NHS England

National Cancer Patient Experience Survey

2024 qualitative results webinar

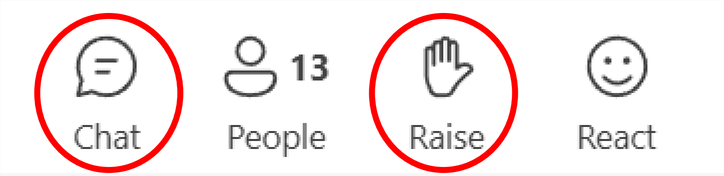
Agenda

	Time	Item	Speaker
1	09:30 – 09:35	Introduction and housekeeping	Joanne Loughlin-Ridley: NHS England
2	09:35 – 10:05	NCPES 2024 qualitative report overview	Josie Harrison: Solutions Research
3	10:05 – 10:35	Patient and Public Voice (PPV) panel – reflections about the thematic report	Victor, Michael, Farida: Patient and Public Voice Partners Joanne Loughlin-Ridley: NHS England
4	10:35 – 10:45	Your thoughts and reflections	Open to all
5	10:45 – 10:55	Closing statement	Jodie Moffat: NHS England
6	10:55 – 11:00	Close and request for feedback	Joanne Loughlin-Ridley: NHS England

Introduction and housekeeping

Microphones will be **disabled** whilst the presentations are ongoing.

You can ask questions using the **chat function** throughout the webinar. During the Q&A, please feel free to **raise your hand** and ask questions verbally.



Our ask of you today

Questions

What **surprises** you the most?

Which insight **resonates most** with the work you do?

How will you prioritise the improvements to make from the opportunities shared?

NCPES 2024 qualitative report overview

Josie Harrison

Solutions Research

Open questions

Two open questions were positioned at the end of the 2024 survey

48,375 comments in total, 76% of the survey sample answered one or both open questions

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

Qualitative analysis – approach

Sampling

- Purposive sampling to ensure diversity
- A minimum of 30 comments on **all** characteristics
- Total sample of 1,782 analysed

Analysis

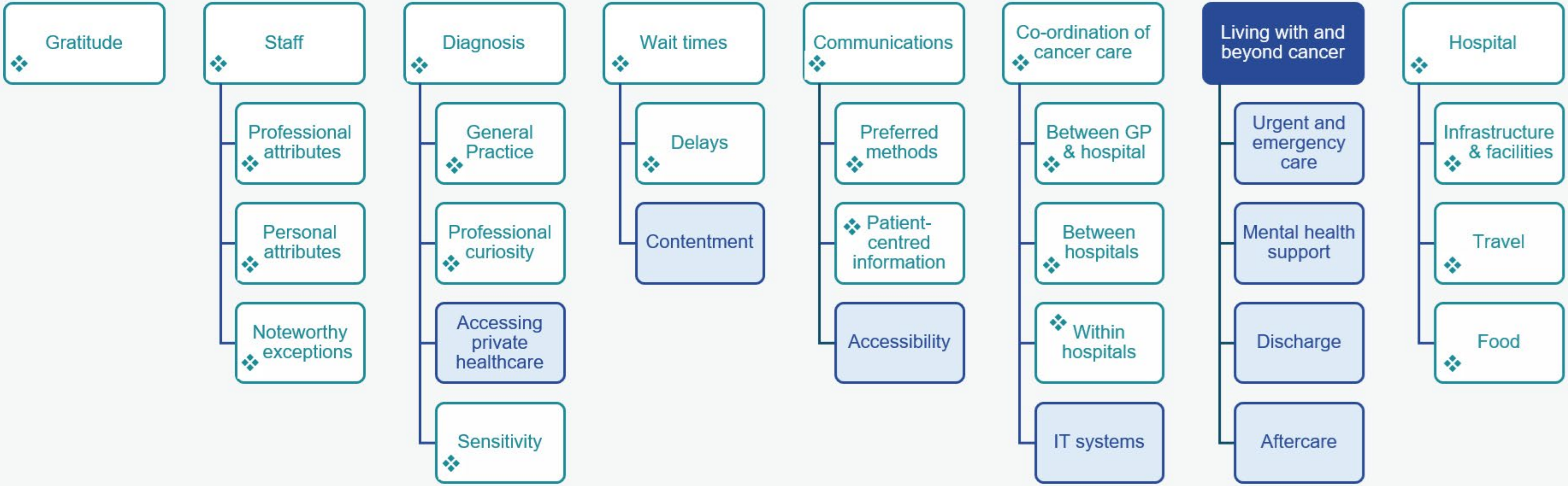
- Thematic analysis to achieve deep understanding
- Deductive approach – thematic codes created in qualitative analysis of 2023 data used for initial coding


