

National Cancer Patient Experience Survey 2021

Qualitative deep dive report

Contents

Introduction	3
Understanding the results	6
Headline findings.....	9
Subsample findings: people living in the most deprived areas	11
Subsample findings: people from ethnic minorities	19
Subsample findings: people reporting a mental health condition	25
Subsample findings: people with Learning Disabilities	31
Subsample findings: people aged 16 to 44	36
Conclusions.....	44
Appendix: sampling information	47
Appendix: summary of national parallels.....	73

1

Introduction

Introduction

The National Cancer Patient Experience Survey 2021 was commissioned and managed by NHS England. The survey asked respondents a range of questions about their experience. This included three open-ended questions at the end of the survey allowing for qualitative written feedback.

The national quantitative results showed that nationally the average rating of care was high at 8.92 out of 10. In line with this, a strong sense of gratitude was identified as the main theme in national qualitative analysis.

Set against this context of high levels of overall care experienced and gratitude, it is important to note that there was variation, with analysis of some groups revealing that¹:

- People living in the most deprived areas scored on average 8.87 out of 10 for overall rating of care experienced
- People from ethnic minorities had different average ratings of overall care experienced:
 - Mixed - 8.71 out of 10
 - Black - 8.55 out of 10
 - Asian - 8.54 out of 10
 - Other - 8.59 out of 10
- People reporting a mental health condition scored on average 8.43 out of 10 for overall rating of care experienced
- People with Learning Disabilities scored on average 8.01 out of 10 for overall rating of care experienced
- People aged 16 to 44 had different average ratings of overall care experienced:
 - 16 – 24 - 8.63
 - 25 – 44 - 8.49

Consequently, NHS England have commissioned individual analyses of the qualitative data gathered within each of these groups as part of the national survey. These ‘deep-dives’ aim to understand what is underpinning any variation in experience of care in these groups referred to as subsamples throughout this report.

In addition, to ensure actionable insight, the qualitative analysis undertaken within these deep dives has focused solely on data provided in QB ‘was there anything that could have been improved?’. This focus is most likely to identify specific opportunities for improvement and development to reduce the variation and improve experience even further.

¹ *Please note that base sizes for ‘other’ ethnic group, learning disabilities and the 16 – 24 age group were relatively small so these figures should be treated with caution. In particular, the score for 16 – 24 bucks the decreasing trend for younger age groups but we can’t be sure this isn’t due to the small number of responses.

Presented within this report are the findings from five individual thematic analyses completed on the subsamples. A findings section is dedicated to each subsample analyses to detail the key themes that have been identified as unique in context of the national thematic findings reported [here](#).

For further information on the survey including eligibility, survey methods, fieldwork dates, data cleaning and the approach to qualitative analysis, please refer to the national report [here](#).

2

Understanding the results

Sampling

In terms of sampling approach, there were three stages applied:

1. Stage one used a random sampling technique to ensure representativeness. The size of each sample was calculated to ensure a 95% confidence with a 3% margin of error.
2. As a second stage, for quality assurance, proportions of the different demographics were tested between the deep dive subsamples and overall population responding to the survey.
3. Finally, the principle of data saturation was applied to the analysis which ensured that no new themes emerged from the data by the end of the analysis.

The volumes are provided below as to the subsample size for each deep dive analysis undertaken. Within the appendix (page 47) there are detailed breakdowns of the subsamples to demonstrate how representative each was of the whole population focussed upon.

Population	Overall sample that provided response to QB	Subsample for thematic deep dive
People living in the most deprived areas	4,215	932
People from ethnic minorities:	1,930	725
<i>Mixed</i>	318	200
<i>Black</i>	574	200
<i>Asian</i>	913	200
<i>Other</i>	125	125
People reporting a mental health condition	1,750	700
People with Learning Disabilities	191	191
People aged 16 to 44:	1,687	858
<i>Aged 16 to 24</i>	122	122
<i>Aged 25 to 44</i>	1,565	736

Please note that three exceptions were made in which whole datasets were analysed due to low volumes of qualitative data rendering a sampling approach unnecessary. Of those who provided a comment to QB in the survey, the whole dataset was analysed for people with learning disabilities, the 'other' ethnic minority group, and those aged 16 to 24.

