NHS England

National Cancer Patient Experience Survey 2023: National Qualitative Report

Contents

1. Introduction and methodology

The National Cancer Patient Experience Survey 2023 was the thirteenth 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 www.longtermplan.nhs.uk/online-version/.

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 2023 survey involved 132 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 2023.

Fieldwork

The fieldwork for the survey took place between November 2023 and February 2024.

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 121,121 people, 63,438 people responded to the survey, yielding a response rate of 52%. 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.

47,374 written responses were collected in total, meaning 75% of the survey sample provided qualitative data in 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 2,745 comments were removed in this way, leaving 44,629 comments for the sample to be drawn from. For QB 16,660 comments were removed in this way, leaving 30,714 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 only 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 3,137 responses were analysed, including 1,651 for QA and 1,486 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 for the geographical area of respondent postcode, 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 50 comments were included on other characteristics including tumour group and sexuality. 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 3,137 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. Please note that the data is not edited 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:

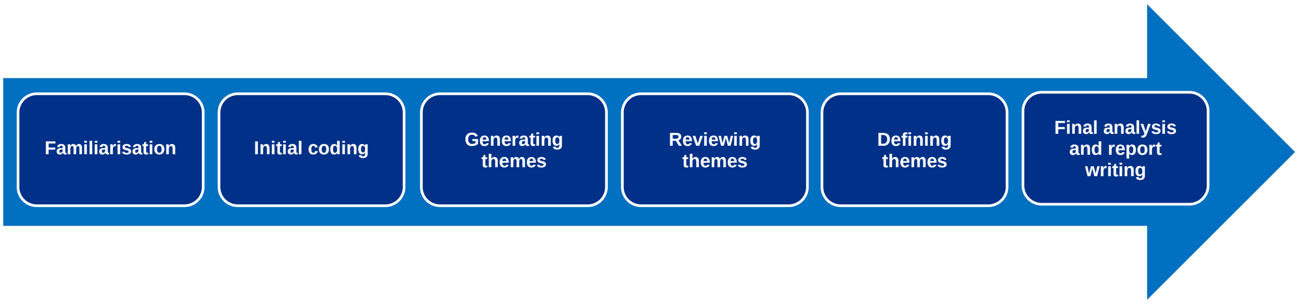
- Names of patients or staff replaced with “(name)”
- Names of wards, units or hospitals replaced with “(location name)”
- Names of specific services replaced with “(service name)”
- Specific dates replaced with “(date)”

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.

To analyse qualitative data, the standard six steps of thematic analysis were used to identify patterns of meaning within the data and explore commonality and contrast – see Figure 1.

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 or positive experience evidenced in the survey data, the thematic findings offer an opportunity to understand why there was not 100% agreement or 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

Positive experiences of care are notably richer in detail than previously found in the 2021 publication of qualitative analysis for this survey. This could in part be explained by the change in the questionnaire design whereby QA asks specifically for positive feedback. It is also useful context that while QA and QB are very distinct in design, responses sometimes overlap. Slightly more than one in ten respondents 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 five answered QB about what could be better by stating all positives or stating they had no negatives to report.

It should also be noted that while the questionnaire invited patients to consider their last 12 months of treatment and care, many included details about their first interaction with a healthcare practitioner including pre-diagnosis interactions and subsequent dealings, from which it was inferred that this extended beyond the suggested 12-month timeline.

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. Patients described their care as 'good' and 'excellent' and while this could be broad and non-specific, for some they highlighted individuals and teams explicitly.

Staff

Staff were central to experience, with positive commentary including praise of professional and personal attributes such as efficiency and kindness. There were noteworthy exceptions also shared which further demonstrates the important role of staff in experiences of care.

Diagnosis

Enablers and barriers to diagnosis were shared, with experiences at General Practice and A&E. Some called for professional curiosity and greater sensitivity, with timeliness and clarity of delivering diagnosis also important.

Wait times

Feedback about wait times was very mixed. There were experiences of delays and lengthy waits shared in a range of contexts while others expressed delight with the speed at which they had been treated and cared for.

Communications

There was variation in experiences around both the methods of communication as well as what was found optimal in the levels of information shared. Feedback spanned diagnosis through to post-treatment and discharge.

Co-ordination of 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, between hospitals, and spanned diagnosis through to discharge and beyond.

Hospital wide

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

4. Thematic analysis findings

Key themes

Seven key themes were identified from the thematic analysis, listed below. Within each key theme are several sub-themes which support with interpretation and use of the insights. There are 21 sub-themes in total.

- Gratitude
- Staff
- Diagnosis
- Wait times
- Communications
- Co-ordination of care
- Hospital wide

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 8.89. For respondents who answered QA and/or QB, their overall experience score was 8.90.

A prevalent theme was overall gratitude, seen in response to either or both open ended questions. This included expressions of satisfaction with experience and articulations of care as ‘good’ or ‘excellent’.

> *“I could not have been treated any better. It was a very scary time but the staff put me at my ease; and I thank them for it, and so do my family.”*
>
> *“For me the experience of hospital stay and operation was amazing the staff looked after me was 1st class. You all work so hard to make me feel at ease, well done to all the staff who were so professional just like a well-oiled machine. All I can say is, A big thank - you to you all.”*

> *"I have had excellent care and attention !!!"*
>
> *"I received excellent care and attention throughout, and could not complain about treatment received at (location name) or at my doctors in (location name)."*
>
> *"From the outset, my treatment and care by (location name) has been handled with great professionalism and real concern for my welfare, both during hospital treatment and at home. I have only the greatest respect for the whole organisation and personal attention received from all the different teams that managed my treatment."*
>
> *"I can't fault the care, support and treatment I have received since being diagnosed in April this year. I am a very lucky patient to be cared for in the NHS."*
>
> *"I'm receiving first class care."*

Often statements expressing thanks referenced specific hospitals, teams or individual members of staff. This highlighted how valued staff and whole services were.

> *"Great treatment from (location name) and (location name) treatment centre from all staff. Thank you"*
>
> *"I'm thankful for all support I received from team care, especially (name) centre (location name)."*
>
> *"(location name) - Oncology Department specially Breast Care Unit is exceptional. I was very well treated. Thank you!"*
>
> *"The oncology team were absolutely amazing and I can't really put it in any other words. Day or night, they were consistently brilliant, Shout out to (name) oncology nurse + (name) oncology nurse."*

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

> *"I cannot praise the NHS highly enough - the care support and help were second to none. I feel extremely fortunate to be given such quick, effective care from the administration team to the consultant and everyone who dealt with me were truly wonderful - I can't speak highly enough of all of them - thank you so very much."*
>
> *"How couldn't we find, not being positive about these modern times we live in. God bless the NHS and thank you for everything you've done for us."*
>
> *"Appreciated for good care from NHS staff during my cancer care experience. They are very professional and considerate to cancer treatment."*

Gratitude expressed in responses to QB which asks what could have been better about care, were shared either without further feedback on areas for improvement or were shared alongside a perception of the NHS and its staff succeeding in challenging times.

> *"A sincere and heartfelt thank you to all staff from me and my family. What is a traumatic experience was made bearable by the conduct and professionalism of all the technicians, carers and reception staff, despite the conditions imposed by the current administration. Our thanks to you all."*

> *"I was amazed to find all of my appointments/follow-ups/treatment/results happened in these tight time frames. Amazing job in challenging circumstances."*
>
> *"Overall, a massive THANK YOU TO NHS! I have been given extra time."*
>
> *"Could not be bettered. Thank you, N.H.S. Top Class."*

Theme: Staff

What does the quantitative data tell us?

- 75.8% said they definitely got the right level of support from hospital staff for their overall health and wellbeing (Q28).
- 77.4% said they had confidence and trust in all of the team looking after them during their stay in hospital (Q31).
- 72.8% said they could always get help from ward staff when they needed it (Q34).
- 64.8% 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, 84.1% said this was always the case (Q36).
- 87.4% felt that they were always treated with respect and dignity while they were in the hospital (Q37).
- Most respondents (89.9%) felt the whole care team worked well together to provide the best possible care for them (Q56).

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.

It should be noted that occasionally comments showed there was not always a clear understanding of the role of individual staff in their care. At times some professions were spoken of interchangeably.

Professional attributes

Being treated and cared for was described in many ways which referenced professional attributes such as skills, knowledge, competency, efficiency, and responsiveness of staff. In terms of impacts this was positively experienced as reassuring, achieving good or better outcomes as a result, as well as being treated with dignity and respect.

