotted in (date) but it took until (date) to have a surgery was booked, during which time my cancer has significantly spread. COVID impacted this but I wouldn’t want anyone else experiencing the same hand off process.”*
- *“I was diagnosed in (date), and operated on in (date), which seemed a long wait, and the ovarian cancer had spread quite a bit.”*
- *“My mum was diagnosed on (date) and did not commence treatment until (date) - by the end of the treatment (date) the cancer had spread, and it was too late. If tests had been done sooner*



*and more efficiently, she may be still with us today. The NHS needs to 'up its game' in the overall care and processes they currently have in place. It cost my mum her life."*

Respondents also discussed the length of time spent physically waiting for appointments or procedures in hospital. In some instances, appointments would be delayed for hours, increasing their experience of distress.

- *"Before surgery was left in a hospital gown on a chair in the corridor from 7.00 am until 2.00pm was not offered water or given any information as to when I would be operated on. Became very stressed as was not allowed to put my clothes on, this resulted in my blood pressure rising."*
- *"Time waiting for immunotherapy treatment. This has been as long as 4 hours and rarely below 1.5 hours."*
- *"Yes, Treatment which I was having was not ready when I was called in on one occasion, I was there over three and half hours."*
- *"The waiting time for the surgery, 5-6 women in a small room, not having eaten for hours and waiting for another 4-5 hours was stressful for most of us and torture for the woman whose surgery was a life-or-death situation."*
- *"Not really, apart from my 10 hours wait for the surgery I had in (date), but once the operation was carried out, it was done expertly."*

A final important aspect of this theme was the length of time taken to receive information, particularly when waiting for test results. Having to wait for test results added extra worry. For some, they indicated that this delay could be misinterpreted as there being good news. As with other findings, it also led to some questioning whether the outcome could have been different had the results come back more quickly.

- *"The results should be reported much quicker than patients having to wait 2 weeks - this is unacceptable."*
- *"I have to follow up on appointments often after scan results, sometimes weeks after I expect to have the results."*
- *"Overall, the treatment and follow-ups have been excellent. When required the treatment was changed to suit the needs. My one and only 'gripe' has been the time required to receive results of tests such as CT and PET scans. In one instance I went to (name), without an appointment, to get the results of a PET scan but still had to wait for an explanation of the results. I have spoken to other patients who have had similar problems. In all I waited over 3 months from the scan to the explanation. I had to assume that, if anything serious was happening, it would have triggered a response from the specialist."*
- *"My initial diagnostic tests and their analysis were delayed, and I feel this may have affected the final outcome."*

## Negative experiences with hospital staff

### *What does the quantitative survey data tell us?*

- Six out of ten (60.6%) respondents who had stayed overnight said family / someone close to them were definitely able to talk to someone on the team looking after them if they wanted to (Q32).
- 76.2% said they could always get help from hospital staff when they needed it (Q34).
- 89.2% of respondents felt that they were always treated with respect and dignity while they were in the hospital (Q37).
- During their hospital stay, 66.9% of respondents said they could always talk to the hospital staff about their worries and fears if they needed to (Q35).

With staff playing a critical role in patients' experience, any negative interactions with hospital staff stood out when describing what could be improved in experiences of cancer care.

For some, these issues revolved around staff availability. There was a concern commonly expressed that staff were 'too busy' and/or wards were 'understaffed'. Respondents expressed that the consequence to this was that they didn't always receive the time and care that they needed.

- *"There is a shortage of nurses and too many auxiliaries. Covid has been blamed for this but there was a shortage before due to government and management cut backs. More nurses to be on the wards especially at night e.g., a nurse was having to deal with emergency. Drips beeping but auxiliaries cannot deal with this, so you have to listen to the beeping for an hour or more."*
- *"Problem with porters on day of first operation was a matter I could have done without. Radiology department staff were calling for me from early morning for US guided skin marking- this was delayed due to no porters available and when one finally appeared another patient was sent rather than myself."*
- *"I did feel that my appointments with my oncologist were rushed, and I wasn't always given the opportunity to ask all of the questions that I'd have liked. I also never met either of my specialist oncology nurses. I appreciate that the oncology department is extremely busy at the time, so this was perhaps the reason why."*

