

# National Cancer Patient Experience Survey 2024: National Qualitative Report



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## 1. Introduction and methodology

The National Cancer Patient Experience Survey 2024 was the fourteenth iteration of the 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 which is available at <a href="https://www.longtermplan.nhs.uk/online-version/">www.longtermplan.nhs.uk/online-version/</a>.

The survey was overseen by a National Cancer Patient Experience Survey 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. The survey provider, Picker, was responsible for technical design, implementation and analysis of the quantitative data for the survey. Solutions Strategy Research Facilitation Ltd (Solutions Research) undertook the analysis of the qualitative data for the survey detailed within this report.

## Eligibility

The 2024 survey involved 131 NHS trusts in England. The sample for the survey included all adult (aged 16 and over) NHS patients, with a confirmed primary diagnosis of cancer, discharged from an NHS trust after an inpatient episode or day case attendance for cancer related treatment in the months of April, May and June 2024.

#### **Fieldwork**

The fieldwork for the survey took place between November 2024 and February 2025.

## 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. For more information on the methodology and to explore results in detail visit www.ncpes.co.uk.

## 2. Understanding the results

Out of 127,021 people, 64,055 people responded to the survey, yielding a response rate of 50%. Two open questions were included in the survey which allowed respondents to use their own words to respond. These questions were positioned at the end of the survey and included the instructions as follows: 'Thinking about the hospital named in the covering letter, if there is anything else you would like to tell us about your experience of NHS cancer care, please do so here.' Respondents were then invited to write into two boxes about their experience of cancer care:

- QA. Please tell us in the box below what you found to be positive about your experience of cancer care.
- QB. Please tell us in the box below how your experience of cancer care could have been better.

48,375 respondents (76% of the survey sample) provided a written response, either answering one or both open questions.

### Qualitative data cleaning

Before sampling, further data cleaning was carried out to identify and remove extremely short comments which were of no analytical value, for example those which simply stated 'No', 'N/A' or consisted of a single character.

For QA, 2,111 comments were removed in this way, leaving 42,264 comments for the sample to be drawn from. For QB 16,511 comments were removed in this way, leaving 31,864 comments for the sample to be drawn from.

## Sampling

The initial analysis of the data set determined there was a significant minority of respondents who were answering one of the two questions to be analysed. It was decided to sample each question separately so that all respondents with a viable response to an open question had the potential to be included in the final sample for analysis. A total sample of 1,782 responses were analysed, including 880 for QA and 902 for QB.

To ensure a robust approach to sampling, a purposive sampling approach was taken. This is an established best practice technique when analysing qualitative data, as it ensures that the data has enough diversity across the most relevant criteria to allow the impact of the criteria to be explored and compared. For example, if age is a criteria, including responses from all the different age groups in sufficient volume means that differences in experiences between age groups can be explored.

The criteria chosen to sample on were the age, ethnicity, and deprivation level of respondents, as these were key demographic groups recorded in the data. A sample matrix was drawn up to establish how many comments from each of the demographic groups were to be included in the analysis to allow for sufficient coverage.

In addition to the three key demographic groups a minimum of 30 comments were included on <u>all</u> other characteristics, including tumour group and sexual orientation for instance. Please note that as there was a low volume of data from respondents identifying as non-binary or self-defined gender identity, all of these were included in the sample. The breakdown of the volume of comments in the sample by these different criteria is provided in the Appendix of this report.

Once the original sample of 1,782 comments had been analysed it was seen that data saturation had been reached, i.e. no new themes were emerging from the data. Had this not been achieved, additional comments would have been added to the sample as necessary, in line with best practice in qualitative analysis.

#### Use of illustrative quotes

Throughout the report, quotes are included to illustrate respondents' experiences in their own words and substantiate the findings. The quotes are transcribed as accurately as possible; however, the process can introduce spelling errors or question marks where the writing was not legible. Please note that the data has not been edited after transcription in the interests of correct spelling and punctuation for example, to stay as true to the words of respondents as possible.

Certain information from the qualitative comments used in the report has been redacted to protect the identity of survey respondents and any other individuals referenced. A summary is shared below of the information that has been removed:

- Names of patients or staff replaced with "[name]"
- Names of wards, units or hospitals replaced with "[location name]"
- Names of specific services replaced with "[service name]"
- Specific dates replaced with "[date]"

#### Qualitative analysis

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

Given the high levels of consistency seen across the 2021 and 2023 qualitative analysis, a deductive approach to the data analysis was undertaken. 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. The thematic codes created in the qualitative analysis of 2023 data were used for the initial coding of the 2024 sampled data verbatims to make initial observations. Applying this existing structure was viable and desirable, with a small number of changes identified which are highlighted in this report.

Figure 1: Thematic Analysis Approach



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. Where variations were observed in the national sample, this has been included within commentary. It is recommended that further focused sampling would allow for in-depth exploration of how experiences of cancer care may vary for different groups. Observations included will unlikely be exhaustive due to the national sample and focus.

## Context to support interpretation

It is useful context that while QA and QB are very distinct in design, responses sometimes overlap. Slightly more than one in ten answered QA on positive experiences negatively. While some included this as a caveat to the areas with which they were happy, others were entirely negative and had nothing good to say at all. Similarly, over one in four answered QB about what could be better by stating all positives or stating they had no negatives to report.

Throughout the report there are observations on any notable variation to the comments compared with the 2023 survey. There are likely multiple influences on this, including a different cohort of respondents. It is important to note that any differences, including the absence of sub-themes found in 2023, cannot be taken as an indicator that issues are resolved. It may be potentially relevant to note there have been significant changes to the political context when reflecting on the timing of when this data was collected. A new government was elected in July 2024 with explicit manifesto commitments around cancer treatment. Subsequently, an independent review of the NHS was first published in September 2024<sup>1</sup>. This review included the assertion that cancer care in England lagged other countries and that while survival rates have improved, the UK has higher cancer mortality rates compared to other countries.

It should also be noted that while the survey results are attributed to a single provider based on a respondents most recent discharge for cancer related care, many veered away from this substantially in the written feedback. Some respondents would reference all the settings where they had received care without providing clarity on whether their feedback was specific to some or all settings and the timeframes of when care had taken place.

<sup>&</sup>lt;sup>1</sup> https://www.gov.uk/government/publications/independent-investigation-of-the-nhs-in-england

## 3. Headline findings

Thematic analysis of the qualitative data revealed the following key themes:

#### **Gratitude**

A strong theme was gratitude with patients expressing thanks and appreciation. While sometimes broad and non-specific, often individuals and teams were explicitly highlighted and identified.

## Diagnosis

Enablers and barriers to diagnosis were shared, with a focus on speed. Access to private healthcare was driven by negative perceptions and experiences in seeking inital investigations. A strong call for greater sensitivity in sharing a diagnosis was also found.

#### Communications

There was variation in experiences of communication with high value placed on being able to ask questions and having proactive contact. The case was made for patient-centred and accessible information too.

#### Living with and beyond cancer

Various unmet needs were described in context of urgent and emergency care, mental health support, discharge and aftercare.

Improvements would mitigate a risk of physical and/or psychological harm of needs not being met.

#### **Staff**

Staff were pivotal to positive experiences praised for professional and personal attributes such as competence and kindness. There were noteworthy exceptions which futher demonstrate the important role staff play in experiences of care.

#### **Wait times**

Experience of wait times was mixed. While delays and lengthy waits were shared in a range of contexts, there was also found to be contentment from others as to the speed at which they had been seen/moved through the journey.

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

Areas of improvement were found in how services and organisations work together. Issues were experienced in co-ordination between the GP and hospital, within hospitals, and between hospitals. IT systems were identified as a key issue to resolve.

#### **Hospital wide**

A variety of other areas for improvement were shared which were not specific to cancer care. Issues included a lack of cleanliness, maintenance, travel and food, including not meeting or considering needs.

## 4. Thematic analysis findings

#### Key themes

Eight key themes were identified from the thematic analysis, listed below.

- Gratitude
- Staff
- Diagnosis
- Wait times
- Communications
- Co-ordination of cancer care
- Living with and beyond cancer
- Hospital wide

Within each key theme are several sub-themes which support with interpretation and use of the insights. There are 23 sub-themes in total.

This section of the report contains the detail of each theme with a range of quotations shared 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.

#### Theme: Gratitude

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

Respondents were asked to rate their overall care (Q59) on a scale of 0 (very poor) to 10 (very good). The average rating of care given by all respondents was 8.94.
 For respondents who answered QA and/or QB, their overall experience score was 8.95.

As seen in previous years, an overarching theme was overall gratitude. The language in these comments was not as profuse as found in 2023 though some respondents were clearly exceptionally happy.

Comments of gratitude were directed at the NHS generally and broadly.

"I found my whole experience positive. I have been so well looked after, I cannot fault anyone from the moment I was diagnosed, the scariness of it, I have felt so supported. I cannot fault the NHS and am so grateful to everyone who has helped me."

"All has been positive. Help when needed concerns addressed when raised. Thank you. N.H.S."

"To date I have been most fortunate in my experience of cancer. In addition I have not experienced any real pain. My thanks to the NHS for their care and consideration."

"Very excellent care from the start to finish. Thank you to the NHS."

"From day one I was looked after. Excellent service from my GP Practice very quick to get results. Hospital care I cannot fault, or both occasions. Both surgeries went well and my care from them excellent. No concerns at all. Well done N. H.S."