Of note, skills, knowledge, and competence were mainly, though not exclusively, mentioned in relation to consultants, surgeons and their teams.

> *“The consultants all knew what treatment I needed.”*
>
> *“I saw more than one consultant. They were all very competent and helpful.”*
>
> *“My surgeon was very nice and explained everything to me about what was going to happen and she made a scar look very neat and tidy and I was very pleased.”*
>
> *“Staff had a great deal of skill and knowledge most things were explained to me staff were understanding.”*
>
> *“Every healthcare professional I have encountered at both hospitals has been unfailingly kind, professional, caring and highly competent.”*
>
> *“I would like to compliment my surgeon Dr (name), his surgery was brilliant as I was complicated and his bedside manner is very good.”*
>
> *“I was very impressed with my very professional and compassionate surgeon, who spent time with me explaining and answering any questions. I had the greatest of confidence in her. I requested [them] for my second surgical intervention.”*
>
> *“The care I received from consultants before surgery was really good Dr (name) Mr (name).”*
>
> *“Generally speaking my care was very efficient from a rash of diagnostic scans to on-going treatment paths.”*

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

> *“I found all the staff to be outstanding, caring and professional. In my opinion I could not have had better treatment anywhere else. I can only sing the praises of every member of staff at all the hospitals I attended during my treatment. Keep up the excellent work NHS staff.”*
>
> *“I found my treatment from start to finish has been very good. I was pleased with the care I received at all times. All staff were friendly and professional.”*
>
> *“The care on the ward following surgery was excellent and the student nurses were so very capable and professional.”*
>
> *“All the medical & administrative staff were very professional, understanding and helpful. They went out of their way to help me and my husband.”*
>
> *“From the first diagnosis through the scans and the final operation to remove my prostate cancer. I consider I was very professionally and diligently cared for, and cannot praise the surgeon, doctors and nurses enough.”*

Being treated with respect and dignity was often spoken of alongside professionalism. Note that being treated with respect and dignity meant commonly for the patient that they were seen in the round as an individual and not as a number in a system.

> *"Staff were very professional in their care of duty. Treated me with respect and dignity."*
>
> *"The teams have been very professional and treated me as an individual and not a disease."*
>
> *"My experience was very positive I was treated with great care, respect and dignity from the consultant to the care workers on the ward I could find no fault."*
>
> *"From the first appointment it felt very calm & welcoming on the unit. All the staff were calm & friendly & approachable, knowledgeable & understanding. I was a very nervous patient when it comes to needles, but the staff were great with me & allowed my partner there at every stage to support me."*
>
> *"I'm a chronic claustrophobic. The radiotherapy team were outstanding and helped me get to a paint where I could deal with the treatment with no chemical assistance! Brilliant."*
>
> *"Every appointment with the surgeon & Breast care Nurses. They have provided Holistic care for me, explained everything well, offered me choices, listened to me and generally cared about me."*
>
> *"I am always treated with respect + care, and everything is explained very clearly. I always have 1st class care and always feel cared for. From my consultants to nursing staff in outpatients and during my inpatient stays to the cleaners, catering staff, porters theatre staff + recovery staff. Thank you."*

In terms of further impact of professional attributes, expertise of staff equated to a reassured patient in a lot of cases.

> *"From my diagnosis on (name) filled me with confidence that everything possible was being done for my benefit. His smooth handover to (name) and the team at the (location name) was exemplary; the specialist nurse support from (name) and (name) was exemplary and they were always available to give advice and support."*
>
> *"There is a high level of consultant expertise in all areas, and testing has been extremely thorough, which although caused delays in treatment has been reassuring that investigations have been thorough."*
>
> *"Everyone was very helpful and professional and had read up on my notes so there was no need for me to have to repeat my story. I felt this gave me confidence in them."*

In a context where things had gone wrong, feedback about professional attributes of staff spoke of quick and efficient action being taken which led to a positive outcome.

> *"Whenever I had a medical issue as a result of my cancer treatment, Triage staff would not take any chances and told me to come in straight away. I feel that this is the best way to be."*
>
> *"My consultant (name) & Lung Care Specialist Nurse (name) and her team have always been very supportive with nothing being too much trouble. And any problems being dealt with*

> *quickly + efficiently. I have always found reception and admin staff on the oncology unit friendly, efficient and always ready to go the extra mile."*

> *"Fast [first] year of showing no growth. 2nd year was noticed it had started to grow. Hospital acted quickly…Appreciated (location name) quick response. Had no signs felt healthy."*

> *"I had a reaction to the immunotherapy on one occasion, I had phenomenal pains in the kidney area, (name)/the male nurse) injected something into the canula and almost instantly the pains ceased."*

Personal attributes

Many comments about staff referred to their personal qualities and characteristics that were found to serve them well in caring for patients to a high standard and sometimes beyond expectations. Distinct from professional attributes, those which are personal spoke more often to emotional care and the high value placed on this. Notably, the most-used descriptor in the feedback about personal attributes of staff was the word 'care' as opposed to 'treatment'.

> *"Everyone involved in my care has been really nice, from consultants to surgeons to nursing staff."*

> *"My consultant is very helpful and understanding. Really like the way my care is handled. With regards to the staff nurse in the day unit, they're all lovely."*

> *"The staff were brilliant from start to finish I had the best care and staff were informative very helpful and always polite helpful and smiling the care, relieved was 100% perfect."*

It is noteworthy that descriptions of care linked to personal attributes were made largely, though not exclusively, in relation to nurses. Being 'warm' was a key example of this though other descriptions such as being 'reassuring' and 'kind' were personal attributes valued across a range of staff groups. Being cared for with empathy and sensitivity were also impactful on patients.

> *"Going through chemo is not easy but the nurses always made me laugh and smile. This is definitely something that helps you get though treatment. I am very thankful I had such amazing nurses around me who took very good care of me."*

> *"The Nurses on the Day Unit are always warm and welcoming."*

> *"The nurses were excellent without exception."*

> *"All nursing staff very reassuring and competent."*

> *"My initial contact with (location name) nurses was warm, positive and reassuring."*

> *"The care given by the nurses and HCA's, in the (location name) was absolutely the best, during treatment and appointments. I'd also like to complement the volunteers that were on*

> *duty during all my treatments - they were warm, welcoming and helped to make sure we were all compatable."*
>
> *"The Nurses on the Day Unit are always warm and welcoming."*
>
> *"The oncology nurses at both departments who have been kindness itself i have been treated so kindly and nothing was /is too much trouble."*
>
> *"The nurses became my friends when I needed them to be and treat me amazingly. They made me feel comfortable. My oncology doctor (name) also did amazing work to save my life; she fought for what I wanted and needed but also sympathise with me."*
>
> *"I have been treated w/ warm and empathy by the dedicated staff. Their ability to provide comfort and reassurance during what was undoubtedly been a challenging time for me was fully remarkable."*
>
> *"Everything was positive about the care at (location name) - from the 1st clinic visit, to the surgery, and now the continuing aftercare. Every step was provided with professionalism, empathy and in a timely manner. All of the staff went over and above what we expected at each visit. They are to be congratulated in these difficult times for the NHS."*
>
> *"Oncologists at (location name) have explained to me about my treatment with consideration and empathy. The nursing staff follow this upbeat approach and help to make you feel important throughout all procedures undertaken."*

For a small number of patients there were strong connections described with staff. Note a quotation above articulates a friendship was formed with nurses as an example. In a similar vein, feeling ‘special’ and ‘important’ was the result of observing the actions of staff to have exceeded expectations in going ‘above and beyond’.

> *"Each consultant Dr or nurse were marvellous in their manner and information given was really impressed and thankful for this. You really felt you were the only one that mattered. Just brilliant. Cannot fault any part of this journey."*
>
> *"Very gentle delivery of treatment throughout. It has been a beautiful social encounter throughout the course of treatment. Communication and interpersonal relationship -Excellent."*
>
> *"Excellent care & treatment most important I was made to feel important nothing too much bother for anyone from the top/down."*
>
> *"The positive experience of my cancer journey is quite exceptional because the staff, nurses, doctors and everyone involved cared for me above and beyond the duties."*
>
> *"The care over getting me food I could eat was very touching - the main cook even went specially to a supermarket after her shift. The reiki whilst on the ward was fantastic. Some of the care from one particular nurse was so amazing it will remain with me for life."*
>
> *"Excellent care from a very knowledgeable oncologist (location name) & amazing care from 2 nurses (name) + (name) at (location name) Unit who bend over backwards + go out of their way to support you in treatment + make sure you are getting the best possible care + outcomes."*

While less common, honesty was highlighted as important and valued in interactions with staff as well.