It is important to note that respondents may be included in several subsamples to reflect the reality that protected characteristics, demographics and experience of deprivation can overlap. As an example, a respondent who identified in the survey as aged 16 to 24 and of Black ethnicity, may have been included in both the under 45s and ethnic minorities subsamples.

It is helpful for context to keep in mind that the national qualitative sample is made up largely of those aged 45 and over, of white ethnicity, from less deprived areas. Please refer [here](#) for more details of the national qualitative sample.

Format of the findings

A key aim of the deep dive analyses was to identify differences between the views and experiences of subsamples in comparison to the views and experiences identified in the thematic analysis of the national qualitative sample. The purpose of this was to allow for in-depth exploration of any variances in experiences of cancer care for the specific subsamples.

The findings have therefore been structured with a focus on any differences identified specifically between each subsample and the national sample. It is important to note that there was no comparison made between subsamples as part of the analytical process and each subsample was drawn and analysed separately.

Where differences have been identified this has been introduced as ‘unique insights’ and the themes offer an opportunity to consider why this may have been found in the analysis of the subsample but not in the national sample.

Where there were similarities found in experience between the subsample and national sample (referred to as ‘national parallels’), these have been highlighted for context only as full exploration of those themes can be found in the national report [here](#), i.e. the way the theme has been articulated in the national report is sufficient in describing the experience of the same theme in the subsample. In this way, the deep dive qualitative report can be considered an extension of the national qualitative report. A summary of themes found in the subsample analyses which have mirrored the national insight, is captured within the appendix (page 73).

As in the national qualitative report, example quotations are shared as were captured in the written feedback and the findings for each subsample have been 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 support us in understanding why people may feel that way. Please note that where quantitative survey findings are not included for context, this reflects that the survey did not capture quantitative data relevant to the qualitative finding being described within that section of the report.

3

Headline findings



Headline findings

The overwhelming response from those providing a comment to the question QB ‘was there anything that could have been improved?’ was an expression of ‘gratitude’ for the care experienced in four of the five subsamples.

The exception was for the subsample of respondents aged 16 to 44. While there were a vast number of comments made expressing gratitude, it was not found to be the overwhelming majority in this cohort.

An example of gratitude expressed for each subsample is given below with more shared within each subsample chapter.

- *“No one could of done anything any better, thank them all”*
(Subsample: people living in the most deprived areas)
- *“Everything was great”* (Subsample: people of ethnic minority)
- *“No one could have done anything any better thank them al.”*
(Subsample: people reporting a mental health condition)
- *“Everything was just fine. Could not have wished for more”*
(Subsample: people with a Learning Disability)
- *“Excellent, first class, compassionate care following diagnosis”*
(Subsample: people aged 16 to 44)

There was also synergy between the national sample and the subsamples which extended beyond ‘gratitude’. The appendix (page 73) details which themes were found to be mirrored in the comparisons drawn between each subsample and the national sample, referred to as ‘national parallels’. For example, physical waiting while in the hospital for appointments or procedures was found in all subsamples.

Focussing then on what was found to be unique for subsamples, with an aim to understand why experiences of care may vary for these groups, it is interesting to note the similarities that have emerged. While comparison between subsamples was not part of the analytical process to deliver the deep dive analyses, it is noteworthy that four key themes were found across several subsamples in detailing what could be improved about their experience of care:

- Administration – examples of errors and the impact of this
- Mental health support – examples of being unaware or unable to access
- Financial support – examples of being unaware or unable to access
- Sensitivity in communications – a consistent example was around diagnosis

4

Subsample findings: people living in the most deprived areas

Gratitude

When asked what could be improved about their cancer care, the overwhelming majority of respondents from the most deprived subsample made no suggestions and expressed gratitude for the care experienced.