1. Familiarisation with the data
2. Generate initial codes
3. Search for themes
4. Review themes
5. Define and name themes
6. Produce report

Findings

Eight key themes

Key themes and sub-themes



- ❖ Gratitude
- ❖ Staff
  - ❖ Professional attributes
  - ❖ Personal attributes
  - ❖ Noteworthy exceptions
- ❖ Diagnosis
  - ❖ General Practice
  - ❖ Professional curiosity
  - Accessing private healthcare
  - ❖ Sensitivity
- ❖ Wait times
  - ❖ Delays
  - Contentment
- ❖ Communications
  - ❖ Preferred methods
  - ❖ Patient-centred information
  - Accessibility
- ❖ Co-ordination of cancer care
  - ❖ Between GP & hospital
  - ❖ Between hospitals
  - ❖ Within hospitals
  - IT systems
- Living with and beyond cancer
  - Urgent and emergency care
  - Mental health support
  - Discharge
  - Aftercare
- ❖ Hospital
  - ❖ Infrastructure & facilities
  - ❖ Travel
  - ❖ Food

❖ Insight evident in 2023

Gratitude

A strong theme with patients expressing thanks and appreciation.

Comments were directed at NHS generally and broadly.

Often comments referenced specific hospitals, teams or individual members of staff.

"Very excellent care from 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... No concerns at all. Well done N. H.S."

"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 [way]."

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.

Staff

Staff were pivotal to positive experiences, with noteworthy exceptions further demonstrating the important role staff play.

Professional attributes

"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."

"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."

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

- Being cared for was described in many ways referencing professional attributes such as skills, knowledge, competency of staff
- Mention of professionalism often combined with positive interpersonal interactions
- Being listened to seen as a priority by some patients
- Impact is reassurance and reduced anxiety for patients

What does the quantitative data tell us?

78.2% said they had confidence and trust in all of the team looking after them during their stay in hospital (Q31).

Staff

Personal attributes

“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.”

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

- References to personal qualities that were seen to support delivery of high-quality care (‘warm’, ‘kind’) – were highly valued
- Extending support to family was highlighted
- ‘Exceptional’ care was seen as a direct result of staff going above and beyond

What does the quantitative data tell us?

77.5% said they definitely got the right level of support from hospital staff for their overall health and wellbeing (Q28).

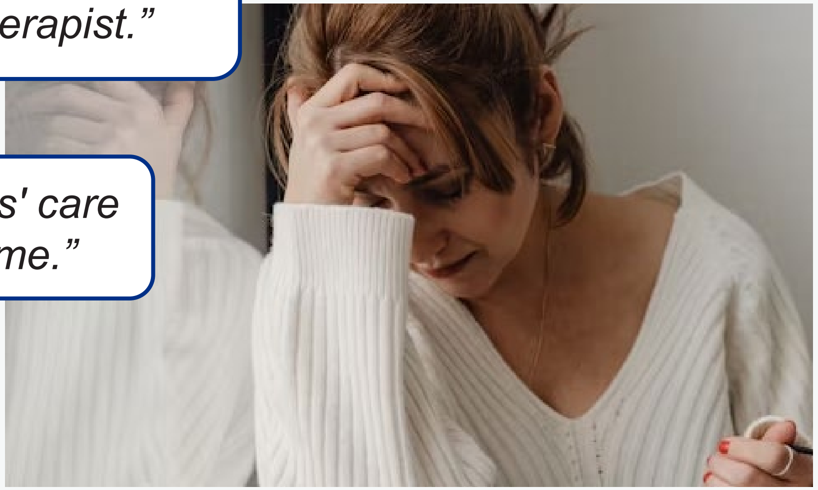
88.0% felt that they were always treated with respect and dignity while they were in the hospital (Q37).

Staff

Noteworthy exceptions

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

“There's a culture of indifference to patients' care and relative toxicity demonstrated by some.”