Often statements expressing thanks referenced specific hospitals, teams or individual members of staff. These stand out as the patient took the time to name and remember specific people to whom they wanted to extend their thanks.

"I must say that my initial treatment but the team at [location name] was superb and such a whirlwind from stoke symptoms to tumour diagnosis. The Consultant [name] and Registrar [name] who broke the initial news to us when i was first admitted, after scans, was superb and really helped my wife and daughters understand the next steps. Also to [name] who took me from the ambulance and settled me in before the first CT scan. After admission to the ward the process was equally speedy with [name] and [name]... who would be operating. Arranged after the bank holiday back in May. The whole team from [name] and [name] anaesthetists to [name] in the recovery room were superb. All ward staff in [location name] were great including [name], [name] on the first night / day. [name] / [name] and [name] need particular mention, including overnight wake ups for obs and meds. Also, the cleaning, food, other staff were great."

"I am very grateful to the staff concerned from consultant's to - the lady's who came round the ward's with the tea. Lovely people. I am still receiving follow up, check ups once again thank you."

"The Care and surport I have received has been fantastic. I dont think I could have received better care or a better team if I would have gone to a private hospital. My Oncologist [name] and the Specialist Nurse [name] have been excellent and very surportive answered all qusitions concerns. The Team based at [location name] in all the departments I have had contact with have been excellent. The [team] have been great and handle my illness issues quickly and effectively provided me with the additional medcation to help with the illness. The CT Scan team the Phlebotomist team are all great and have been very efficient. My own GPS [names] at [location name] have been so surportive and helpful through out my journey. The Surgical team at [location name] where great helpful and surported during and after my op. Lead by [name]."

"My oncology team were brilliant. [name] was and is brilliant. I feel very blessed to have him looking after me. My situation was bad and some how he worked Magie [sic magic] and saved me by doing things in a different."

#### Theme: Staff

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

- 84.9% said that their family and/or carers were definitely involved as much as they wanted them to be in decisions about their treatment options (Q22).
- 57.5% said they could get further advice from a different healthcare professional before making decisions about their treatment options (Q23).
- 77.5% said they definitely got the right level of support from hospital staff for their overall health and wellbeing (Q28).
- 78.2% said they had confidence and trust in all of the team looking after them during their stay in hospital (Q31).
- 70.9% said family, or someone close, were definitely able to talk to someone on the team looking after them if they wanted to (Q32).
- 74.0% said they could always get help from ward staff when they needed it (Q34).
- 65.9% said they could always talk to the hospital staff about their worries and fears if they needed to (Q35).
- When asked if the hospital staff did everything they could to help control pain, 84.4% said this was always the case (Q36).
- 88.0% felt that they were always treated with respect and dignity while they were in the hospital (Q37).

Closely linked to gratitude were expressions of satisfaction with staff. When staff were a focus in feedback this was largely positive and focussed in two key areas of professional and personal attributes. For the majority, these were not mutually exclusive, with comments covering both types of attributes when sharing observations about staff.

#### Professional attributes

Being treated and cared for was described in many ways which referenced professional attributes such as skills, knowledge, and competency of staff. In terms of impacts this was experienced as reassuring, contributing to a more positive experience.

"I found all the involved clinicians very competent, while initially the process was slow once it had been determined to be a lung cancer the treatment proceeded without delay."

"The whole experience was extremely positive. The consultants were clear and precise, the nurses were in the ball and caring and the support teams were kind. It genuinely felt like I was in good hands in a world leading cancer hospital."

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"The treatment care, supervision and support whilst I was in hospital at the [location name] was exceptional, kind, considerate caring and professional."

"Highly skilled, caring staff, excellent teams working together to do what they can to prolong life and help patients. A brilliant surgeon, female (I am goad of that) & very professional nurses at [location name]. They [location] staff are so committed, I am very grateful. Also great Ct scan staff!"

"Doctors I interacted with seemed very competent and I trusted their advice and viewpoints."

"Breath of knowledge & experience nurses/specialists/consultants have. Ongoing communication which helps build a positive, supportive and trustworthy relationships when going through trauma, therapy, surgery & recovery. Positive, friendly and approachable attitude of nurses (breast specialist + oncology nurses), consultants/specialists which help the process when undergoing procedures."

"All stall were helpful and positive and encouraging everything was done very efficiently and quickly. Was all in all a very positive experience. Staff made what situation a lot less stressful than it could have been."

Where standards were met or exceeded there was often mention of professionalism. For many this combined with positive interpersonal interactions.

"I had a great experience with [name] and [name]. It's always reassuring to be under the care of professionals who are not only skilled but also compassionate."

"I just wanted to single out the incredible ACU team at the [location name] who looked after me during my day visit treatments. They were absolutely incredible and made the whole treatment process such a positive experience. They were all highly professional, kind, and patient, and made such a difference. I really can't praise them highly enough. I think the ACU model is the way to go for cancer treatment wherever possible."

"Everyone involved in my cancer care has been friendly, professional and approachable. Everything concerning my treatment has been carefully explained with patience + knowledge. Being able to make use of the mobile cancer care unit has been incredibly helpful. This is an efficient and much appreciated service."

"The positive things in my cancer experience is the people who took care of the surgery. They were amazing and are the best. The doctors, the nurse and everybody on duty were all amazing. This is one of the best hospital I've ever been. I will be forever grateful for the professionalism, and they love and patience. God bless them all."

Being listened to was often spoken of alongside professionalism. This is seen as a priority by some patients, as being part of the conversation about their care helps to put them at ease.

"Upbeat caring professional staff who listened."

"The doctors, consultants and specialist nurses are all very professional and helpful and look after you as best as they can. They are good listeners and will act on any concerns you have."

"I felt confident in being able to raise concerns with them (re surgery) and they listened, researched and came up with options which we discussed & agreed."

"Overall, all of the staff answered any concerns or questions we had, & made us feel at ease. The nurses at [service name] were fantastic and really caring. They always listened to my concerns & pain, and pain were managed efficiently. It was reassuring to be around people that listen. Compassionate staff and doctors. My oncologist was also helpful in informing us. I was always directed in the right direction when I needed someone to talk to about side effects."

#### Personal attributes

Many comments about staff referred to their personal qualities and characteristics that were seen to support delivery of high quality care. Being 'warm' and 'kind' were personal attributes that were highly valued as they provided comfort and helped to relieve any anxiety.

"Through my cancer treatment journey, I found out that all staff from consultants, doctors, nurses and all the healthcare staff are very kind and caring about patients, they are working very hard and they are very patient and polite."

"From the moment I arrived I was greeted by people who showed me where exactly to attend - they were very kind and considerate and I have not experienced that in any other hospital. It put me at ease straight away."

"The staff at the hospital have been incredible. Very kind, warming, put me at ease when getting stressed. Very accomodating for my needs and worries."

"I have found all staff to be very kind & sensitive to the stress I have had during my illness. My care has been almost all excellent."

"My experience of cancer care at [location name] has been very positive. Staff are kind, compassionate & caring. My consultant has conveyed difficult information sensitively and has allowed me time to ask questions or express my feelings."

"Surgical team welcome, friendliness & explanation of what they were - going to do. Physical care & attention of most nursing staff allowing me to recover quickly. The physiotherapist's enthusiasm, friendliness & warm smile. She uplifted my spirits."

"I found that the staff at [location name] were so helpful throughout my treatment post and after. They were very kind and lovely towards everyone. They would also always sit and talk with me if I was bored or had any problems. On the [location] all the staff and nurses were the best! They really helped me get through my cancer treatment and I do believe I couldn't of done it without them and everyone at [location]."

Extending support to family members of patients was highlighted as contributing to a positive experience.

"The support- all of the nurses/doctors have been very supportive and understanding. Not just to me but also my family."

"From diagnosis to treatment plan starting treatment was very quick - Help + Support from my main care team throughout. Treatment was great. The inclusion of family in regards to treatment."

"Everyone at the hospitals I have been treated at have been amazing, my surgeon, oncologist, nurses ensured on the chemo ward etc. All very caring and always was listened to [name] (my surgeon) especially made Sure that all my questions were answered and also made sure that my mum's questions answered as she came with me to appointments."

For a small number of patients, they described their 'exceptional' experience as a direct result of staff to have exceeded their expectations in going 'above and beyond'.

"Care and treatment that I received was impeccable from start to finish. I felt like a celebrity taking a lead roll in a 3month miracle. I never felt pain, fear or discomfort at any time. Now at 6months post op, I feel that I took an amazing and fascinating journey and find myself missing all those wonderful professionals who treated me as a friend and left me in perfect health."

"The breast cancer team at [location name] are exeptional. The service I have received is fantastic. [name] has been so good with everything - I feel she has gone above & beyond what is expected of her to make sure that I am receiving the care I need to get over my ongoing symptoms."

"All the staff, surgeons, and the team that looked after me during my treatment at [location name], went above and beyond. I have a phobia of hospitals, needles, I was terrified. They supported me, I am austictic, I got overwhelmed, and how I was looked after meant a lot to me. They took time to listen to my needs and me as person, I am very grateful for all they did for me."

#### **Noteworthy exceptions**

While most of the feedback which mentioned staff was very positive, there were noteworthy exceptions which further reinforce the important role staff play in experiences of care. In direct contrast to the positive experiences shared, those reporting negative interactions highlight feeling they were not treated as an individual.