- *“Yes, when the bleeping noise came on to reset the drug going through my body nurses would be too busy or ignore me. Eventually it was reset by the nurses ... I think there should be more nurses covering in the chemotherapy ward to look after patients.”*
- *“The staff on the ward were very busy and as a young cancer patient who had just had life altering surgery that left me practically disabled, I feel they didn't always have the time to give me the care they wanted to. I was often left waiting a long time to be taken to the toilet which left me very desperate ...”*
- *“Just a few little things while in hospital. Often nurses took a long time to respond to call button - I know they are busy. Once my drip was not actually in my vein, the fluid leaked all over my bedding. A few occasions (after surgery or washing) I had to ask for my surgical stocking to be put on again as it had been forgotten.”*
- *“More staff in the clinic and the consultants should see the patients and give them updates when needed.”*

Additionally, respondents highlighted that unprofessional attitudes from staff members and occasional lack of consideration and care could impact negatively upon their experiences. Importantly, these tended to be isolated incidents and were not a reflection of their care as a whole.

- *“Good overall apart from a few individuals who were rude to me / just ignored me when waiting for treatment. However, some nurses were outstanding and very kind, knew exactly what to say when I have been upset and gave me lots of time, never rushed me.”*
- *“The oncologist nurses were really good but some of the nursing staff looking after me post operation were very un-professional. The level of care from individual staff members in the same department varied greatly. Even some of the more senior staff in the department seemed un-professional at times.”*
- *“It was (name) that mostly treated me. When I was admitted initially for 2 weeks, I feel that some of the nurses & professionals lacked common sense & a caring attitude. You never knew who the 'lead' was. The night staff were noisy & I felt unsupervised and inconsiderate!”*

Specific to cancer care, a small number of respondents highlighted they felt there was a need for staff to undergo more specialist training. A few specific examples included training in clinical skills, in particular relating to difficulties in intravenous access for cancer patients or regarding how to protect highly immunocompromised individuals. Some respondents also discussed the need for improved communication skills amongst staff to help with the delivery of difficult or upsetting news.

- *“Maybe more training for nurses with regard to blood taking and canular insertion.”*
- *“I had a stay on (name) which was awful, the staff did not understand about reverse barrier nursing or how to protect me from infection, this was the only place in the whole hospital where I felt vulnerable and unsafe.”*
- *“The clinician who told me that the biopsy following a routine mammogram had found some cancer cells was very nervous and rather emotional about giving me the diagnosis. I feel that she should have had either. 1. More training. 2. More supervised experience or 3. Not been asked to deliver that diagnosis to a patient.”*

## Wider hospital issues

The common thread across the issues detailed below is that they are anticipated to impact a wide range of patients including but not limited to those receiving cancer care. As such they are considered collectively to be ‘wider hospital issues.’

### Hospital wards

Hospital wards were mentioned by respondents for various reasons, primarily concerning lack of privacy. They felt that receiving news or treatment in private would have reduced a feeling of being overwhelmed and helped them keep their sense of dignity.

- *“At the initial chemotherapy treatment, I was very anxious. Perhaps if there was a separate area for patients who were just starting chemotherapy it might help them not feel overwhelmed at the situation. Processes and treatments were given efficiently.”*
- *“No privacy when talking to medical staff about my conditions or treatment in hospital settings on a ward is always a problem.”*
- *“If there is any criticism it was when I went to have the catheter removed. I was amongst 3 other patients; we were in a corridor outside the urology department. The experience wasn't very pleasant and seems to let the overall experience down.”*

Related to the impact of COVID-19, when the pandemic was commented upon it was largely in relation to restrictions around visitors for inpatients and being accompanied for outpatients. The impact was a lack of emotional support.