“The staff were excellent all be it rushed.”

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

- Those reporting negative interactions highlight feeling they were not treated as an individual
- Other improvements noted included dismissive attitudes towards patient concerns
- Feedback sometimes explicitly mentioned staffing levels being too low (acknowledged as systematic problem)
- For small number, need for reassurance that best course of action was being taken

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).

57.5% said they could get further advice from a different healthcare professional before making decisions about their treatment options (Q23)

Diagnosis

Enablers and barriers to diagnosis were shared, with a focus on speed.

General Practice

- Some positive experiences with GP acting 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, proffessionally and quickly."

"I think had I had the ultrasound scan instead of the colonoscopy the tumour would have been found nearly 12 months sooner."

"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."

- Improvements to experience often linked to delays accessing a GP
- Not feeling listened to seen as a barrier to timely diagnosis
- GPs sometimes considered accountable for a delay when initial referrals did not result in diagnosis, and further referrals were felt to elongate the journey

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

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).

Diagnosis

Professional curiosity

Improvements noted included a need for greater curiosity – spanning roles in primary and secondary care

“It took me 6 months from first going to my GP… 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… and was continually fobbed off.”

Accessing private healthcare

Newly observed this year – consideration and uptake of private healthcare. Predominantly done when seeking investigations

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

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

Sensitivity

Comments about receiving a diagnosis via ‘phone – and newly observed, via text message or NHS app – not seen as appropriate

“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 don't think patients should be told they have cancer over the phone.”

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).

Wait times

Experience was mixed – delays shared in a range of contexts along with contentment from others for the speed they were seen/moved through the journey

Delays commonly mentioned across:

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

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

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

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

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)

Wait times

Contentment

- Patients that expressed positive surprise in how quickly they were seen and treated
- Descriptions used less demonstrative language than in 2023 (‘amazing’, ‘impressive’)

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

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

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

Communications – preferred methods

Variation in experiences, with high value placed on being able to ask questions and having proactive contact

Satisfaction with communication when given time to talk, to be listened to and have their questions answered

Sharing information face-to-face makes patients feel supported

Written comms needs to keep pace with treatment – where clearly stated, preference for email or text

> *"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 was given time to make my own decisions and the information needed."*

> *"My consultant has conveyed difficult information sensitively and has allowed me time to ask questions or express my feelings."*

> *"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."*

What does the quantitative data tell us?
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).

Communications

Patient-centred information

- Feedback on need to improve consideration of patient’s response to determine the pace, volume and quality of information
- Lack of ability to make contact had negative impact on patient wellbeing
- Regular proactive contact had a profound positive impact on patients

Accessibility

- Further feedback on improvement focused on need to simplify information, particularly explaining medical terminology

> *“Huge amount of information provided. This could be reduced/simplified. Very difficult to absorb everything.”*

> *“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.”*

> *“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.”*

> *“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.”*

Co-ordination of cancer care

Feedback on how services and organisations work together across elements of a patient's cancer care focussed most on what needed to improve for a seamless experience.

Examples show the negative impact on patients who felt 'lost' when information wasn't shared

Between GPs and hospitals

Within hospitals

Between hospitals

IT systems

Co-ordination of cancer care

Between GPs and hospitals

- Comments included need to share information throughout treatment
- When it is not clear where responsibility lies, can be perceived to contribute to delays – particularly noticeable relating to prescriptions after hospital discharge

"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."