> *“I appreciate the time taken to answer my questions and the honesty when an answer could not be provided with any certainty.”*
>
> *“All questions/ queries I had were always answered openly & honestly.”*
>
> *“The nurse specialists are very knowledgeable about the type of cancer I have and answer any questions honestly.”*
>
> *“Their dedication was obvious for all to see, they were always positive and cheerful, whilst always being honest when the news was not as favourable as had been hoped for.”*

Similarly, humour was part of creating a positive experience for a smaller number of patients.

> *“There is a collegiate approach at the hospital amongst staff, a wonderful sense of humour and determination to provide the best care.”*
>
> *“They, doctors & nurses were very good, took really good care, had a great sense of humour making me feel comfortable during my stay.”*
>
> *“Supportive staff, caring, helpful and equipped with sense of humour.”*

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.

Two interesting patterns were observed in these comments; 1) experience could be improved through staff training in what are perceived to be simple procedures to minimise pain for patients; 2) these experiences most commonly took place at night and/or were involving trainee or junior staff.

> *“Most Dr's/nurses could not take a blood sample due to collapsed veins colleague from Phlebotomy department managed without causing one too much pain. On one particular day 7 [seven] different people prodded me black and blue to get blood. Need trained staff to do this for patients Who have had chemo.”*
>
> *“One or two nurses couldn't get needles into me causing dreadful bruising.”*
>
> *“When I got my biopsy done, this was a very scary and painful experience. Unfortunately I also think I had a trainee nurse or doctor who performed this and the supervising doctor had to re-inject into my neck and extract the 4 times. This was painful and challenging experience that made me upset and emotional.”*
>
> *“I have a portacath so I don't need to be cannulated for chemo however no one else is trained to use it. Everyone doing scans should be trained so I don't need my veins accessing, and*

> *people in (location name) should be able to take bloods from it so I don't have to go to (location name) just for blood tests."*
>
> *"Night staff capability varied greatly, didn't feel safe. E.g. bank nurse, couldn't insert drip and had to call upon junior doctor to facilitate, she seemed very unsure and didn't give confidence of being in safe hands."*
>
> *"During unexpected overnight visit, several student nurses were given the opportunity to cannulate. However, after the first failed quite horrendously and put me in a great deal of pain as a result, I think the Senior nurse should have stepped in to complete this. Instead, 2 other students were allowed to practice on me, both failing. I was crying and begging them to stop practicing on me before a senior nurse stepped [in]."*
>
> *"Too few night nurse didn't seem to know how to change a drip very scary I told her how to do it no confidence in night staff."*

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.

> *"Basic care was haphazard due mainly to severe shortage of staff, both nursing staff & health care assistants. I was on the ward for a week and so witnessed at first hand the dire state of the nhs."*
>
> *"The department has one specialist nurse who was my main point of contact but they have been signed off sick and have not been replaced. I have been advised to go through my consultant's medical secretary instead but the nurse was able to provide a different level of emotional support."*

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 for earlier diagnosis or treatment were missed or ignored.

General Practice

What does the quantitative data tell us?

- 78.3% of those who had contacted their GP practice said they only spoke to a healthcare professional once or twice before their cancer diagnosis (Q02).
- 66.6% 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 referred quickly to the local trust or hospital.

> *“From starting at G.P. to having surgery my treatment was completed within 8 weeks which I find to be excellent care.”*
>
> *“Frankly from the early referral from the (location name) practice, through the administration, the nursing care and the consultation with specialists the whole treatment cycle has been quite brilliant.”*
>
> *“From the time I found a breast lump and filled out an e-consult, I was seen at my GP practice within 1 week. I was referred on… seen at 2 weeks. I had 7 scans & 5 biopsies and x 3 WLE's. The support I have had from start to finish has been brilliant.”*

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.

> *“When I first had serious pain in my right back, my wife rang our GP for an appointment... She was told, quite bluntly, no appointments available for at least 10 days +++. But if she was concerned. Take 'him' to A&E. This is what my wife did and so began the process. No thanks to our GP.”*
>
> *“Cannot find any fault with the care I have been given during cancer treatment, but the lead up to being diagnosed via G.P. not seeing one face to face not following up with tests, results being lost in system referred to other specialists and me having to chase up results of test's. Which could have lead to earlier diagnosis.”*
>
> *“When I first addressed my concerns with my GP I was advised to take a photo and send it through, after speaking with the GP on two occasions I informed I wanted it looked at rather than just photos being sent. I feel that I had to push to be seen.”*
>
> *“If GP had responded to my a Consult questionnaires sooner and taken my symptoms seriously and acted upon them. It took 3 attempts on my part over the course of a year before a GP contacted me by phone and hearing about my symptoms, brought me in for a face- to-face consultation.”*

Not feeling listened to by a GP was a further barrier to timely diagnosis, which ultimately meant a worse outcome for patients. The role of the GP was described as a ‘gatekeeper’ to further treatment positioning them as responsible for delays and poorer outcomes as such.

> *“The problem was with the treatment of the GP practice. I was in pain for more than five weeks while I was given unnecessary treatment. It would have been better if I was referred/treated immediately. The delay from the GP led to the growth and spread of the cancer. I was given pain killers for five weeks while I was trailing from day to day.”*
>
> *“My GP weren't good they were too slow to refer me for more testing. Just kept assuming I had water infections and giving me antibiotics. It took about 3 visits to GP and a few weeks of tablets before I was referred to hospital too long.”*
>
> *“The GP could have gave me an MRI way earlier. I said I think I have a brain tumour and really bad headaches I couldn’t get out of bed and I was told it was anxiety. Despite me*

> *saying multiple times the pain I had. When they finally booked my MRI and I got a date I had already had 3 brain surgeries and told I had cancer and been in hospital for 34 days."*
>
> *"It was so frustrating seeing different GPs who all suggested Omeprazole etc and ignored me by saying it was anxiety! ????"*
>
> *"I had been going to my gp for at least 18 months with this ongoing problem before my diagnosis. I was finally referred to see a specialist. I received an appointment to see this specialist sixteen months later. Within this time my condition got much worse and I was put on a 2ww cancer pathway where I was diagnosed with stage 3 cancer."*

Concerns raised also included GPs being slow to identify problems or even misdiagnosis causing delays to access of the right care.

> *"I should have been referred for cancer treatment 12 months earlier. How could this happen. Do GPs not know this."*
>
> *"My initial GP (who has been struck off) ignored my rising PSA results and told me we would just keep checking on it every 6 months. I, also have concerns over my GP's practice awareness of my hospital history with my cancer."*
>
> *"Unfortunately, when I started to feel the symptoms in (date), I consulted (name). In these two years, I had many symptoms and lost 8 kilos of weight, and the treatments I received were not enough. After these two years, I had to complain and change to another Doctor. The second Doctor, (name), a general practitioner, immediately made the correct diagnosis in a single appointment and, ordered several tests and found I had cancer."*

Accident & Emergency

For some positive experiences of diagnosis were in the context of a hospital visit, often at A&E, at which point something serious was identified and treatment quickly followed.

> *"I went to Hospital with stomach pain and ended up having surgery next morning. It was found I had a mass on my colon. My experience with the care I received was very good and made me feel very confident that I was being given the best care."*
>
> *"I have had very good care from the beginning of my cancer treatment I was actually diagnosed in (country) on holiday (date) and on returning from (country) I needed A&E treatment and from that it has been completely faultless for me, from being admitted and treatment commenced shortly after that."*
>
> *"I was diagnosed with lung cancer when I attended A+E at (location name) after coughing up blood. I was seen by a young junior house doctor who promptly ordered a chest x-ray and after spotting an anomaly instigated further investigations and referral to the specialist team. I would like to say a huge thank you to all the teams involved in my investigation and treatment."*

Professional curiosity

Patients commented that across a range of healthcare practitioners, sometimes specified though often not, greater curiosity about their symptoms could have been shown 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.