"Felt I was a statistic, felt by the consultants oncologist and rushed radiotherapist."

"I felt some clinical staff could have listened more to my concerns eg about the overall health effects of proposed treatment, and about follow-up, rather than just going through the motions of listening. It felt more "production line" than "patient centred" at times though I understand the time pressures."

Other improvements noted around staff interactions highlight the negative impact of dismissive attitudes towards patient concerns.

"There's a culture of indifference to patients' care and relative toxicity demonstrated by some [name] ward staff at [location name] hospital, especially by some nurses and support staff."

"Agency staff who were passing my bed, were annoyed when I asked for help. They put a cardboard receptacle under me, but left me lying down, so when I urinated it went under me

and all over the bed. They were then move annoyed, and pushed me over so quickly whist changing the sheets, that the ligaments or the top of my thigh were pulled."

"When I was having treatment I was having trouble sleeping. When I mentioned this a couple of nurses commented they have trouble sleeping. This was not helpful, I had cancer and was having treatment and they were not. It didn't seem very sensitive."

Another noteworthy exception was that feedback relating to staff sometimes explicitly mentioned staffing levels being too low and this impacting on experiences of care. In these examples it was acknowledged to be a systemic problem and not a criticism of the staff as individuals.

"All the staff who look after me are working incredibly hard. While very grateful for this, I hope that ways can be found to make things less stressful for them; that they have sufficient breaks, water, access to fresh air - whatever they need, to maintain their own health and well being while at work.

"The staff were excellent all be it rushed."

"Need more nurses. Not enough time to care."

For a minority of those discussing staff there was a strong desire to be reassured that the best course of action was being taken, indicating a lack of confidence. This was expressed through the desire for a second opinion.

"In hindsight, we learned we could pay for a second opinion & did so which only supported [name] but it gave peace of mind that there was no conflicting information."

"If patient can get 2nd opinion would be nice."

"I would have preferred to be given the time and or opportunity to seek a second opinion before commencing treatment."

"An option to discuss treatment with other doctors/opinions."

## Theme: Diagnosis

Respondents shared enablers and barriers to diagnosis. A common area highlighted was the speed with which diagnosis happened. For some this was quick, with evidence that expectations were sometimes low and/or exceeded. However, there is also the counterview in the data, when opportunities were missed or patients felt ignored. There are also comments which demonstrate both perceptions and experiences of delays meant that patients accessed private healthcare.

#### General Practice

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

- 78.6% of those who had contacted their GP practice said they only spoke to a healthcare professional at their GP practice once or twice before their cancer diagnosis (Q02).
- 67.3% of respondents who had contacted their GP practice said that the referral for diagnosis was explained in a way they could completely understand (Q03).

For some with positive experiences this started with their GP who acted quickly.

"From start to finish I have been looked after very well. Since I went into my GP, to now the care & urgentness of my cancer has been treated swiftly, proffentionally and quickly."

"I was seen by my GP within 2 hours of me finding a lump. My treatment, both medical and as a person, has been amazing throughout."

"From day one I was looked after. Excellent service from my GP Practice very quick to get results."

For others who spoke more about improvements to the experience of diagnosis, comments often linked to delays in accessing a GP when symptoms first appeared.

"GP support is difficult to access, uncoordinated and on occassions dismissive."

"It was difficult to get an appointment with my GP to raise my worries that I may have cancer or something serious. Latterly, I could not see the same GP and normally saw a trainee or locum. Not good."

"My GPs, [location name] were not good. It was impossible to get a face to face with any GP."

Not feeling listened to by a GP was a further barrier to timely diagnosis and meant that the role of the GP in referring to further treatment positioned them to patients as responsible for delays.

"My initial signposting by GP took longer than I would like. I should have been fast tracked due to a previous treatment I had and this was pointed out to GP. I hope the learning will mean any future patient gets referred the correct method."

"GP support exceedingly poor including referrals to other services not made when already discussed at appointments. Not being able to make an urgent appointment let alone a routine one."

"My GP requested a CT scan after on examination. I was disappointed as the hospital required more information before agreeing to this. There was a lack of communication from my Doctor to the hospital. I had to chase it up. I had an ultrasound instead but then needed a CT scan. A lot of wasted time!"

"Early diagnosis and detection. The GP's could have referred me early for blood and urine tests, I explained the symptoms I had, but they took it for something else, A new Dr, a locum, was able to identify the likely ????, the first time I met her."

"At the G.P. level, my experience was very poor. The G.P. looking after me was not competent at doing dre's, never referred me to a specialist urologist when he wasn't sure. My PSA suddenly increased, but did not tell me for a year after the test. G.P.'s need better training if they are to look after patients who may have prostate cancer."

"My GP practice failed to do necessary tests in time for me. They ignored my requests for too long."

"The initial diagnosis (via my G.P.) was very slow and involved a large number of visits. At times I trought my concerns were dismissed."

Other examples were given where GPs were considered accountable for a delay when initial referrals did not result in diagnosis and further referrals were then felt to elongate the journey to diagnosis.

"I believe my initial diagnosis of cancer could have been made a lot quicker. The GP, surgery I go to have a number of GP's and you get to see who is available which I do not think is as efficient as seeing the same person. I. first went to my about GP 14 months before cancer was diagnosed and I was examined and sent for a colonoscopy, which showed no trace of cancer. However I had more visits to my local GP surgery where I saw other doctors until one sent me for an ultrasound scan which showed a 5cm mass. A CT scan then confirmed this to be cancerous. I think had I had the ultrasound scan instead of the colonoscopy the tumour would have been found nearly 12 months sooner. I was told by the specialist consultant,I had the tumour for at least two st two years. It is not a complaint just an observation."

"The only thing is that it was only after I went to A&E that I was diagnosed. I had symptoms (bowel problems) around 10 months before diagnosis and spoke to my GP a couple of times but was told that it was nothing after a stool test for a bacterial infection (and at that time, it may well have been nothing), though it was known that I have [condition]. Just before going to A&E, I went to see the GP about my terrible abdominal pain which had been going on for a few days but was told it was probably IBS and told to take some Buscopan - the GP did say that if the pain didn't go away, I should go to A&E, which I did. Having said all that, I understand that a GP just can't refer everyone who comes in with bowel problems or abdominal pain for diagnostic tests."

"It took me 6 months from first going to my GP with symptoms caused by cancer to being diagnosed with cancer. In the time I had multiple GP appointment took myself to A+E, saw gynae doctors and was made to feel I was a hypochondriac and told my symptoms were just my period/PCOS. I was very scared as was unable to roll over in bed due to severe bleeding and was continually fobbed off, I feel due to my age [30s]. Nobody told me I could have cancer until I was in the room being diagnosed. I had two hysteroscopies and felt left in the dark/ was told there was nothing wrong with me until my biopsy came back."

#### Professional curiosity

Patients commented that across a range of healthcare practitioners, sometimes specified though often not, they could have shown greater curiosity about their symptoms as a lack of investigation was seen as contributing to delays in diagnosis. Mentions span primary and secondary care based on the roles commented on, e.g. GPs, consultants.

"It took me 6 months from first going to my GP with symptoms caused by cancer to being diagnosed with cancer. In the time I had multiple GP appointment took myself to A+E, saw gynae doctors and was made to feel I was a hypochondriac and told my symptoms were just my period/PCOS. I was very scared as was unable to roll over in bed due to severe bleeding and was continually fobbed off."

"In [date] I had my appendix out. It wasn't tested but it was cancerous [date] my stomac swelled & it transpired I had a full hysterectomy. They thought they had cut it but no. My cancer was 1 in a million. I have my stomach drained every month. The cancer is getting bigger in my stomach. The treatment is draining with suction under ultra sound. I just wish [name] had taken more care, and saved me a lot of pain."

"It took a long time for me to be diagnosed and I was told several times that I was very unlikely to have cancer. My first GP dealt with the situation terribly, and when I finally was able to get a referral for testing it was changed to a non-urgent referral as my symptoms didn't match up with those expected for cancer. Obviously this was incorrect."

"My 1st appointment at my GP, was negative, I was told that as I was screened 2 yrly, there was no need for hospital referral despite a family history & fatality due to cancer. Another GP took my concerns & more seriously & quickly referred my for a colonoscopy."

"Initial GP care before diagnosis was very poor. Seemed to want to prescribe stronger pain killers rather than finding root problem. CT & MRI results can sometimes take too long to be reported on."

#### Accessing private healthcare

A new sub-theme is observed in the data this year around the consideration and uptake of private healthcare. Predominantly respondents who shared that they accessed healthcare from a private provider had done so when seeking investigations of symptoms. This could be due to perceptions of difficulties in accessing GP appointments or referrals, or after a negative experience in primary care.

"I paid for a private G.P. because I didn't feel my NHS G.P. would take me seriously or be quick enough."

"Diagnosis was by a private doctor in the course of treatment for another condition. I was compelled to seek private treatment for that other condition due to difficulty in getting treatment on the NHS. GP was unable to diagnose."

"GP did not believe I had cancer, I had to see skin specialist privately to get a correct diagnosis. This wasted at least six weeks."

"I was misdiagnosed by the NHS for five months. And I had to go through my private healthcare cover at work in order to get an MRI scan, that detected an avocado sized tumour, that later was diagnosed cancerous. If I hadn't had private healthcare, then I don't know how far my cancer could have advanced, as the NHS only gave me an ultrasound scan, and this did not for some reason detect this tumour."