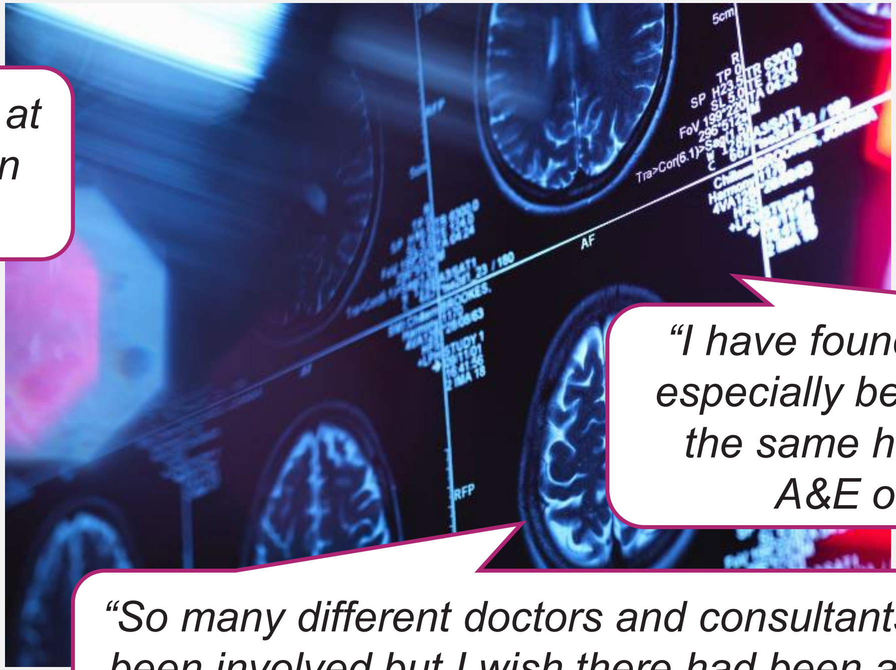
"If they could be digitised that would make everything run a lot smoother Post-surgery I was told I'd be discharged and was waiting for a long time, causing issues for the driver additionally, some appointments/ results aren't visible on the NHS app, meaning there is a breakdown in communication between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

What does the quantitative data tell us?
Patients were asked if they got the right amount of support from staff at their GP practice during treatment. 40.1% of respondents answered that their GP practice was not involved and 0.8% answered don't know/can't remember. Of those that said their GP practice was involved, 47.7% said they definitely received the right amount of support from staff at their GP practice while they were having cancer treatment (Q51).

Co-ordination of cancer care

“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!”



Within hospitals

- Expectation that all departments have same information – when not experience is seen as cause of delays

Between hospitals

- Expectation that information held in one hospital is freely available by another – lack of information sharing disrupted patient’s experience

“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.”

“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.”

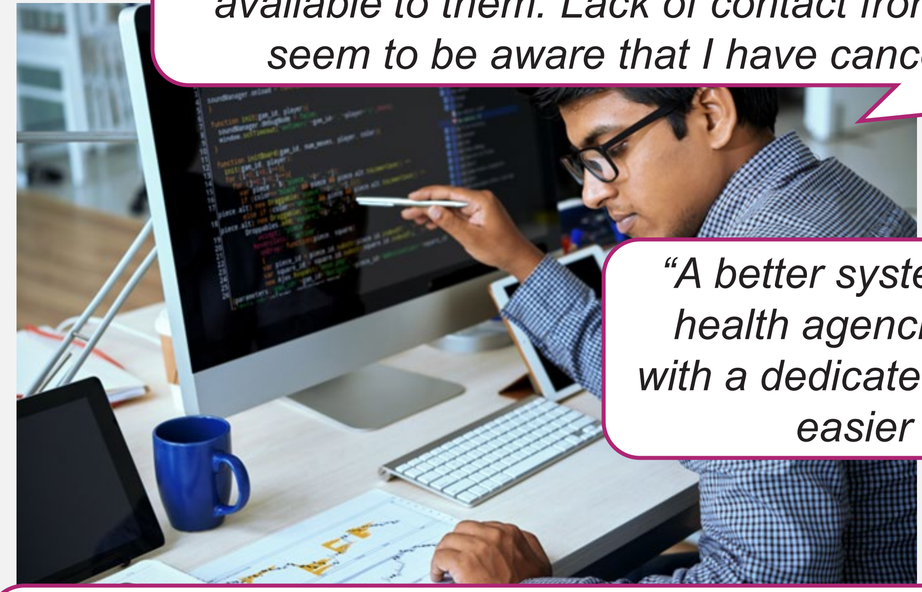
What does the quantitative data tell us?
Most respondents (90.4%) felt the whole care team worked well together to provide the best possible care for them (Q56)

Co-ordination of cancer care

- Patients highlighted negative impact of lack of cohesive systems
- Comments recognised contribution of IT systems to their experience, and raised questions about the role improvements in these could make to both staff and the administration of their care

IT systems

“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.”



“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.”