> *“I think that they could have done more when there was something in my lungs. Could have been investigated earlier before it got to the terminal stage.”*
>
> *“I told the consultant the last 2 weeks I have had difficulty in breathing when I pushed a wheelbarrow or carried something this was back in (date) and he said it maybe I am over working: what rubbish he still sent me down for my chemotherapy 2 days later.”*
>
> *“A year prior to my diagnosis I was an inpatient at (location name) and my bloods which led to my diagnosis were abnormal but not acted upon by the consultant. This delayed my diagnosis and treatment.”*
>
> *“The problem was with the treatment of the GP practice. I was in pain for more than five weeks while I was given unnecessary treatment. It would have been better if I was referred/treated immediately. The delay from the GP led to the growth and spread of the cancer. I was given pain killers for five weeks while I was trailing from day to day.”*
>
> *“My GP Practice midwife did not take my concerns seriously enough. They dismissed it as part of pregnancy, as I was pregnant at that time. Only when I was admitted to the A&E did they take me serious and soon after started treatment for a stage 4! cancer (if identified earlier I would probably not had stage 4).”*

Sensitivity

What does the quantitative data tell us?

- When asked how they felt about the way they were told they had cancer, 74.4% said they were definitely told sensitively (Q13).
- 85.5% 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 which emphasised the need for sensitivity and consideration. Further, some comments indicated that information about diagnosis being shared by telephone was not seen as appropriate.

> *“I was told I may have blood cancer, over the phone while I was at work with all of my colleagues around me. This was upsetting for me and my wife who was also working when I told her. I felt like there wasn't any sensitivity from the GP who called.”*
>
> *“Don't tell patients over the telephone that they have cancer.”*

> *“Some phone calls have been highly triggering for me. Most recent being that my MRI showed I had a change in my lungs and needed a further CT scan. The nurse who handed this over clearly had little experience of talking to someone who had had cancer.”*
>
> *“I received a phone call from my GP. It was a bit of a shock. I had no symptoms.”*
>
> *“I was given my official diagnosis over the phone without any warning when I was sat on the bus going into town.”*

Respondents also identified opportunities for improvements when diagnosis was imparted in person. This includes a need for sensitivity, empathy and professionalism as the negative impact of less careful delivery can create lasting negative impacts on patients.

> *“I was first told I had cancer is (location name) Hospital before they referred me to (location name). The doctor sat sideways on to me, staring at her computer screen, and just said 'Oh yes, that's ovarian cancer', without even looking at me ! I was devastated.”*
>
> *“Initial diagnosis results were dealt with poorly. 'You have terminal cancer, you'll be dead in 6-9 months, go home & put your affairs in order' was my abuse! Still here 4 years later & believe that this is the worst conversation I've ever had with a doctor.”*
>
> *“I was told very bluntly in A&E initially - Shock and desperation were unimaginable to me... I had no idea I had stage 4 breast and bone cancer. I shall have nightmares.”*

Being alone

What does the quantitative data tell us?

- 80.9% of respondents said that when they were first told that they had cancer, they had been given the option of having a family member, carer or friend with them (Q12).

Issues were also seen when patients were alone (or could have been) when given their diagnosis and this was not what they wanted. Care is needed here though, as once told that patients should have someone with them for an appointment, it almost always will signal that something serious is amiss.

> *“You must make sure that family members are in attendance when informing someone that they have cancer.”*
>
> *“The doctor who gave me the result said something like - 'you know we are dealing with cancer here?' I didn't know and it was a massive shock. Luckily my partner was with me. I wasn't told to take anyone.”*
>
> *“I felt like I was hit by a bus, and angry at the previous consultant telling me it was all ok, I would have taken someone with me had I known it was serious.”*

Timeliness & clarity

What does the quantitative data tell us?

- Of respondents who had tests that helped to diagnose their cancer, 92.4% said they received all the information needed about the diagnostic test in advance (Q05).
- 83.4% said that diagnostic test staff they saw appeared to completely have all the information they needed about them (Q06).
- 78.5% of respondents said that the diagnostic tests results were explained in a way they could completely understand (Q08).
- 76.7% said their cancer diagnosis was explained in a way they could completely understand (Q14).
- 84.0% said they were told they could go back for more information about their diagnosis after they had time to reflect on what it meant (Q16).

When the diagnosis has been made this needs to be communicated in a timely and transparent manner to the patient. Comments highlight the importance of making no assumptions about what patients already know (including when attending for tests or treatment) to reduce anxiety and shock that a cancer diagnosis can create.

> *“There was we communication following the initial scan - so when I was called for a colonoscopy I had no idea that it was for further investigation. I thought it was just a face to face consultation. There was no warning that the first scan had shown a possible problem - so a bit of a shock.”*
>
> *“My only slight problem was that during my various tests I was sent results on MFT App. one of those mentioned an ovarian mass, This was before I was told this by my Consultant. It was a bit of a shock but not unexpected.”*
>
> *“The team at (location name) did not explain that I had cancer instead they said there was something wrong with my blood after I attended accident and emergency 3 time with stomach problems they then took me in an ambulance to (location name) and here I was wheeled on a trolly to the (name) ward my heart sank.”*
>
> *“I was told at me pre op assessment that I had cancer as I asked what the operation was for. The nurse assumed I had already been told and said it was to remove a tumour.”*
>
> *“Strange though it may seem- I cannot recall being told " you have prostate cancer. I do recall being told "you have acute retention and a psa reading of something in excess of 100 ".”*

Theme: Wait times

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, 77.6% felt the length of time was about right (Q07).
- 78.5% felt the length of waiting time at the clinic or day unit for cancer treatment was about right (Q43).

There was a real mix of feedback about wait times overall. While some respondents articulated struggles with delays there were examples too of patients feeling delighted with the speed at which they had been treated and cared for.

Delays

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

- Diagnosis
- Scans
- Results
- Referrals
- Surgery
- Chemotherapy
- Appointments
- Medication

The language used by respondents describing these experiences of waiting and delays is useful to reflect upon as to how strongly patients felt and were impacted:

> *“The length of time to wait for scans and results is appalling, I waited 7 wks for the results of my last CT. I am also currently awaiting referral to another specialist which (unless there is a cancellation) will be 10 months from referral till appointment date. Cancer patients already have so much to deal with and this only makes things worse.”*
>
> *“From Biopsy to wait over 6 weeks and needing to follow up and push your a response was not Satisfactory.”*
>
> *“Very long waits - 3x longer than nice guidelines - For test results, surgery, and chemo start date. Also up to 3.5 hrs wait to see the doctor.”*
>
> *“The amount of scans were too far apart. I would get the result of one only to be sent for a different one two weeks later.”*

> *"I often had to wait a considerable time after my appointed time to go in for my chemotherapy."*
>
> *"Surgery wait was 7- 8hrs in a cold waiting room we were provided with thick socks and blankets and sips of water."*
>
> *"Maybe in the chemo' unit things could be better, you can sit for over 1 hour in the waiting room after your appt time, sometimes longer, then they call you in and you can sit in the treatment room for another half an hour sometimes longer before they treat you."*

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 clearly considered to be systemic issues that impact negatively not only on patients but on staff too.

> *"Waiting times to be treated could be a lot better, if there was more staff to cope. Currently I believe that the existing number of staff are pushed far to hard with the amount of patients. More staff would mean less waiting times, less stress for existing staff and a better working environment all round."*
>
> *"At times, staff shortages appear to put staff under significant pressure and lengthen waiting times."*

Long waits for pharmacy to prepare medication was also raised as an issue by respondents. In some instances, this was believed to have caused delays to treatment.

> *"(location name) pharmacy not very good waiting time rubbish."*
>
> *"Long wait when collecting medication when date + time had been arranged.*
> *Chemo drugs being available on time instead of being supplied with 3 weeks worth for a 6 week cycle and chasing them a week ahead if time and it coming down to the wire 10 minutes before I needed them before the next radiotherapy session."*
>
> *"There were times that there could be 2 hr waiting before treatment starts at the explanations were that the drugs had not been dispensed yet as the doctor led not prescribed them or the nurses are running behind. Generally, I think time keeping for treatment could be improved and doctors need to send prescription in time so medication can be dispensed promptly."*
>
> *"Having to collect meds for (location name) is ridiculous. Why can't they be dispensed to a local pharmacy?"*
>
> *"Better coordination between pharmacy and chemo day unit to reduce long waits and wasted trips when medication wasn't ready."*

Delight

In contrast to the experiences so far described in this theme, there were also patients that expressed strong feelings of delight at how quickly they had been seen, treated and cared for following their diagnosis. Descriptions of how 'amazing' and 'impressive' this was, infers that patients who had such positive experiences in this regard were often surprised and their expectations were exceeded.