"I was also disappointed that I had to get a private PSA test done at the onset. I was never offered a PSA test by my GP surgery and this didnt sit well with me."

There were also comments from those who had accessed private healthcare when their initial diagnosis needed further tests and exploration, to overcome delays or long wait times.

"I should have had a 6 month follow up appointment. I was given a telephone app in [date] - cancelled - Moved to [date] cancelled moved back to [date] cancelled. It's extremely hard to contact anyone on numbers given me. I paid privately to see a consultant, he recommended I get another MRI/consultation and wrote to my NHS."

"I decided to get my diagnosis privately at a cost of £6500 because the receptionist at my GP practice advised me to wait to hear about my first hospital appointment after the 2 week wait target date had passed. I was so concerned that I had a mammogram and further diagnostic tests and scans privately."

"I had to organise my own mri as they did not put me under urgent."

"I waited far too long before I was first seen by a specialist. I was compelled to contact private doctors on numerous occasion to seek advice and prescription to manage my pain."

"The diagnostic stage was very prolonged. We were told we couldn't have a TURBT and biopsy for about 7 weeks, despite the team being fairly certain that I had cancer. For this reason, I had to have this stage private. From that point on, things happened quickly."

#### Sensitivity

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

- When asked how they felt about the way they were told they had cancer, 75.0% said they were definitely told sensitively (Q13).
- 77.2% said their cancer diagnosis was explained in a way they could completely understand (Q14).
- 85.9% said that they were definitely told about their diagnosis in a place that was appropriate for them (Q15).

There were comments about receiving a diagnosis via telephone, and observed for the first time this year, via text message or NHS app. These experiences emphasised the need for improved sensitivity in communicating diagnosis. Comments indicated that information about diagnosis being shared in these ways was not experienced as appropriate. A preference was inferred whereby speaking to someone sharing news of diagnosis was preferred over methods not involving human interaction.

"Receiving a text message about a follow-up appointment indicating I had cancer before my consultant had the chance to deliver the diagnosis was both distressing and inappropriate."

"I don't think patients should be told they have cancer over the phone."

"I was told over the phone by someone from [location name] that I had cancer/biopsy results. 1.5 hour late - and then told its not a type of cancer [location name] deals with so I'll be referred to a CUP team but could not tell me where/when I'd be contacted. Got of the phone would not even recall what the person had said. This was horrendous."

"I received confirmation that I had cancer after my colonoscopy on the NHS APP before I had the appointment with the surgeon about 1 month later. This was distressing and led me to googling that increased my anxiety."

"I was waiting results of a CT scan in the early stages and was expecting a call from my consultant. I went on the NHS app and discovered a document setting out my diagnosis. I contacted my consultant, who asked me to email the results to him. It was not a great start!"

"I actually fond out that I had lung cancer that had metailised to my rib/spine etc via the NHS App. I found am quite shocking and appalling that such sensitive information was posted on the app before I was officially told of the finding from CT scan and other tests. This should never be allowed to happen as it was devastions to read this information when I was stood in a supermarket! Clinicians need to make phone calls again please and not rely on techology apps. We are human not robots."

Respondents also identified opportunities for improvements when diagnosis was imparted in person. This includes a need for sensitivity and compassion as less careful delivery can create negative impacts on patients.

"Anything to do with pre-diagnosis or direct diagnosis was at a different hospital, [location name] in [location]. They were rather problematic about my diagnosis. My lymphoma was diagnosed, the doctor came in, bluntly stated I have lymphoma, no further information was provided and left. Luckily my mother was with me, and my own mind (at the time)."

"I did not get any emotional support. I think I was given a leaflet for [service] but found it confusing and complicated how to find any of this help. I was never told my cancer stage and my results info for other issues which arose took a while for me to be informed."

"The way that I was informed that I had cancer. I was informed on a busy ward in [location]. The doctor that informed me said - 'It's not good news, you have cancer.' She then left to carry on with other patients. A bit more compassion would have helped."

#### Theme: Wait times

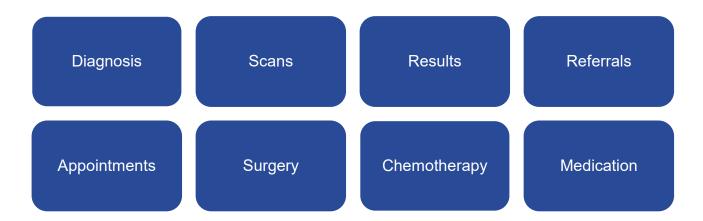
There was a shift in tone seen in the feedback about wait times compared to 2023, with both negative comments and some expressions of positive surprise at the speed patients were treated and cared for. This surprise is muted in comparison to the 2023 insight.

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

- When asked how they felt about the length of time they had to wait for their test results, 77.5% felt the length of time was about right (Q07).
- 79.4% felt the length of waiting time at the clinic or day unit for cancer treatment was about right (Q43).

#### **Delays**

Further to the delays described within the theme 'Diagnosis,' feedback highlighted that areas for improvement also included waiting times and other delays commonly mentioned across the following areas:



Respondents described the negative impact of delays on their physical and mental health, particularly relating to test results:

"It would be a lot less worry for the patient if results were processed quicker."

"Delays in test results/treatment and waiting for treatment and not knowing how bad the cancer was almost unbearable."

"It is concerning that it took so long for the operations to be performed once identified as the impact would not have been so severe if the operations had been completed at the time of identification."

"I only attended [location name] hospital for my surgery. I was there from 8 am and surgery didn't take place until around 3.30pm. So extremely long nervous wait with no company and nothing to pass the time."

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"Time between test results and review from the multidisciplinery team could have been shorter. Some specific advice on what to expect after surgery I had some pain, swelling and what looked like an infection. It did pass but I was not expecting it and was a shock to see."

"Radiology reports could have been handled better, time on reporting an MRI was more than 4 weeks and I think this could have been better."

Staffing levels were also mentioned in the context of waiting. Consistent with the earlier insight shared relating to the 'Staff' theme, issues with staffing levels were considered systemic issues that impact negatively on experiences of care.

"I fully appreciate the NHS is stretched and all the staff were lovely and worked really hard but for something as Cancer, I feel there should be more resources. the waiting and not knowing what type of cancer you have is really stressful and sent my anxiety levels soaring."

"The waiting time to be seen to for cancer treatment a couple of visits was rather long. I understand it is not the staffs fault as are under-staffed."

"Long waiting times at pharmacy outpatients. Shortage of nursing staff meant longer, wait times for medications and blood tests."

Long waits for pharmacy to prepare medication stood out as an issue which had a significant impact on experience.

"Sometimes when i arrived to have my Chemotherapy the pharamcy was running behind and my chemotherapy wasnt ready which meant i had to wait around, most of the time it was near enough on time but there was a couple of cases where it was 3/4 hours late."

"After being allowed to go home I had to wish several hours for my medication both occasions."

"The only little niggle I have Is sometimes waiting quite a while for medication to come up to the ward from the pharmacy, Especially if you have finished your treatment and just waiting for that before you can go home."

"Pharmacy is mega cause for very long delays at [location name]. It can extend hospital times by 2-8 hours."

"Pharmacies in hospitals need more staff and are a weak spot."

"The pharmacy services at [location name] were at times chaotic. Specifically very long waiting times for medications after seeing my doctors after appointments."

"The only thing which could be better is when collecting medicine from the pharmacy at the hospital. The wait needs to be shorter. When going for radiotherapy for several days & round trip from home with family is 7 hours. (more if hospital trasport is needed). To add at least 1 hour to wait for medicine is not good."

#### Contentment

In contrast, there were also patients that expressed positive surprise in how quickly and efficiently they had been seen, treated and cared for following their diagnosis. Descriptions, while positive, used less demonstrative language than in 2023 when this surprise was expressed using language such as 'amazing' and 'impressive' which infers delight rather than the contentment seen this year.

"Since I was reffered to [location name] my treatment was fast and the Information I was worried about I got reasured as quickly as they could when I asked."

"Wait times for cancer related appointments and tests were generally very good, and I've been able to get appointments at short notice when needed."

"From diagnosis, all appointments came thick and fast, meaning that the dreaded unknown waiting game was cut as short as possible. This helped mentally as I knew I wouldn't have to wait long for the full facts."

"Time between diagnosis and treatment was prompt and efficient. Staff were caring (whilst under pressure)"

"I started treatment within 10 days! from Blood test, at [location name]. I was in shock as I was expecting an op. actually CML cancel your op! They were very efficient + quick with starting treatment."

"I rarely had to wait more than 10 minutes for a clinic or imaging appointment - which I thought was brilliant."

"I was diagnosed on [date] and had my op on [date]. I don't think I would have been treated any faster any where."

"Honestly cannot fault the system since my brain stem cancer picked up incidentally in a Biobank health scan- NHS fast track cancer pathway delivered fully within 2 weeks from referral by my GP to review of MRI scan and discussion of care plan at the [location name]."

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#### Theme: Communications

Overall, there was mixed feedback and varied experience about communication. Comments provide insight into what good communication with staff looks like, with the highest value placed on being able to ask questions when there was something unclear, as well as there being proactive contact. Comments on written communication evidence a need for this to keep pace with treatment and to ensure patients are easily able to understand by using simple language.