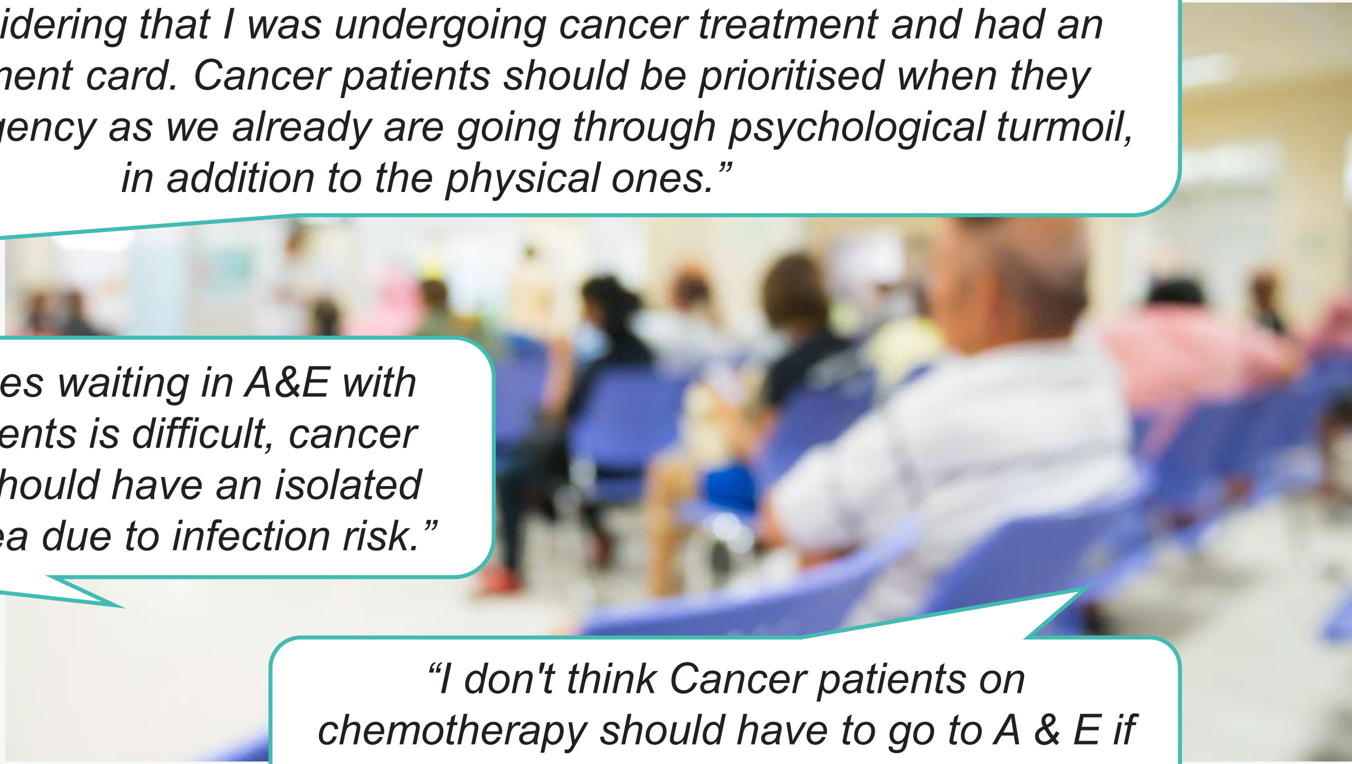
““The obvious problem that I experienced was the lack of a joined-up IT system across the various hospitals, test centres, GP practice and social care. Tests at one location are not shared with other within the group. Each blames the lack of a cohesive IT system.”

Living with and beyond cancer

Various unmet needs were described; improvements would mitigate risk of physical and/or psychological harm of needs not being met

Urgent and Emergency Care

- Concerns raised by some who felt vulnerable when accessing urgent and emergency care
- Strong inference that cancer diagnosis should be accessible and/or shared with the UEC department to enable mitigations
- Perception they could be putting themselves at risk of infection created anxiety and strong feelings on need for different access



"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."

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

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

Living with and beyond cancer

Mental health support

“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.”

“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.”

- Not being offered any or timely support for the psychological impacts of cancer diagnosis and treatment was highlighted as an area for improvement
- Also comments highlighting need for improvements once treatment finished – particularly where patients were struggling emotionally or had concerns about recurrence

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).

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).