> *“11 weeks from GP appointment to surgery. I think that's amazing, considering the current challenges faced by the NHS.”*
>
> *“When the GP told me the blood test results, she said that everything would happen very quickly and it did. I saw a specialist within two days who said it would all happen within two weeks and it did. I was deluged with letters and test appointments, all to happen very quickly. Then it settled down to regular and confirmed appointments. Very impressive.”*
>
> *“The NHS were amazing at the beginning. I went to my GP with a lump and the following day the hospital phoned and had me in for tests. I was also booked for my surgery so quickly completely amazing!”*
>
> *“The whole experience has for exceeded my expectations. The treatment process from being diagnosed to where I am on my cancer journey has been seemless only the highest quality. I cannot praise the NHS enough as the entire process has been superbly handled, so much so what I don't recognise the NHS as portrayed by the media.”*
>
> *“I was impressed by the speed with which I started to receive treatment after initial diagnosis. I am pleased to say that this momentum has continued throughout my treatment.”*
>
> *“The speed of detection + prompt progression to surgery was excellent.”*
>
> *“I was seen, diagnosed and treated very quickly, contrary to national press reports!”*
>
> *“My referral was via the dentist and I am grateful it was spotted at stage one. The speed of initial referral was impressive.”*

Theme: Communications

What does the quantitative data tell us?

- 82.5% of respondents said treatment options were explained to them in a way that they could completely understand before their cancer treatment started (Q20).
- 91.0% of respondents said staff provided them with relevant information on available support (Q27).
- 88.3% felt they were given easily understandable information about what they should or should not do after leaving hospital (Q38).
- 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), 87.0% of respondents said the administration of their care was ‘very good’ or ‘good’ (Q57).

- 74.4% 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), 70.1% said they always were (Q45).
- 87.0% said they were given information that they could access about support in dealing with immediate side effects from treatment (Q46).
- 60.1% 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).
- 54.6% said they were definitely able to discuss options for managing the impact of any long-term side effects (Q48).

Overall, there was mixed feedback and varied experience about communication. There were two main aspects to communications raised by patients: methods of communication and the need to consider what is an optimal level of information at each interaction tailored to patient needs.

Methods of communication

Feedback on methods of communication spanned face-to-face and written communications as well as experiences of the post. 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.

Preferences were often shared in context of what could have been better and often this began with feedback about diagnosis or soon after as at the outset there is a need for patients to fully grasp the implications of their diagnosis and treatment. Overall comments point to this information being better received face-to-face, even if the patient is not taking it all in, and time is allowed for questions to be asked as well as answered. The two are inextricably linked in the comments, almost as if there is no point in giving information unless there is time to discuss it.

> *“Both consultants were informative about my care during surgery, even though I didn’t pay much attention. My family member listened attentively.”*
>
> *“My consultant (name) was very knowledgeable and informative of my cancer and the treatment I would be given. He explored everything to me so that I my fiancé + mum could understand the plan for treatment, timescale and everything else that would happen.”*

> *"I have been informed about my treatment every step of my journey. Everything was explained to me. Pro's + con's of all treatment offered."*

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.

> *"I felt safe and supported all the way from start to finish. Mainly because surgeons doctors nurses explained exactly what would be happening with my treatment and operations plus aftercare. I was and still am encouraged to ask any questions."*
>
> *"My experience of radiotherapy was very good - the radiographers and specialist nurses were kind and explained everything well and supported me."*
>
> *"Everything explained clearly, what to expect & whole process & procedures clarifies & what is going to happen by who & where, full information given & give opportunity to ask questions or clarify."*
>
> *"Radiotherapy team were the best team when it came to treatment and being able to access the nurses & Oncologist for information."*

For some patients there was a strong desire to be reassured that the best course of action was being taken. This often went hand in hand with 'care' and personal attributes included in the 'Staff' theme such as 'kindness'.

> *"The surgeon was wonderful, he caught up with me every 3 months. Very helpful and helped me understand everything so well and gave me so much confidence in the process."*
>
> *"Their ability to provide comfort and reassurance during what was undoubtedly been a challenging time for me was fully remarkable."*

In context of reassurance, written information was seen as a helpful resource to refer to when patients felt unsure of something. It is useful to note that written information which signposted to further support which was not in a written format, such as a phone line, were most popular and helpful.

> *"All literature has been forthcoming and helpful, being able to refer to it for any unusual symptoms that may have occurred. The contact number for the nurses is a wonderfully organised system. Knowing that you are able to make contact is very reassuring."*
>
> *"I was given lots of information about cancer charities, webinars, counselling."*
>
> *"Information given at the right time- and links to areas where I could access further support I was astounded by their exceptional professionalism and unwavering support. They graciously imparted all the essential information pertaining to the upcoming procedure and provided invaluable guidance for post-operative care."*

Some comments also highlighted the value of written information which documented discussions patients had about treatment and care, or what next steps might be. In these examples the discussion was confirmed again as highly valued alongside written follow-up of the interaction.

> *“Once the intervention route was taken there has been the usual excellent advice/support, plus importantly, transcription type letters to follow.”*

> *“The regular appointments with an oncologist were useful as were the follow-up letters miraculously summarising the meetings.”*

> *“The information they gave us were excellent, so we knew where we had to be and what time. Also, the time and how much medication was needed.”*

In terms of how the written communication is received, some patients raised concerns that there was a reliance on ‘snail mail’ which was hampering the speed at which information could be shared with them and with others involved in their care. 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 which offered the benefit of speed as well as a written record.

> *“Over reliance on sending information by post. Especially since Royal Mail Service is so poor at the moment. (Plus additional admin cost.) Email! would be more efficient.”*

> *“I had to deal with 3 different NHS trusts, none of which shared a common IT system. Correspondence was by letter @ the vagaries of Royal Mail.”*

> *“Communication is bad. Letters arrived very delayed, if they arrived by post.”*

> *“Serious delay in sending letters following consultations from Consultants at (location name) to other medical entities despite the Consultants actually dictating / preparing the letter during the consultation.”*

> *“Getting my appointment details via email or phone rather than post. I had two appointments missed because of this & it could have been more. I wasn't always at my home address whilst being cared for, & post isn't very reliable anyway.”*

> *“Letter of appointment change (colorectal surgery) not sent out in time and I only learned about the change by accident during a phone call.”*

Levels of information

Linking to the theme on ‘Diagnosis’ there was feedback shared that information given at and around this stage of ones’ experience needs to be sensitive in considering the patients’ response to diagnosis and how this should determine the pace and volume of information that is then shared.

Examples below demonstrate that for some who felt overwhelmed there was too much too soon shared, while for others there lacked sufficient information to meet their appetite to know more. In both scenarios, this demonstrates the need to be responsive and use judgement in the moment to then tailor communication to deliver information in a way that is then experienced as sensitive, timely and reassuring.

> *“There was not enough time allowed between being told I had breast cancer and the discussion about treatment I was in a state of shock and remembered little or nothing of what the consultant surgeon said to me thank God my daughter was with me.”*
>
> *“I would have preferred not to have been so bombarded with medical details immediately after being told that I had cancer. All I felt was I could deal with at the time was the diagnosis. My capacity after this was limited because of the shock so the medical information wasn't necessary for me at this point.”*
>
> *“After a brief rectal examination and a cursory wish at my scans, my condition was said to be incurable and I was handed a box of (name) cancer care leaflets with some numbers on which were not explained to me and then dispatched to a nurse to give me my first hormone injections.”*
>
> *“We saw the doctor for 3 minutes, given no information regarding the cancer, Ideally we should of had somebody from haematology in with us as well to explain or at least give us information on the type of cancer. Shouldn't have to go home and google what I have got.”*
>
> *“Whilst I was able to find a lot of information about both, and discuss this, nobody was able to advise or mediate on what might be the better option in my circumstances.”*
>
> *“At times the system is disjointed and like trying to do a jigsaw puzzle from a box with a different picture on the lid, also I would have liked more specific information regarding my test results other than the politically correct " you are doing ok" ... that’s really no good to me and I personally don’t work that way.”*

Moving beyond diagnosis being communicated, there is a call for staff not to make assumptions at later touch points as to the level of information already digested and understood by the patient. Checking in on what patients know and addressing unmet needs for information and clarity, would avoid scenarios where the patient felt uninformed.