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

- Of the respondents that said they had a main contact person within the team looking after them, 84.6% said it was very or quite easy to contact their main contact person (Q18).
- 83.0% of respondents said treatment options were explained to them in a way that they could completely understand before their cancer treatment started (Q20).
- 92.3% of respondents said staff provided them with relevant information on available support (Q27).
- 74.7% said that before they started their treatment(s), the possible side effects were definitely explained in a way they could understand (Q44).
- When asked if they were offered practical advice in dealing with the immediate side effects of their treatment(s), 70.9% said they always were (Q45).
- 87.9% said they were given information that they could access about support in dealing with immediate side effects from treatment (Q46).
- 60.9% said that before they started their treatment(s) the possible long-term side effects, including the impact on their day-to-day activities, were definitely explained in a way they could understand (Q47).
- 55.6% said they were definitely able to discuss options for managing the impact of any long-term side effects (Q48).
- When asked how they would rate the administration of their care (getting letters at the right time, doctors having the right notes/tests results, etc), 87.6% of respondents said the administration of their care was 'very good' or 'good' (Q57).

#### Preferred methods

Feedback on methods spanned face-to-face, telephone and written communications. Fundamentally those who shared they were satisfied with communication were patients who

were given time to talk, to be listened to and to have their questions answered. The impact of feeling fully informed and involved is to put patients at ease and make treatment more manageable.

"The staff I am dealing with (Specialist nurses and consultants) have been amazing at giving information and support. They respond on time and well to questions asked. Though the situation of having cancer is daunting and scary, the staff is very good at reassurance and giving support."

"The cancer nurse team have been amazing. I have always been able to contact them if needed and they are very knowledgeable and thorough. The oncologist was very clear when explaining my treatment options and impact on future health. I flet I was treated with respect once diagnosed with cancer and the team reassured me I would be having best evidence based care. I was given time to make my own decisions and the information needed."

"The explanations that were given to me throughout my treatment were thorough with both my consultant and oncologists. I felt that I could ask the questions that I needed to ask for my own peace of mind."

"Excellent communication, very supportive, listened carefully & took me in as a person rather than a bundle of symptoms."

Comments show that the time taken by staff to share information face-to-face had the added benefit of putting patients at more ease and gave them a sense of being supported.

"My consultant has conveyed difficult information sensitively and has allowed me time to ask questions or express my feelings. I believe that my treatment was the best available for my condition though it unfortunately has failed to cure me. My consultant has generously suggested I seek a second opinion on future care."

"I did want radiotherapy because I thought it would be better after my surgery but the consultant assured me they had looked at the pros and cons and would have been more dangerous so the medication I take was better and I understood then why, Can't praise them all enough excellent."

Comments on improvements further highlighted the high value of conversation / face-to-face interaction, even where written information had been shared.

"A lot of the information given pre-surgery and chemotherapy was in writing in various forms. It was a lot of reading at a time when I was not in the right headspace. I'm not sure now that I read everything I needed especially about long term side effects of chemotherapy."

"Being more truthfully informed of the effects of chemo and how grueling it is. Perhaps I was just naive, but I did not expect to have to have so much time away from my usual work and other activities. After a couple of treatments I was able to plan a bit for these, but could never entirely foresee how fatigue would affect me. I realize written information has to be general as not every patient reacts in the same way, but would have been helped if someone on the care team had said outright that chemo is a tough call and why, and not just 'you may have such and such a reaction."

"Where there are questions like this, I'd recommend having a phone appointment to go through the information available in the NHS pamphlets. Or even just confirmation that it's ok to get started with the pamphlet. - At the end of treatment (and before the follow-up appointment), the next steps were not entirely clear. It created a bit of limbo."

"Felt that more time could have been given to me as I still have questions. I had to do my own research. No one went through the information complets that I had been given. No groups available in my area. No follow up checks about the medication I am taking and how it is impacting on me. Felt I was a statistic, felt by the consultants oncologist and rushed radiotherapist."

"I felt on a conveyor with no choice or reassurance to what was a shock to hear the treatment plan delivered with no regard to how it affected me. Too many sheets of notes and confusion on letters, tests, emails. Sometimes 4 copies of same thing."

In terms of written communication, the importance of keeping pace with treatment to avoid delays or missed appointments was underlying this concern for some. Where preferences were articulated clearly, many patients spoke of alternatives to post such as email or text message which offered the benefit of speed as well as a written record.

"Inconsistencies in how i was updated with appointments. Texts/calls/emails/links have all been fine but often appointment details sent in the post arrived after the appointment. I am aware that this is an issue with the post and not my care, but thought it was an important thing to be aware of."

"If patients could the given the options for receiving appointment notifications I would have opted for email/text message only. Receiving multiple letters in the post often after the appointment late was not only unhelpful - it is a waste of NHS money!"

"Communication via email would have been easier due to the postal service not being too reliable."

"Also, consultation notes were sent by post rather than email, so I was receiving information which was actually out of date by the time I received it."

"I was sent letter for appointments. Sometimes I was notified via the my medical record app. Quite often I received a letter or phone call as well as & my medical record notification, but not always. It would really be useful to ensure all appointments are notified via post and app. It gives reassurance to have both and insures against post going missing which I have experienced."

#### Patient-centred information

Linking to the theme on 'Diagnosis', there was feedback on the need to improve consideration of the patient's response to determine the pace, volume and quality of information that is shared. Examples below include patients who felt overwhelmed as for them there was 'too much too soon'. This demonstrates the need to be patient-centred and responsive when providing information, using judgement in the moment to tailor

communication to deliver information in a way that is then experienced as sensitive, clear and reassuring.

"I felt bombarded by written information."

"There is no time for you to consider the information away from the hospital setting for any length of time, before going ahead with the treatment. No one ask you how are feeling about the planned treatment."

"I also found her to be quite abrupt - calling me after a follow-up scan showed more cancer and expecting me to make a decision about lumpectomy vs mastectomy there and then during the call. I needed more time to process the news."

"Huge amount of information provided. This could be reduced/simplified. Very difficult to absorb everything."

The need for additional information and reassurance from staff is further highlighted by comments which outlined a lack of ability to make contact to ask questions, even when provided with dedicated telephone numbers. This has a negative impact on patient wellbeing, especially where messages are left unanswered.

"During my chemotherapy treatment, I felt that nurses that were there for me to be contacted, had too much as at times I was unable to get through to them. Even after sending messages with regards to my issues, on quiet few occasion I've never had anything back. Quiet disappointing as they are there as your main point of contact and not to be able to speak to them, wasn't helping me personally."

"Communication. At a very stressful time in my life and on so many occasions I called the phone number I had been given to call if I needed advice or help and I left messages and nobody ever got back. I was literally in tears once leaving a message because I was so worried and frustrated."

"The care I received was very good but the lack of communication and inability to contact people was not good."

"It's extremely hard to contact anyone on numbers given me."

"Did not return my calls and when I did get in touch with a question, told me to ring the [service] hotline for an answer the breast team gave me In 5 mins!"

"Trying is contact specialist nurse is difficult. Despite a contact number it is after on answer machine. Don't always get back to you promptly."

In contrast, those who shared positive experiences of contacting staff demonstrates the profound impact this can have on their experience. Particularly notable are the strong positive feelings around regular proactive contact from staff.

"I have found consultants completely open to questions - of which I have many, and involvement of my wife in every meeting and offer to update my adult children if they too have

queries has been really appreciated. Cancer support nurses have answered all queries and greatly appreciated their weekly calls during my 6 weeks of radiotherapy."

"My cancer nurse [name] was amazing, I really appreciated her phone calls during the first few weeks after my diagnosis. If I ever had any questions she was really quick to either call me or send a reply by e-mail."

"If I had a further question, I rang one of the nurses on the dedicated line."

"Staff always returned calls if I had questions."

While less prevalent, there were examples given where written information was understood but the ability to discuss with staff was also appreciated to give confidence to the patient that they were fully informed.

"Any information I needed was easily accessible and I knew which staff member to ask about this information. The information I was given was clear and easy to understand and if there was anything I was unsure of, the specialist nurse would explain things in more detail so that I could understand easier and used non professional terminology to help me understand better."

"Admin side of care was very well organised, and provided me with more than enough information about charities, pre-surgery and post surgery care etc. Nurses were very caring and always made sure I was compatable with information and any decisions to be made mere my choice."

#### Accessibility

Another area highlighted for improvement was a need to simplify the information provided, particularly in terms of explaining medical terminology, to ensure that patients found it easy to understand. This spanned both conversations and written information.

"I would have liked more information on the equipment used after surgery, in layman terms so ond people would understand the Jargon not medical Jargon."

"Better explaining in simple."

"More basic info, simple terms one can understand as helpful. I was scared and my knowledge isn't at ????. Cohesion isn't good please tell us in Laymans terms so we can better understand what is happening to us. Not every one can grasp what is being said easily."

"A lot of letters and documents were abbreviated and was frustrating to the to figure out what the letters meant. Letter should be fully explained with no short-hand terms as we are not all medically trained to understand what letters in capitals mean."

#### Theme: Co-ordination of cancer care

Feedback on how services and organisations work together across elements of a patient's cancer care such as appointments and tests, focussed most on what needed to improve for patients to have a seamless and joined up experience. Information sharing was a key component of this and a common thread running through several examples shared here, demonstrate the impact being stress for patients due to feeling 'lost' and that their care wasn't a priority.