Living with and beyond cancer

Discharge

"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."

"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."

- Need to improve experience of discharge raised – particularly where there was a lack of clarity on what next steps in treatment would be
- Also sense from patients that they were discharged too early, based on experiencing issues soon after

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).

Living with and beyond cancer

Aftercare

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

“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.”

“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.”

- Across comments on need for improvements in aftercare, patients describe expectations of continuation of intensive support experience when in treatment
- Post-treatment descriptions of being ‘disappeared’ from the system, with no clarity on who was responsible and no proactive communication
- Also a perception from some that they had to take control of their care post-treatment
- With a small number sharing they accessed private healthcare when post-discharge needs not met

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).

Hospital wide

Various unmet needs were described; improvements would mitigate risk of physical and/or psychological harm of needs not being met

Infrastructure and facilities

Most mentioned were issues with cleanliness of buildings, and comments around broken machinery – examples varied but highlighted how facilities can impact on experiences of care

Travel

Across range of examples patients highlighted how their experience could have been improved – including locating care closer to home and in one location

Also comments on negative impact of parking issues

Food

Most feedback on food was negative, but how important this was varied. Focus on quality and commentary on how this did not align with supporting their recovery

Also concerns raised when specific needs not considered

NHS England

Thank You

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NHS England

Patient and Public Voice (PPV) panel

Victor, Michael, Farida: Patient and Public Voice Partners

Joanne Loughlin-Ridley: NHS England

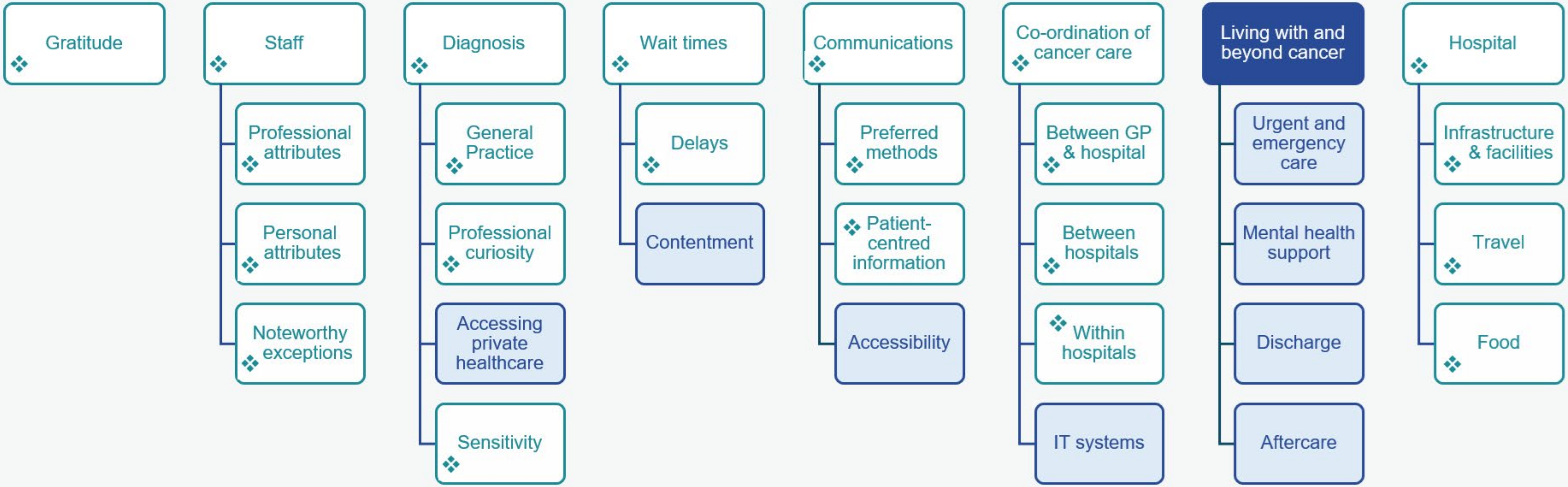
Your thoughts and reflections

Your thoughts

What **surprises** you the most?

Which **insight resonates** most with the work you do?

How will you prioritise the improvements to make from the opportunities shared?



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Closing statement

Jodie Moffat

NHS England

Thank you

Please share your feedback:

https://forms.office.com/e/1k112XzQxt