> *“A further CT scan after 5 cycles of chemotherapy, however, showed that the cancer was progressing and that no further treatment was possible. This outcome came as a shock and this possibility was not explained at the beginning of treatment.”*
>
> *“Although after surgery I knew my tumour was malignant, I had no idea before I went to my first oncologist appointment the extent of the post-surgery treatment I would have to undergo.”*
>
> *“Possibly a little more explanation of side effects but sometimes it’s best not to know !”*
>
> *“Consultants consistently fail to advise impact on life expectancy unless notably prompted.”*
>
> *“My pathway was laid out too quickly. On reflection, and subsequently I changed my treatment plan after receiving a second opinion.”*

Post-treatment and discharge from hospital, some patients described feeling that they ‘disappeared’ from the system with no one proactively communicating with them to ask questions of, spanning a range of topics including finances, benefits, nutrition, lifestyle changes and medication.

What does the quantitative data tell us?

- 70.1% said that they were offered information about how to get financial help or benefits (Q29).
- 61.6% said their family or someone else close to them were given all the information they needed to help care for them at home (Q49).
- Respondents were asked whether once their cancer treatment had finished, they could get emotional support at home from community or voluntary services. 32.3% of respondents that needed care and support said they could definitely get this (Q53).

> *“More hospital aftercare support.”*
>
> *“Post care has been patchy. Contact after 3 months was very poorly organised and I had to go to same lengths to re-organise it - Poor. Post care concerning medication is poor, little or no proper advice by (location name) or my GP Surgery - Very poor.”*
>
> *“More support with diet and lifestyle changes.”*
>
> *“Even with support at home I would have liked some visits at home from a district nurse to check on me, but apparently not possible.”*
>
> *“I would like some more help in terms of benefits care.”*
>
> *“The hospital staff could signpost more about benefits like PIP and earlier information about neutropenic diets.”*

Theme: Co-ordination of care

Feedback on how services and organisations work together across elements of a patients 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 in which they feel they must take on a role themselves in coordinating their care at a very difficult time.

Between GPs and hospitals

What does the quantitative data tell us?

- Of those that said their GP practice was involved in their cancer treatment, 46.5% 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. Ideally a joined-up system across primary and secondary care as a remedy would support with this, as noted in some responses.

> *"The problems arose when I was referred from (x location name) to (y location name). Again, operationally (y location name) has been brilliant. But there have been administration issues at (y location name). I was sent an appointment letter and text for an appointment which didn't exist. And I did not find this out until arriving in (y location name). Separately, the tripartite arrangement between (x location name), (y location name) and the GP hasn't worked. (y location name) asked the GP by letter to organise a blood test appointment. The GP didn't do this. (y location name), due to a different computer system, cannot see my (x location name) urology records. Neither could my GP initially. So I had to act as middle-man/detective to track down my PSA results for the (y location name) consultant. The NHS does not have a joined-up information system, in my experience."*

> *"I feel that there is a definite lack of communication between my GP/my cancer ward/different hospitals that I attend - should there not be a central data bank that all interested parties can access the latest information?"*

> *"I have had huge problems between my local GP + the hospital (results, blood tests, prescriptions etc.) There should be a much more joined up approach. I was told from had different computer systems!"*

In terms of information flow, as noted in examples above, the GP not having access to records and results from the hospital was one facet to this. The other was when the hospital was not in receipt of what was needed from the GP in a timely manner. While in some instances it was not clear if the GP was responsible, delays were perceived to begin there. This was particularly noticeable in relation to appointments.

> *"Fast track was overdue as documents took 2 weeks to even arrive @ the Hospital, delayed by my doctor surgery?"*

> *"Had a CT scan in (date). Numerous calls to GP for results. It took an AE doctor to obtain results in (date) 6 months later. I owe everything to that wonderful AE doctor at (location name) for getting my results the same day."*

> *"If GP and hospital worked together, and I did not have to chase appointment at times."*

> *“Integration with GP surgery is generally very poor - I have to 'manage' appointments bloods, etc, & make sure no mistakes are being made… I was asked to attend a doctor appointment on one occasion, & the GP said he didn't know why I was there - I said neither did!!”*

> *“Improve the link between the GP surgery and the hospital. With my ongoing immune system issues it can be hard to know whether I need to contact my GP or my CNS - I have a fervent desire not to waste either's time, and it can put me off bothering either in case I go the wrong way. It's not really to do with my cancer care so much as the NHS in general.”*

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 when the lack of information sharing between hospitals disrupted the patients’ experience and care was not felt to be well coordinated.

> *“Communication between the 3 hospitals that carried out my treatment was not always very good, for example, test results from one were not easily visible at another because they used different IT systems.”*

> *“There was poor liaison between (location name) & (location name) to the latter knew nothing about my circumstances or medical history and to no reasonable adjustments were made during treatment planning and no on-site support was offered.”*

> *“A referral for physio went missing between (location name) and (location name) So it took longer than it should have done to be seen.”*

> *“Contact from (location name) & (location name) hospitals do not appear to be compatible. Needs one system that is accessible by both units, that is not pass at the moment So very distressing. Urgently needs rectifying.”*

In this context several patients shared how this led to them having to take on a role in coordinating their care in absence of anyone else doing so. For the majority this created additional anxiety that something would then be missed as they lack access themselves to all the information needed to move things along or to clarify something.

> *“I am not really sure when my next review is? It may be January - Why do I need to chase medical.”*

> *“I have been referred to (location name) for genetic testing for (diagnosis). I have not received results and now feel lost as my G.P. are unable to help with this and gos are not responding to by request for information. This is frustrating as I worry I could fall out of the system.”*

> *“My scans/checks ups for the op I had 5 yrs ago in (location name) were handled by (location name) but after some time I was accidentally left off the list of check ups when a new team took over. It wasn't till I noticed this because of the operation I had last year and all the check ups for that I queried this and check ups resumed.”*

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 confounds patients and can be seen as the cause of delays to their treatment.

> *“When I attended (location name) hospital for my ultrasound the team didn’t know why I was there, I was sent to the wrong department first time round, I then had to be re booked in at a later date as they didn’t have my original appointment booked. Upon the second visit I was then asked again why I was in as it didn’t seem the correct notes were passed through.”*
>
> *“The information pathway for referred patients seems to be patchy: - communication problems meant I didn’t have my assigned team for my first session, which is something they aim to provide. - I was meant to be talked through the process on the first day and that didn’t really happen.”*
>
> *“The only tricky part was the handover process between the departments, (ward name) to plastic surgery. I think my case got lost and it was hard to identify who in the plastic department I had to go to, to get it resolved. It was fine in the end, which is great and I fully believe it's not a person/ people problem but a process one that needs to be looked at.”*
>
> *“Poor communication between departments : caused some issues and delays in treatment.”*

Discharge

A small number of patients spoke explicitly and only of the need to improve their experience of discharge within the hospital. The common thread in this feedback was a sense from patients that while they were no longer in need of immediate attention and care, they felt ‘side-lined’ and that they were left responsible for coordinating their own discharge. This inferred a lack of coordination between different departments and services within the hospital such as patient transport and pharmacy.

> *“On the two occasions when I was kept overnight in hospital I was told in the early morning that I was to be discharged that day. On both occasions, I hung around until late afternoon before I could get a Member of staff to discharge me.”*
>
> *“My discharge from the hospital was horrendous I had to leave by 8am in the morning. No porter, no chairs to get to the discharge lounge. Nurses were dealing with ward medication I was left do deal with discharge on my own. To find my own wheelchairs, no lifts.”*
>
> *“Patient discharged without family being told despite patient having dementia. Patient found on discharge lounge. Dreadful.”*
>
> *“I think it would be good if more attention could be given to the efficiency and speed of discharging patients from the hospital. The necessary paperwork took a long time to appear. Lack of relevant staff? There seemed to be difficulties in liaising with the relevant district nurses and social services. If that is the patient's responsibility, then that should be made clear.”*

At home

Following discharge and once back at home, there was a continuation of this sense from patients that they had to take control of coordinating the care they needed post-treatment, being otherwise left ‘adrift.’ Examples spanned a wide range of needs and services which highlighted that coordination needs to be improved between health and social care as well as across primary, secondary and community care including mental health services.