#### Between GPs and hospitals

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

• Of those that said their GP practice was involved in their cancer treatment, 47.7% said they definitely received the right amount of support from staff at their GP practice while they were having cancer treatment (Q51).

Comments included a need to ensure information sharing between GPs and hospitals is maintained throughout treatment. This includes ensuring that information is available to all teams involved in a patient's care, as while it is not always clear where responsibility lies, there is the perception that lack of information sharing contributes to delays.

"My doctor was not informed of when i had surgery and was discharged."

"I had been diagnosed with incurable cancer the initial care was excellent but now one and a half years later I feel like I have been forgotten and my GP is too overloaded for me to see her."

"I am being treated in [location] but live in [location] - communication between these hospitals and with my GP is almost impossible. There seem no systems for them to collaborate in my care."

"The admin side was not good. Notes weren't written down or shared with my GP. There were delays due to this, then further delays due to understaffing. No update on blood tests."

This was particularly noticeable in relation to prescriptions after hospital discharge, with patients unsure who is responsible and therefore who to contact to resolve problems.

"If they could be digitised that would make everything run a lot smoother Post-surgery I was told I'd be discharged and was waiting for a long time, causing issues for the driver additionally, some appointments/ results aren't visible on the NHS app, meaning there is a breakdown in communication between the hospital and my GP- a lot of chasing for repeat prescriptions set up by consultants at the hospital."

"The connection between the hospital (oncologist) and GP needs to be clearer. After any day -case treatment in the hospital (chemotherapy), they gave me calcium tablets for 28 days. Do I need to continue these tablets from the GP or not? It seems that the GP doesn't have clear instructions from the hospital about my repeat prescription. Every month the pharmacist asks

me about the items I need in the next prescription! It will be great if I have a blood test (for calcium, haemoglobin....) to decide if I need such medications, and for how long. I mentioned this point to oncologists in phone call follow up consultations. I also mentioned it to the GP in few visits. Still I don't know whose responsibility it is."

#### Between hospitals

There is an expectation that information about the patient held in one hospital would be freely available and easy to access by another. This was raised as another opportunity for improvement, as noted in the 'Communication' theme earlier, when the lack of information sharing between hospitals disrupted the patients' experience and care was not felt to be well coordinated.

"To share information for different departments in different hospitals. [location name] – [location name]."

"More care and follow up from hospital support staff would have helped. Better patient liaison was needed - I had to chase everything and was often given misleading/inadequate information, or had to follow up things myself and then inform the hospital admin team of things they should have been telling me! I felt I was having to do their job for them. All this at a time of great stress and when I was in pain. More staff and/or better training required? A system that would have allowed me to check on my appointments and results electronically (as used at [location]) would have made things less stressful and exhausting all round."

"The communication between [location name]and [location name] Oncology Department is non-existent."

"Information systems not joines up. Scans at [location name] not on system for [location name] to access so repeated!"

"Lack of communication between hospitals. I had my operation at the [service] My chemo at [location name] and radiotheraphy at the [location name]. When I needed a wig, the seperate trusts [location] did not know where the funding came from. A lady from [service] joining the dots."

"Use of a single hospital. I was seen at 5 hospitals across 3 NHS trusts. The medical records are not stored centrally and therefore time (and cost) are wasted in explaining my situation at each hospital appointment. The lack of inter-departmental work flow is inefficient."

#### Within hospitals

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

 Most respondents (90.4%) felt the whole care team worked well together to provide the best possible care for them (Q56).

As patients were often treated in several departments, there was an expectation that all departments within a hospital have the same information. When that is not the experience

this can be seen as the cause of delays to treatment and creates a desire for a single point of contact who is responsible for cancer care.

"I have found communication to be a problem especially between healthcare professionals in the same hospital for example when having A&E or having to stay in hospital."

"Suspect better communication is needed between the different departments involved e.g. on [date] I had an appointment with my oncologist and they kindly took a blood test as I was due back at the hospital on the [date] for treatment; I was just about to receive the treatment when the nurse went to check everything was alright with the doctor in charge; I was unable to have the treatment as my last heart scan was too long ago - waste of everybody's time."

"Dialogue between different teams and between doctors/consultants and nurses. So many different doctors and consultants have been involved but I wish there had been at least one who was in overall charge of my care. I also feel that some of the consultants are so focussed on their specific area, that they don't consider 'the bigger picture'."

#### IT systems

Some patients highlighted the negative impact of the lack of cohesive systems that enable streamlined information sharing between all staff and services involved in their cancer care. Comments recognised the contribution of IT systems to their experience and raised questions about the role that improvements in these could make to their interactions with both staff and the administration of their care.

"Poor IT systems - I repeatedly have to explain my conditions to health care Professionals when this information should be available to them. Lack of contact from GP. They do not even seem to be aware that I have cancer unless I tell them."

"The introduction of the new computer system part way through my treatment caused a number of issues on particular confusion regarding my surname sometimes using my maiden name and others my married name, sometimes both."

"A better system for sharing patient records across health agencies, and for having a point of contact with a dedicated case manager would have made life easier and more treatment efficient."

"The obvious problem that I experienced was the lack of a joined-up IT system across the various hospitals, test centres, GP practice and social care. Tests at one location are not shared with other within the group. Each blames the lack of a cohesive IT system."

#### Theme: Living with and beyond cancer

The feedback about urgent and emergency care, mental health support, discharge and aftercare, makes a compelling case for why cancer care does not begin and end with diagnosis and treatment. Across the sub-themes patients describe various unmet needs and an inference is observed that their context as cancer patients should be better accounted for to mitigate risks of psychological and physical harm that can otherwise occur.

#### **Urgent and Emergency Care**

Concerns were raised by some respondents as to feeling vulnerable when having to access urgent and emergency care. There was a strong inference from patients that their cancer diagnosis should be accessible and/or shared with the department to enable mitigations to be put in place. The perception that they could be putting themselves at great risk of infection created anxiety and strong feelings were noted on the need for different access to urgent and emergency care as a result.

"I don't think Cancer patients on chemotherapy should have to go to A & E if they become unwell as its a major risk."

"Cancer patients should treat in separate area while going in Emergency (A&E) Department. As they are in high risk of getting infection quickly. They are unable to just sit more than 6 hrs. They should have a seprate (OPD) or ward 24 hrs with care available."

"Most of my visits to A&E and associated departments were difficult because of my chemotherapy and I found it very difficult to get any special treatment. I was exposed to TB while in the A&E holding ward."

"I was admitted at A&E for severe abdoming pain during my cancer treatment. A/E didn't have a policy or guidelines on how to accomodate or look after an immuno compromised patient like me. I was mixed with other patients putting me at a great risk of catching an infection!"

"Sometimes waiting in A&E with other patients is difficult, cancer patients should have an isolated waiting area due to infection risk."

"A&E visit - nightmares, I had multiple on I had a red card and fever meant going to [location]. Long wait and no guarenter of any bed availability even when I was high risk of mortality with sepsis is unacceptable for any patient."

"I would be advised to go to A and E for urgent care which I would never get on time, considering that I was undergoing cancer treatment and had an urgent treatment card. Cancer patients should be prioritised when they arrive at Emergency as we already are going through psychological turmoil, in addition to the physical ones."

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#### Mental health support

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

- 65.9% said they could always talk to the hospital staff about their worries and fears if they needed to (Q35).
- Of those who had been treated as an outpatient or day case, 80.0% said they
  were always able to talk to hospital staff about their worries or fears if they
  needed to (Q39).
- Respondents were asked whether once their cancer treatment had finished, they could get emotional support at home from community or voluntary services.
   33.5% of respondents that needed care and support said they could definitely get this (Q53).
- 64.9% of respondents said they were given enough information about the possibility and signs of cancer coming back or spreading (Q55).

Not being offered any or timely support for the psychological impacts of cancer diagnosis and treatment was highlighted as a key area for improvement.

"Therefore I have had 4+ years of no mental health help at all! Finally, I have an appointment with a psych. Didn't know I could!"

"Cancer treatment was a whirlwind. Physical needs cared for but mental/psychological needs not addressed. Needed counselling from local cancer charity to come to terms with the psychological impact. Care finished like falling off a cliff from all systems go to nothing."

"I flagged to my team that I think I'd benefit from some support from the psychologists to help me process everything, I flagged this a month ago and still have not heard anything about the process of getting an appointment."

"I also was not offered support/ for my mental health at any point."

"I feel like there needs to be more support once treatment is finished. Once treatment is finished we are just supposed to get on with our lives however thats not always easy due to the effects of treatment on mental health."

"I was told to fill out a questoinare about my concerns and feelings about being diagnosed and if I would like to talk to someone about my upcoming treatment. I put in that questionare that I was nervous would like to speak to someone before my surgery. I was called but unfortunately this was after I already had the surgery, so it wasnt very useful."

There were also comments highlighting a need for improvements once treatment finished, particularly where patients were struggling emotionally or had concerns about recurrence.

"My biggest problem is post-surgery because I need some answers that I don't have. How do I really know if the treatment is being effective or not? and there are some problems that I need these answers for and I haven't had them yet."