- *“Initially I had to go into my results app alone due to covid restrictions. This was incredibly stressful. Only when Dr was about to break the bad news was, I asked if I'd like someone in with me. My partner was then allowed in. I was told day before I could ring or ask if partner was allowed in but knew if told yes it would have been because it was bad news, so I didn't ring the day before as I would have become pretty stressing that the results were bad.”*
- *“All my appointments/op took place during covid restrictions and family were not permitted to attended at any stage. Whilst to a large degree I coped, the whole process could have been easier with a family member in attendance.”*
- *“Visitors would have helped but I understand why this could not be due to covid 19 restrictions.”*

Additionally, a small number of respondents described that immunocompromised cancer patients should not have been on full wards or in public spaces, especially during the COVID-19 pandemic.

- *“The weekly blood test required before the weekly dose of chemotherapy should have been taken in the treatment department. I, with a compromised immune system, should not have been asked to wait in a crowded, not covid secure area, to be seen by the over busy blood room.”*
- *“I was very grateful for all the treatment I received especially the nursing staff and urology team whilst in hospital, but the ward I was in would normally be for day stay and was too cramped with some beds not two metres apart this was caused because of covid elsewhere.”*
- *“The cancer centre, (name) has no restrictions as to who enters. I’ve seen members of the public come in, unmasked to use the toilets. No checks at reception. No masks or hand sanitizing or temperatures taken. There is a Cafe in the cancer patient waiting area that is open to the public. We have to sit at the Cafe tables while waiting for our treatment. Dozens of people walking past, some without masks and clearly not patients attending cancer care. I find all this terrifying and after check in choose to wait outside until my treatment.”*

Other, issues mentioned about wards included noise levels making sleep difficult; having uncomfortable beds or chairs; and suggestions that decorating would help improve the mood of inpatients.

- *“The ward I was on was very noisy it was difficult to get rest and to sleep at night.”*
- *“Bedding is poor, sheets are too heavy and do not keep one warm. Adding sheets didn’t help as weight was uncomfortable. Thank heavens for a home delivered quilt.”*
- *“I appreciate space is at a premium, but could it be a bit more creatively decorated? so that it gives a feeling of optimism, such as bright colours, yellows, landscapes, children’s drawings to inspire patients?”*

### **Parking and drop off areas**

A small number of respondents reported issues concerning the availability and/or cost of parking.

- *“Car Park fees are excessive.”*
- *“There was also not always parking available, but that is pretty standard with any hospital visit.”*
- *“Car parking at the (name) is a problem.”*
- *“Yes, the cost of car parking.”*

## Food and drink

Food and drink were also highlighted as areas that required improvement. Many respondents simply commented on the quality and choice of food available in hospital.

- *“The food was sometimes inedible.”*
- *“Food and menu should be improved, very poor quality.”*
- *“Food - Poor. Hardly any choice. Just jacket potatoes.”*
- *“Appalling lack of appropriate dietary guidance - I'm vegetarian and it has been a battle to find correct, relevant information.”*

Importantly, a few respondents discussed the role of poor food choice within their cancer care specifically. They felt that available choice did not meet different dietary requirements and that this had a negative impact on recovery. Food options were also not felt to be accommodating to the side effects of treatment.

- *“The food is difficult for people with a number of eating difficulties. It is very hard to find anything that would allow multiple diet requirements to be met which does not help recovery. During my hospital stay I became malnourished.”*
- *“One small thing, but for someone who in the aftermath of the operation was told to expect severe constipation, the first meal of mince and potatoes was very stodgy.”*

# 5 Conclusions



A summary of the key findings of this thematic analysis have been shared below. Within some of the themes a range of ideas and suggestions for improvement have been highlighted. It is recommended that these are considered as conversation starters and that further patient engagement would support understanding of priorities and what matters the most to patients undergoing cancer care.

Further thematic analysis of this data with focused sampling would also allow for in-depth exploration of how experiences of cancer care may vary for different groups.

## **Gratitude**

This analysis demonstrated a very high level of gratitude from respondents towards those responsible for their cancer care. In particular, the kindness and compassion of staff were frequently mentioned as having a positive impact on respondents. The remaining themes should be understood within this context.

## **Negative experiences with General Practice**

Importantly, this analysis suggests that expectations from cancer patients regarding the care they can expect from GP practices are often unmet. Some respondents reported a poor diagnosis experience, feeling that GPs failed to address concerns and symptoms resulting in misdiagnosis. It was also highlighted patients felt that GPs often offered minimal to no communication or follow up.