> *“After discharge I felt completely cut adrift. There was no assessment of any home support I might need. Not having the energy to arrange anything or prepare meals I just lived as best I could on what I had. At 80 more help was needed.”*
>
> *“I would have liked someone to come to my home to tell me what help I was entitled to. I couldn't take everything in over the phone my head was all over the place having just had the op plus being re admitted with a problem.”*
>
> *“I was very frustrated at the lack of physiotherapy input advice… when they did - eventually visit me, I was only shown how to get on / off the bed and walk, using a walking frame. No exercises were given to me and so my leg remained virtually useless. Worse still, there was no referral to my local hospital for in going physio when I was discharged, nor a request for support from adult social Services occupational therapy.”*
>
> *“Dietician had assured me that I would have a diet in hospital appropriate to my condition-it didn't happen. Only had speech therapy after chasing it up. I have never been in hospital before to have nothing to compare it with but I couldn't imagine it being a worse experience.”*
>
> *“Better physical and emotional support from the stoma nurses when sores developed, bags kept coming unstuck, and dietary advice on what to eat longer term moving forward in my recovery.”*
>
> *“Post care has been patchy. Contact after 3 months was very poorly organised and I had to go to same lengths to re-organise it - Poor. Post care concerning medication is poor, little or no proper advice by (location name) or my GP Surgery - Very poor.”*

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 & facilities

From there being no beds to no toilets available, to broken machinery, insufficient seating in waiting areas and poor Wi-Fi, examples were varied though collectively highlighted how hospital infrastructure and facilities can impact on experiences of care. While less common, there were patients who raised issues with the cleanliness of buildings along with other issues relating to building maintenance including disabled access.

> *"The lack of beds when admitted as an emergency on more than one occasions caused distress and I was never admitted to the (name) Ward as they were always full."*
>
> *"They were very pushy to get the bed space back which made me feel I was just a number and not a person."*
>
> *"Waiting time in Radiotherapy due to machine break downs."*
>
> *"I had 3 operations as day patient. The 12 operation was carried out in a pre- fabricated operating unit, with no toilet facilities. After the operation I was directed to go to the cafe area where I could obtain refreshment. No recovery room was offered."*
>
> *"I note that the waiting room furniture has been changed to make more seating but they are very cramped and uncomfortable. I think a far larger waiting area for the chemotherapy unit would be a solution."*
>
> *"No problem with care, but (location name) hospital has poor internet connection (in hospital for 22 days) pay TV too expensive to use."*
>
> *"The (location name) is badly let down by the inadequate level of domestic cleaning bathrooms and toilets needed regular cleaning. Despite the unit staff regularly asking for this it was not adequately forthcoming. A real shame & let down."*
>
> *"I didn't like that the hot drink machines in the radio/chemotherapy department in the basement were turned off early."*
>
> *"Standard disabled access points would have been a good place to start. Doorways that were wide enough to accommodate wheelchairs."*
>
> *"Too many patients for the facilities and space available, poor segregation, the room felt run down and the staff close to break down at times, patients standing due to lack of space and shortage of seats."*

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; having treatment in one location as opposed to several; and grouping appointments together to avoid going back and forth to the same hospital on different dates and times.

> *"Would have preferred treatment in my home town."*
>
> *"One organizational thing that could be improved: I travel 25 miles each way to (location name) for (quite frequent) blood tests. It would be easier if I could get these at my local surgery, but these are analysed at (location name) and apparently the results are difficult to access by (location name)."*
>
> *"The only issue I have is that the journey to (location name) is over 30 miles, especially difficult for me as my cancer (glioblastoma) means I can no longer drive. Radiotherapy (30*

> *daily sessions over 6 wks) was very challenging as my husband had to take 6 weeks off work!"*
>
> *"Cancer care on one site, not split between two hospitals."*
>
> *"My treatment has been spread across several different hospitals with inevitable travel complications. It would have been easier to have treatment at the same hospital for every appointment."*
>
> *"Would have apts on different days (e.g bloodtest, scans) when it would have been more convenient to have it on the same day due to travel expenses."*
>
> *"It would have been better if all the scans could have been performed at one medical centre and possibly in the same day (I am not sure if this is possible)."*

Food

Most of the feedback about food was negative, though how important this was to patients was observed to vary. While for some it was the only areas of improvement identified and this could infer a high level of importance, others included food far down or at the bottom of a list of other suggestions which could infer it to be the least important when compared to other aspects of their experience. What was consistent though was the focus on quality as the core issue.

> *"The food was not great, mostly cold and the main catering person that I saw in my ward was very grumpy and not very engaging."*
>
> *"The food in hospitals need to be brought back in-house like they used to do & were generally very good, however now most of it is inedible including toast!! which you would have thought to be impossible to do but if you buy the cheapest bread I guess you can - the only thing edible was jelly & ice cream."*
>
> *"The food on the ward when I had my operation was not very good it was uneatable sometimes and I am not a fussy person."*
>
> *"When I was an in-patient for 3 weeks the food was revolting; really poor. And nobody seemed to notice that I wasn't eating it."*
>
> *"Hospital food is awful and needs to more nutritional."*

The examples shared already include patients not eating well or at all due to the issues with the food available in hospital. For some this was not about quality and was instead the consequence of catering not considering patients' specific health needs.

> *"The ward nurses need training in the dietary requirements for stoma patients, as do the catering staff. Food is well below par. Nurses were worried about me not putting weight on yet the food was very unpalatable and a very restricted choice for me having a stoma."*

> *"Inpatient food menus to include dietary requirements for patients with swallowing difficulties."*
>
> *"I found the food inedible, unhealthy. When recovering from a craniotomy you want to eat healthy food ."*
>
> *"On overnight admissions I was never informed of any food options until many stays in- I would be forced to eat just jacket potato for weeks on end for every meal because they would not cater to dietary (allergic and sensory) needs."*

Other

Below is a 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.

- Noise at night / noise from other patient visitors
- Access to gym / exercise equipment in hospital
- Lack of 'fast track' if attend A&E with chemo side effects
- Harmonise prescriptions so all renew at same time
- Clearer signage in hospital
- Wearing purple gown in waiting area "*so felt I was labelled cancer patient*"
- Need for translators in hospital
- Hospital parking costs
- Timing of discharge from hospital being unclear
- Lack of GP support / contact during treatment

5. Conclusions

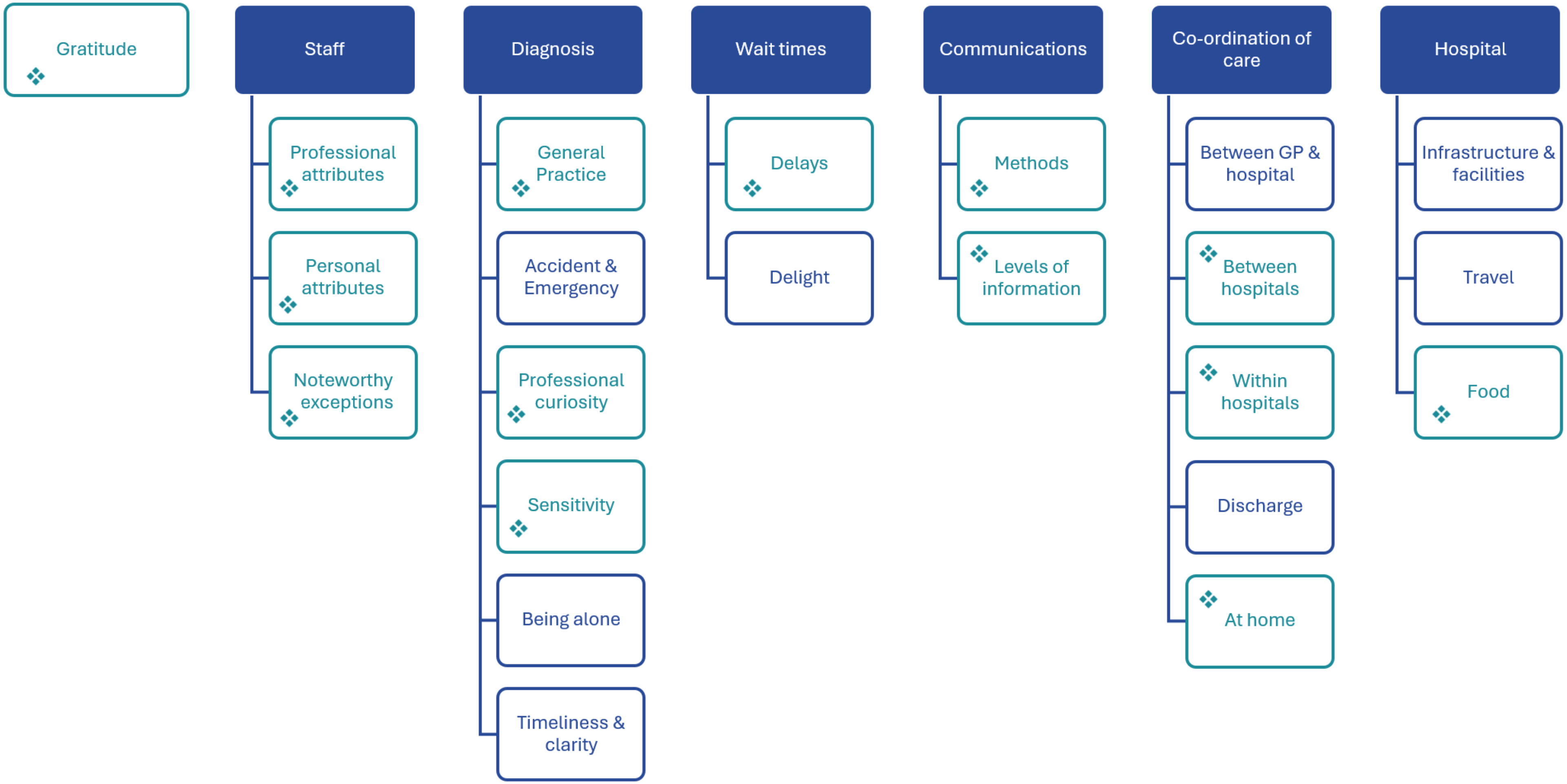
This is the second national qualitative report for the NCPES, and it is anticipated that there will be interest therefore in what has changed since the previous publication for the 2021 survey. Direct comparisons are not possible due to changes with the questionnaire over time, including the specific open questions. Consequently, it is not possible to be confident that the absence of an insight in this report which appeared in 2021, or a ‘new’ insight in this report, is the result of real-world changes in experiences of care. There are also unknown variables which may have impacted on whether respondents chose to include or exclude particular experiences.