"I do not feel I had good follow-up from living post surgery, in terms of managing emotionally however. I sought counselling from [service] locally and am getting help there. My GP rang me post-surgery and put me in touch with the physiotherapist at the surgery, but she admitted there is no follow-on rehabilitation or mobility support in NHS, only privately... I am worried I have another lump and new pain. I feel traumatised every day and worry every day that it was, or will come back any time."

"After care re: body image & how I feel about myself has been neglected. I feel I should feel grateful for the recovery & be going on my way. Maybe at 65 years the surgeon feels body image is irrelevant I have asked for reconstruction of sorts all along. Was led to believe this would be an option, feel I have been dismissed."

"Aftercare: Accessibility to nurses - it was very hard to get hold of them. Physio/exercises: only a leaflet was given. This didn't help as much as a proper in person session would have helped. Follow-up - radiotherapy phone call was not very re-assuring as no one actually looked at the affected area to confirm whether the area is healing as expected... Emotional support. No one reached out to check on my emotional/mental (nurses?) well being. I struggled a lot with my mental health over the summer."

"There was nobody to talk to at all post cancer as I had developed depression soon after chemotherapy. And there was nobody for me, no help, support or anything."

To note, an example of seeking private healthcare is shared within the 'Aftercare' sub-theme pertinent to mental health support.

#### Discharge

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

• 87.3% felt they were given easily understandable information about what they should or should not do after leaving hospital (Q38).

Several patients spoke of the need to improve their experience of discharge, particularly where there was felt to be a lack of clarity on what the next steps would be in their treatment. Another common thread in this feedback was a sense from patients that they were discharged too early, based on experiencing issues soon after.

"Being sent home within an hour of having 50% of my tongue removed under LOCAL anaesthetic was VERY frightening. I had no GP or Community follow up at all. It was very difficult to get through to hospital support. The most help I received was from my wonderful local chemist and by phoning [service name] on their general number. I had 2 [service name] nurse contacts but could never reach either by phone and emails took at least 2 days to be answered. I was supposed to have speech therapy immediately but that took weeks for me to organise myself. Once I made direct contact with the [service] department things moved quickly and I had excellent support from their Admin staff who could not have been more helpful and supportive. All this could have been MUCH better organised and relevant information could have directed me in the right direction. It was VERY unnerving to be

discharged immediately without feeling there was local, competent support I could access easily."

"The discharge procedure was awful was told my next chemo session would be in either 2 or 4 weeks and I would be notified. I queried this a couple of days after being discharged with my SN & was actually meant to start it the following day but had slipped through the net. Sent home with only 1 of the 6 lots of drugs I needed."

"When I was discharged after 1 month I was fitted with a catheter without really being given any instruction, as a result after 2 days I was admitted into [location] hospital with a serious urine infection."

"I was also discharged with no painkillers following a mucousectomy, thus causing extreme pain for the next week."

"On discharge from the hospital I still had in place a chest drain. I was told if I had any issues to go to the GP or A&E dept at my local hospital. I did have some issues and found it difficult to get treatment via the district nurses. It would have been better if I could have contacted by phone or in person the nurses on the ward. I would have also felt more confident in their care than the district nurses who I did see eventually."

"Signing off and discharge needs better coordination between ward doctor /pharmacy and notice given to be made more accurately. One patient was made to vacate bed and taken to discharge lounge in nightwear and having to wait for about 4 hours before being able to leave the Hospital."

#### Aftercare

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

- 63.1% said their family or someone else close to them were given all the information they needed to help care for them at home (Q49).
- 23.4% of respondents said they had a review of cancer care by their GP practice (Q52).
- 80.6% of respondents said the right amount of information and support was offered to them between final treatment and the follow up appointment (Q54).

Across comments discussing a need for improvement to aftercare, patients describe expectations of a continuation of the intensive support they experienced while in treatment and/or hospital and how their experience fell short due to a lack of clarity on who was responsible for this part of their journey. Post-treatment and discharge from hospital, some patients described feeling that they 'disappeared' from the system with no one proactively communicating with them.

"I am also disappointed that my GP practice made no attempt to contact me after my discharge from hospital, or during and after my radiotherapy treatment. I had to make the contact myself and meet with the GP."

"Any contact has been by me contacting this cancer care nurses, as I did have pain issues and still have pain where lymph node were removed, I has more contact re patient care could have been made rather than me think no news is good news felt like once gone you are forgotten."

"Would have liked maybe tel call between discharge & next scan - intensity of proceedings has diminished, understandably, but could feel a bit abandoned."

"I had been diagnosed with incurable cancer the initial care was excellent but now one and a half years later I feel like I have been forgotten and my GP is too overloaded for me to see her."

There was also a perception from some patients that they had to take control of coordinating the care they needed post-treatment.

"Since my treatment, I was told for 12 months I would be seen by dermatology nurse every 3 months. My treatment was in [date], my first follow up appointment is in [date]! I had to ring the department myself, to sort out this appointment, which is 3 months late."

"When I finished my intensive treatment in [date], I was left for 3 months without any further appointments. I became anaemic in this time due to high dose of chemo medication I was on. On reflection I feel it was an error to have been left without blood being checked for 3 months. This knocked back my recovery by a couple of months."

"My final appointment has been put off for about 4+ months due to NHS cancelling it repeatedly -I had specific circumstances that required additional care and help, but never got any -I had to look into a lot of things myself for support - and wasn't really offered much."

There were a small number of patients who shared that they accessed private healthcare when their post-discharge needs were not met.

"Access to mental health services to deal with anxiety was hard and I ended up paying for this privately."

"Lack of access to physiotherapy ment I had to go privately to obtain confirmation I was doing the required exercises correctly."

## Theme: Hospital wide

Additional areas for improvement were raised that have the potential to impact a wide range of patients including but not limited to those receiving cancer care. As such they have been considered collectively to be 'hospital wide.'

#### Infrastructure and facilities

Most commonly mentioned were issues with the cleanliness of buildings, with other comments around broken machinery. The examples were varied though collectively highlighted how hospital infrastructure and facilities can impact on experiences of care.

"Cleaning was best described as a joke. Advice- bring back the hands on Matron who might be able to control standards."

"The only thing was the one toilet I had to go to each time of my four treatments over the year - which amounted to about 5 or 6 times each one was not clean. Urine on the seat no air freshner had to wipe it off with paper towels, need to be cleaned every hour."

"Cleanliness was quite poor. There was blood on the side of the sink for days, despite me raising it with staff. The floor was often dirty."

"The hygine on the word was poor. Towels and clothes often left on the floor limit follow day. Urine and stool ready for the we were often lift. The management on the whole needs improving."

"Less machine malfunctions, creating long delays on occasion."

"Some of the over night hospital rooms had no aircon and sometimes the day chemo ward had no air con. My chemo was in the middle of summer and it would be boiling. Making chemo very hard. Even hard to sleep at night."

#### **Travel**

Across a range of examples respondents highlighted how their experience could have been improved if travel had been minimised. This spanned locating care closer to home where possible and having treatment in one location as opposed to several.

"I had to travel to different hospitals for treatment. I would have benefitted from being able to have my treatment in full in [location]. I travelled to [location], [location], [location] and [location]."

"I would have preferred if the scans required could be done within close proximity to where I live or perhaps at my work place. I'm not a driver, has to commute back and forth which usually takes times and can be uncomfortable."

"All treatments / scans to be at same hospital as travelling to far Flung Hospitals causes worry & stress. (Will I get there on time & will I make afternoon appoint elsewhere)."

Other comments highlight the negative impact of parking issues, from difficulties in securing a space through to the cost.

"More parking spaces in the hospital car parks. I have to wait 10+ minutes."

"Parking and traffic jams is absolutely awful. Due to the traffic/parking situation going to hospital is even more a stressful experience."

"Easier car parking! I have approx 50 mile round trip, public transport is not feasible, and sometimes it was impossible to find a space in the hospital car park on a week day. "underground facility? Boost park and ride? We had to drive around the area outside the hospital to look for parking."

"The car park / appointments procedure needs sorting because trying to park adds to the anxiety of what is by definition a stressful visit. It lets an excellent hospital down."

Mixed experiences of hospital organised transport were also shared.

"Transport, listening to the patient saying not to be picked up 3 hours before appointment as we live so close! People who organise transport do not know distances from patients house to hospital, this should be organised from hospital being used."

"patient transport service was immensely helpful."

"The worst part of my treatment was when I had to travel to [location] hospital for radio/chemotherapy. The trip from home and back is about 3 hours and I had to use hospital transport. Although this worked well it was extremely tiring especially as I was feeling poorly. It would have been a much more bearable experience if the treatment could have been carried out at the [location]."

#### Food

Most of the feedback about food was negative, though how important this was to patients was observed to vary. What was consistent though was the focus on quality as the core issue, with commentary on how this did not align with supporting their recovery.

"I found the food in the hospital to be almost inedible."

"The food served on the ward was inedible and a complete waste of money for the NHS mostly being thrown away, a choice of packed sandwiches with some hot soup surly would have been received better by the majority of patients."

"Catering - ?? Very poor selection for me on a bland diey. Served luke warm gritty soup when the staff must have noticed how I was struggling to eat. Very poor and unfriendly staff. I didn't expect a fine dining experience but this was so poor especially when recovery and feeling weak."

For some, the concern around food was raised as a consequence of catering not considering patients' specific needs.

"How can [they] serve at lunch and diver [sic dinner] puddings, so sweet for a patient who's there for cancer treatment, plus can not swallow. (2) sometimes, the team will forget to get me the food, so I end up having a bowl of ice cream with mashed potatoes."