## **Communication for patients**

Patients wished to feel better informed about their cancer treatment and care. Specific areas mentioned included information on side effects of treatment, detailed information on cancer type, information on type of treatment and post-surgery advice. Findings emphasised the need for a single point of contact during treatment, with respondents expressing difficulties when this did not occur. Further, follow up support was sporadic or absent in many experiences and telephone appointments were found to be problematic and unsatisfactory, especially when receiving diagnosis or particularly key information.

## **Co-ordination of cancer care**

Communication between different departments / hospitals was found to be problematic for many respondents. Critically, respondents felt that this caused delays and resulted in undue anxiety.

## **Waiting times**

Long wait times were highlighted as an issue with a variety of examples shared. This was particularly the case for the time taken for treatment to begin. It is notable that some respondents felt that improvements in these areas would have had a positive impact upon treatment outcome or prognosis.

## **Negative experiences with hospital staff**

Most comments concerning members of staff were overwhelmingly favourable. However, there were issues highlighted relating to staff availability, including patients not receiving sufficient time to ask questions. Whilst not common, when respondents reported poor interactions with staff these had an impact upon general impressions of quality of care.

## **Wider hospital issues**

Respondents discussed problems arising from a lack of privacy on wards. Noise levels on wards were also mentioned, as were issues with parking and the poor quality of hospital food. Whilst many of these issues are beyond the remit of cancer services, it is important to acknowledge their impact on cancer patients.

# 6

## Appendix: Sampling information

This appendix details how the demographic characteristics of the sample of respondents included in the thematic analysis compare to the sample of ‘overall qualitative’ respondents, i.e. only those that provided comments to at least one of the open questions (QA or QB) asked in the survey. Numbers therefore differ to those within the overall quantitative sample because only those who answered any of the open questions (QA or QB) are included for comparison (n=50,348).

For information about how sub-groups were defined, please see the technical documents available at [www.ncpes.co.uk](http://www.ncpes.co.uk).

*Table 1: Age (% in overall qualitative sample vs thematic sample)*

Age	Overall sample of qualitative respondents (50,348)	Sample for thematic analysis (1,501)
16-24	0.3%	0.3%
25-34	0.9%	0.9%
35-44	2.8%	2.9%
45-54	8.8%	7.6%
55-64	21.7%	20.4%
65-74	35.1%	35.9%
75-84	25.9%	27.4%
85+	4.6%	4.7%

Table 2: Gender (% in overall qualitative sample vs thematic sample)

Gender*	Overall sample of qualitative respondents (50,348)	Sample for thematic analysis (1,501)
Female	52.2%	53.0%
Male	43.3%	43.3%
Non-binary	0.03%	0.1%
Not given	4.4%	3.5%
Prefer not to say	1.0%	0.00%
Prefer to self-describe	0.03%	0.1%

\* Self-reported in Q64 of the survey

Table 3: Ethnicity (% in overall qualitative sample vs thematic sample)

Ethnicity	Overall sample of qualitative respondents (50,348)	Sample for thematic analysis (1,501)
Asian	2.3%	2.1%
Black	1.5%	1.6%
Missing / Not known	6.4%	5.4%
Mixed	0.8%	0.9%
Other*	0.3%	0.1%
White	88.8%	89.8%

\*Other includes Arab, and any other ethnic group not listed in Q71

*Table 4: Tumour Group (% in overall qualitative sample vs thematic sample)*

Tumour Group*	Overall sample of qualitative respondents (50,348)	Sample for thematic analysis (1,501)
Brain / CNS	0.4%	0.5%
Breast	23.1%	21.7%
Colorectal / LGT	12.9%	12.0%
Gynaecological	4.8%	5.5%
Haematological	14.3%	13.9%
Head and Neck	2.8%	2.6%
Lung	6.0%	6.7%
Other	10.5%	12.4%
Prostate	9.4%	10.1%
Sarcoma	0.9%	0.5%
Skin	3.3%	2.5%
Upper Gastro	4.2%	4.2%
Urological	7.6%	7.5%