With this in mind, the additional detail and depth captured in this report on positive experiences compared to 2021 is important to reflect on. While it is not possible to say with absolute certainty this is evidence of improvement due to the caveats noted above, it undoubtedly provides a greater opportunity than in 2021 to reflect on what is working well to celebrate successes and spread further good practices.

Regarding feedback that captured what could be better about care, the recurrence of insight over time makes a compelling case that there remain opportunities for improvement from 2021. A visual summary is shown on the page which follows, to highlight which of the 21 sub-themes from 2023 were evident also in 2021. This could mean the insight was either core or part of either a key theme or sub-theme as previously reported in 2021.

As visualised, there is some recurrence in the insight from 2021 to 2023, as well as ‘novel’ insights in 2023 that did not appear in 2021 and vice versa. The result of both analyses and reports is an ever-growing list of areas for focus, without a strong steer on prioritisation. This reflects the limitations of qualitative data collected through survey methods which don’t allow for prompting, probing or deeper discussion to clarify what would be most important or impactful for patients.

In context, the conclusion of this report is the importance of triangulating this insight with other existing datasets that are relevant, and to consider new collections and/or engagement activities which would support better understanding of priorities for patients. Ongoing listening and involvement are of course paramount to ensure any efforts nationally or locally will have the greatest gains to improve the experiences of patients.



- Gratitude ❖
- Staff
  - Professional attributes ❖
  - Personal attributes ❖
  - Noteworthy exceptions ❖
- Diagnosis
  - General Practice ❖
  - Accident & Emergency
  - Professional curiosity ❖
  - Sensitivity ❖
  - Being alone
  - Timeliness & clarity
- Wait times
  - Delays ❖
  - Delight
- Communications
  - Methods ❖
  - Levels of information ❖
- Co-ordination of care
  - Between GP & hospital
  - Between hospitals ❖
  - Within hospitals ❖
  - Discharge
  - At home ❖
- Hospital
  - Infrastructure & facilities
  - Travel
  - Food ❖

❖ Insight also evident in 2021

6. Appendix: Sampling information

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

Characteristic	Sub-group	Number of comments analysed (QA)	% of comments analysed (QA)	% of comments overall (QA)
Age	16-24	50	3.0%	0.2%
	25-34	54	3.3%	0.8%
	35-44	73	4.4%	2.7%
	45-54	164	9.9%	8.2%
	55-64	336	20.4%	21.0%
	65-74	517	31.3%	33.8%
	75-84	393	23.8%	28.5%
	85+	64	3.9%	4.7%
Ethnic background*	White	1284	77.8%	77.9%
	Asian	109	6.6%	1.8%
	Black	78	4.7%	1.4%
	Mixed	55	3.3%	0.5%
	Other	50	3.0%	1.3%
	Not given	75	4.5%	14.0%
Deprivation level (IMD Quintile)**	1 (most deprived)	186	11.3%	10.9%
	2	286	17.3%	16.2%
	3	373	22.6%	21.7%
	4	377	22.8%	24.7%
	5 (least deprived)	421	25.5%	26.0%
	Outside England	8	0.5%	0.5%
Gender***	Female	835	50.6%	51.4%
	Male	717	43.4%	43.4%
	Prefer not to say	3	0.2%	0.1%
	Prefer to self-describe	22	1.3%	0.1%

	Non-binary	13	0.8%	0.0%
	Not given	61	3.7%	5.0%
Tumour group****	Breast	359	21.7%	23.0%
	Haematological	252	15.3%	14.2%
	Prostate	213	12.9%	11.7%
	Colorectal / LGT	158	9.6%	11.9%
	Other	138	8.4%	9.5%
	Urological	90	5.5%	7.0%
	Lung	85	5.1%	6.4%
	Gynaecological	78	4.7%	4.8%
	Upper Gastro	70	4.2%	4.4%
	Skin	55	3.3%	3.5%
	Head and Neck	53	3.2%	2.5%
	Sarcoma	50	3.0%	0.8%
	Brain / CNS	50	3.0%	0.4%
Sexual orientation	Heterosexual or Straight	1417	85.8%	91.0%
	Other	10	0.6%	0.2%
	Gay or Lesbian	50	3.0%	0.9%
	Bisexual	51	3.1%	0.4%
	Prefer not to say	34	2.1%	1.2%
	Don't know / not sure	8	0.5%	0.2%
	Not given	81	4.9%	6.1%

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

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

***Self-reported in Q64 of the survey

****Details of how tumour groups were formed can be found in the Technical Document, available at www.ncpes.co.uk

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

Characteristic	Sub-group	Number of comments analysed (QB)	% of comments analysed (QB)	% of comments overall (QB)
Age	16-24	51	3.4%	0.2%
	25-34	56	3.8%	0.8%
	35-44	65	4.4%	2.7%
	45-54	132	8.9%	8.2%
	55-64	326	21.9%	21.0%
	65-74	455	30.6%	33.8%
	75-84	348	23.4%	28.5%
	85+	53	3.6%	4.7%
Ethnic background*	White	1149	77.3%	77.9%
	Asian	98	6.6%	1.8%
	Black	63	4.2%	1.4%
	Mixed	57	3.8%	0.5%
	Other	50	3.4%	1.3%
	Not given	69	4.6%	14.0%
Deprivation level (IMD Quintile)**	1 (most deprived)	183	12.3%	10.9%
	2	233	15.7%	16.2%
	3	330	22.2%	21.7%
	4	369	24.8%	24.7%
	5 (least deprived)	365	24.6%	26.0%
	Outside England	6	0.4%	0.5%
Gender***	Female	745	50.1%	51.4%
	Male	639	43.0%	43.4%
	Prefer not to say	6	0.4%	0.1%
	Prefer to self-describe	21	1.4%	0.1%
	Non-binary	11	0.7%	0.0%
	Not given	64	4.3%	5.0%

Tumour group****	Breast	323	21.7%	23.0%
	Haematological	214	14.4%	14.2%
	Prostate	156	10.5%	11.7%
	Colorectal / LGT	151	10.2%	11.9%
	Other	110	7.4%	9.5%
	Urological	108	7.3%	7.0%
	Lung	77	5.2%	6.4%
	Gynaecological	68	4.6%	4.8%
	Upper Gastro	53	3.6%	4.4%
	Skin	56	3.8%	3.5%
	Head and Neck	57	3.8%	2.5%
	Sarcoma	56	3.8%	0.8%
	Brain / CNS	57	3.8%	0.4%
Sexual orientation	Heterosexual or Straight	1262	84.9%	91.0%
	Other	6	0.4%	0.2%
	Gay or Lesbian	50	3.4%	0.9%
	Bisexual	61	4.1%	0.4%
	Prefer not to say	24	1.6%	1.2%
	Don't know / not sure	9	0.6%	0.2%
	Not given	74	5.0%	6.1%

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

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

***Self-reported in Q64 of the survey

****Details of how tumour groups were formed can be found in the Technical Document, available at www.ncpes.co.uk