"I am vegetarian and it was never written on my board - so after my OP when I couldn't communicate properly- I had no food for a couple of days as I could not communicate this information and was on medicine that made me drowsy."

"Hospital ward trying to feed me banned food's."

"Better food! Especially for coeliacs/gluten free. I spent the equivalent of a third of a year staying overight in hospital and the food was so limited for me, sometimes to the point where there were no options + all I could have was a potato + beans - this was not going to get me better!"

#### Other

Below is bullet point list of other topics commented upon in the data (all areas for improvement) that were noted during the analysis process. There is a lack of volume of comments or depth and detail to inform themes and sub-themes, but suggestions are noteworthy.

- Desire to have the option of relatives/friends waiting for you while in treatment
- Desire for counselling for family
- Difficulties accessing enzyme treatment/medication from pharmacies
- Not eligible for specific drug treatment
- Lack of access to speech and language therapy
- No access to dietitian or nutrition information.
- Negative experience of noise in the ward during inpatient stay
- Lack of privacy during doctor consultation on ward round
- Negative experience being alone when told diagnosis
- Delight when staff member was able to communicate in patients chosen language (including BSL and Arabic)
- Positive experience on teenage and young adult unit
- Negative experience on children's ward as older teenager

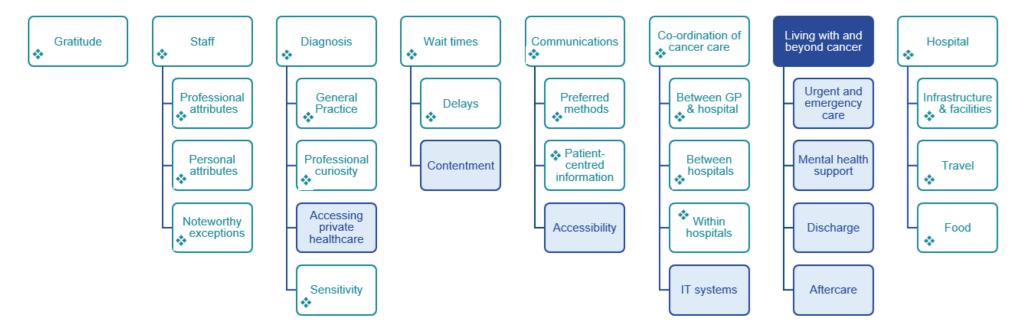
#### 5. Conclusions

This is the third national qualitative report for the NCPES, and it is anticipated there will be interest in what has changed since the previous publications. The open-ended question format in self-completion surveys means we don't know why respondents choose to include or leave out certain experiences. Their responses are shaped by personal priorities, interpretation of the questions, and external influences (e.g. publications, politics) - many of which we can't control or observe. Without knowing the full context behind each response, it's difficult to say whether differences in themes between 2023 and 2024 reflect real changes in care experiences or simply changes in what people decided to share.

In recognition of the challenge in tracking qualitative insight from a survey over time, a deductive approach to analysis was used in 2024. This involved applying a consistent framework to the data, allowing us to see patterns and connections between years. While much was alike in subject and tone, to reflect nuance found in 2024 the framework was adjusted and includes a 'new' theme and several 'new' sub-themes. To explain nuance, take for example the 2023 sub-theme of 'delight' which has strong parallels with the 2024 sub-theme 'contentment' – there is a subtle interesting change in the language used by patients to convey positive experiences which reflected as a change in language used for reporting. A visual summary is provided on the next page of what is consistent across 2023 and what is nuanced like this, and/or 'new.'

While tempting to lean on recurrence of insight to prioritise areas for change and improvement, the impact on patients is a very critical consideration to have in mind. To demonstrate, an example is the 2024 insight which has emerged within the 'sensitivity' subtheme around experience of finding out about their diagnosis of cancer through the/via the NHS app. The significant impact captured in verbatim is itself compelling as a case for change, irrespective that this is not a recurrent finding over time nor was it fed back by large proportions of the sampled respondents in 2024.

Where possible the impact of experience is detailed throughout the findings to support interpretation and assessment of greatest need/priority. The conclusion of the 2024 analysis echoes those of previous publications. Alongside impact that has been captured where possible, it is recommended to triangulate the insights shared in this report with other existing datasets that are relevant, and to consider new collections and/or engagement activities which would support an understanding of priorities for cancer patients. Ongoing listening and involvement are of course paramount to ensure any efforts nationally or locally will have the greatest gains to improve experiences of cancer care.



Insight evident in 2023

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# 6. Appendix: Sampling information

Table 1: Number of comments in analysed sample per characteristic for QA

Characteristic	Sub-group	Number of	% of comments	% of comments
		comments	analysed QA	overall QA
		analysed QA		
		analyses are		
	16-24	33	3.8%	0.2%
	25-34	37	4.2%	0.7%
	35-44	55	6.3%	2.5%
Age	45-54	76	8.6%	8.0%
	55-64	178	20.2%	20.6%
	65-74	239	27.2%	33.6%
	75-84	220	25.0%	29.4%
	85+	42	4.8%	4.9%
	White	634	72.0%	89.9%
	Asian	76	8.6%	2.5%
Ethnicity	Black	74	8.4%	1.6%
,	Mixed	30	3.4%	0.9%
	Other	30	3.4%	0.4%
	Not given	36	4.1%	4.8%
	1 (most deprived)	110	110	10.7%
D	2	164	164	16.4%
Deprivation level	3	182	182	21.9%
(IMD Quintile)	4	211	211	24.5%
	5 (least deprived)	183	183	25.9%
	Outside England	30	30	0.6%
	Female	450	51.1%	51.8%
Mhigh of the	Male	353	40.1%	44.4%
Which of the	Prefer not to say	31	3.5%	0.1%
following best	Prefer to self-			
describes you?	describe	10	1.1%	0.0%
	Non-binary	17	1.9%	0.0%
	Not given	19	2.2%	3.7%
	Breast	197	22.4%	22.5%
	Haematological	145	16.5%	14.4%
	Prostate	95	10.8%	11.9%
	Colorectal / LGT	72	8.2%	11.5%
Tumour group	Other	67	7.6%	9.1%
Tumour group	Urological	57	6.5%	7.1%
	Lung	44	5.0%	6.4%
	Gynecological	44	5.0%	4.7%
	Upper gastro	32	3.6%	4.4%
	Skin	37	4.2%	4.2%

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	Head and neck	31	3.5%	2.6%
	Sarcoma	30	3.4%	0.8%
	Brain/ CNS	30	3.4%	0.3%
Sexual orientation	Heterosexual or	734	83.4%	92.7%
	Other	8	0.9%	0.2%
	Gay or Lesbian	30	3.4%	0.9%
	Bisexual	30	3.4%	0.3%
	Prefer not to say	43	4.9%	1.1%
	Don't know / not	4	0.5%	0.2%
	sure			
	Not given	734	83.4%	4.6%

Table 2: Number of comments in analysed sample per characteristic for QB

Characteristic	Sub-group	Number of	% of comments	% of comments
		comments	analysed QB	overall QB
		analysed QB		
	16-24	35	3.9%	0.2%
	25-34	32	3.5%	0.9%
	35-44	49	5.4%	3.2%
Λαο	45-54	105	11.6%	9.5%
Age	55-64	200	22.2%	22.6%
	65-74	249	27.6%	33.8%
	75-84	197	21.8%	26.1%
	85+	35	3.9%	3.8%
	White	644	71.4%	90.0%
	Asian	80	8.9%	2.6%
Cthoicity	Black	74	8.2%	1.7%
Ethnicity	Mixed	32	3.5%	1.0%
	Other	33	3.7%	0.4%
	Not given	39	4.3%	4.4%
	1 (most deprived)	126	14.0%	10.1%
	2	137	15.2%	16.1%
Deprivation level	3	184	20.4%	22.0%
(IMD Quintile)	4	207	22.9%	24.8%
	5 (least deprived)	218	24.2%	26.5%
	Outside England	30	3.3%	0.6%
	Female	440	48.8%	52.5%
M/biob of the	Male	386	42.8%	44.0%
Which of the following best describes you?	Prefer not to say	27	3.0%	0.1%
	Prefer to self- describe	10	1.1%	0.0%
	Non-binary	15	1.7%	0.0%

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	Not given	24	2.7%	3.3%
	Breast	193	21.4%	23.2%
	Haematological	148	16.4%	13.6%
	Prostate	95	10.5%	12.2%
	Colorectal / LGT	85	9.4%	11.3%
	Other	68	7.5%	9.5%
	Urological	56	6.2%	7.2%
Tumour group	Lung	43	4.8%	6.0%
	Gynecological	33	3.7%	4.9%
	Upper gastro	40	4.4%	4.4%
	Skin	44	4.9%	3.9%
	Head and neck	35	3.9%	2.7%
	Sarcoma	32	3.5%	0.9%
	Brain/ CNS	30	3.3%	0.4%
Sexual orientation	Heterosexual or Straight	744	82.5%	92.7%
	Other	11	1.2%	0.2%
	Gay or Lesbian	31	3.4%	1.1%
	Bisexual	32	3.5%	0.4%
	Prefer not to say	42	4.7%	1.3%
	Don't know / not sure	5	0.6%	0.2%
	Not given	37	4.1%	4.0%

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