*\*Details of how tumour groups were formed can be found in the Technical Document, available at [www.ncpes.co.uk](http://www.ncpes.co.uk)*

Table 5: Sexual orientation (% in overall qualitative sample vs thematic sample)

Sexual Orientation	Overall sample of qualitative respondents (50,348)	Sample for thematic analysis (1,501)
Bisexual	0.3%	0.3%
Don't know / not sure	0.2%	0.1%
Gay or Lesbian	0.8%	0.9%
Heterosexual or Straight	91.7%	92.4%
Not given	5.6%	4.7%
Other	0.2%	0.3%
Prefer not to say	1.2%	1.3%

Table 6: ICS (% in overall qualitative sample vs thematic sample)

ICS name	Overall sample of qualitative respondents (50,348)	Sample for thematic analysis (1,501)
Bath and North East Somerset, Swindon and Wiltshire	1.9%	2.1%
Bedfordshire, Luton and Milton Keynes	2.1%	1.8%
Birmingham and Solihull	1.2%	1.5%
Bristol, North Somerset and South Gloucestershire	1.6%	1.4%
Buckinghamshire, Oxfordshire and Berkshire West	3.2%	2.7%
Cambridgeshire and Peterborough	1.5%	1.5%
Cheshire and Merseyside	2.7%	2.8%
Cornwall and the Isles of Scilly Health and Social Care Partnership	2.1%	1.9%
Coventry and Warwickshire	1.9%	1.9%
Cumbria and North East	6.5%	6.6%
Devon	4.2%	4.6%
Dorset	1.3%	1.3%
East London Health and Care Partnership	1.8%	1.9%
Frimley Health and Care ICS	1.3%	1.4%
Gloucestershire	0.8%	1.0%
Greater Manchester Health and Social Care Partnership	3.6%	3.2%
Hampshire and the Isle of Wight	3.7%	4.0%
Healthier Lancashire and South Cumbria	3.5%	3.4%
Herefordshire and Worcestershire	2.2%	1.7%
Hertfordshire and West Essex	2.5%	1.7%
Humber, Coast and Vale	4.1%	4.3%
Joined Up Care Derbyshire	1.9%	1.5%
Kent and Medway	3.4%	4.1%



ICS name	Overall sample of qualitative respondents (50,348)	Sample for thematic analysis (1,501)
Leicester, Leicestershire and Rutland	1.9%	1.9%
Lincolnshire	1.7%	1.1%
Mid and South Essex	1.3%	1.3%
Norfolk and Waveney Health and Care Partnership	2.9%	2.7%
North London Partners in Health and Care	2.3%	2.3%
North West London Health and Care Partnership	2.6%	2.5%
Northamptonshire	1.5%	1.5%
Nottingham and Nottinghamshire Health and Care	1.1%	1.1%
Our Healthier South East London	1.9%	1.9%
Shropshire and Telford and Wrekin	1.3%	1.3%
Somerset	1.3%	1.2%
South West London Health and Care Partnership	2.7%	3.0%
South Yorkshire and Bassetlaw	2.0%	1.8%
Staffordshire and Stoke on Trent	2.7%	3.0%
Suffolk and North East Essex	1.4%	1.1%
Surrey Heartlands Health and Care Partnership	2.4%	2.7%
Sussex Health and Care Partnership	3.5%	4.0%
The Black Country and West Birmingham	2.1%	2.2%
West Yorkshire and Harrogate (Health and Care Partnership)	4.4%	4.8%

Table7: IMD quintile (deprivation) (% in overall qualitative sample vs thematic sample)

IMD quintile (deprivation)*	Overall sample of qualitative respondents (50,348)	Sample for thematic analysis (1,501)
1 (most deprived)	12.1%	12.3%
2	17.2%	18.4%
3	21.5%	21.1%
4	23.6%	24.3%
5 (least deprived)	24.9%	23.5%
Non-England	0.6%	0.4%

*\*Indices of Multiple Deprivation (IMD) classifies geographic areas into five quintiles based on relative disadvantage*