Some examples are shared below of gratitude found in the subsample analysis:

- *“I was amazed how quickly I was diagnosed and operated on by such amazing staff”*
- *“No, everything was excellent from start to finish”*
- *“Nothing at all - everything was excellent”*
- *“No one could of done anything any better, thank them all”*
- *“As always with the NHS, I feel I am treated like the only patient they have... a service that is second to none”*
- *“I cannot thank the staff, and especially the surgeon enough! They are all amazing, giving me so much care and attention from start to finish. I received first class care”*

National parallels

Alongside ‘gratitude’ a number of insights for the most deprived subsample analyses mirrored the national report as listed below:

- Negative experiences with the GP (delayed diagnosis; lack of follow-up; poor access)
- Communication for patients (more information including cancer type, treatment and side effects, and dos and don’ts of surgery; the need for a single point of contact; more communication and information needed after discharge as an in-patient)
- Co-ordination of cancer care (between and within different hospitals and departments)
- Waiting times (physical waits while in hospital for appointments and procedures; for test results; for prescriptions and medicines)
- Negative experiences with hospital staff (staff availability)
- Wider hospital issues (food quality; noise levels)

Unique insights

Six unique themes were found during thematic analysis of the most deprived subsample, which highlighted a need for improvements to:

Transport	Financial support	Mental health support
Macmillan support	Sensitivity around diagnosis	Quality of care

Transport

The issue of transport was evident in the subsample of those living in the most deprived areas in a range of ways. For example, the impact to health of travelling was mentioned and implied that distance was problematic; the costs of travel were commented on; and some described that transport should have been provided but was not.

- *“Travelling to (name) everyday was exhausting, but I understand why when this specialist unit is used”*
- *“Travelling to (name) is a problem for elderly people – it is expensive and exhaustive”*
- *“According to my condition and appointment, you can improve by giving people travel arrangements to get to the hospital”*
- *“When recovering from treatment, it would be nice to get transport home within 20 mins as sometimes there was a wait of 1 hour. I live locally. It is sad for those who live far away when the taxi picks you up from that long wait. They have said on several occasions that it's not worth their while to take home local patients. I informed reception at the time”*

Furthermore, attention was drawn to the impact of administration errors regarding transportation. Inaccurate appointment times for example were problematic for the patients living in the most deprived areas that were reliant on others for transport such as friends, family members or public services.

- *“Appointment time that I got was wrong on one occasion which is no fun when you have to travel on public transport!”*
- *“Appointments would get messed up and you'd be waiting on transport home”*

- *“Sometimes I would get appointments, turn up to the appointment and it had turned out that my appointment had been cancelled or rescheduled and I was not informed. This would cause me to waste a lot of people’s time such as the transport team or a family member who would often offer to give me a ride, which made me feel bad”*

Financial support

What does the quantitative survey data tell us?

- 67% of patients within the most deprived subsample said they were offered information about how to get financial help or benefits

Some respondents expressed a need for financial support which they did not receive or receive in a timely manner. Improved signposting to financial information, advice, and support would have helped several patients in the subsample.

The role staff can play was also highlighted in two examples shared which described unhelpful experiences with a staff member and how this had contributed to their need for financial support being unmet.

- *“Financial help would have been appreciated”*
- *“At no time was I told by anyone at (name) that I may be entitled to financial help i.e., travel costs etc.”*
- *“I would have liked more information about financial support available (e.g., PIP). I managed to get some information from other patients, but it was too late (as it was at the end of my treatment)”*
- *“Financial support”*
- *“During the chemotherapy stage the parking charge is voided whilst using the carpark, would it be possible to extend the same criteria to urgent cases for medication to stop the CPP demanding such sums as to cause stress since the treatment causes enough stress”*
- *“My overall treatment has been excellent but at the start of my condition when I needed help and advice to sort my financial problems out, I was told it would get sorted by my appointed nurse but unfortunately, she didn't help very much and we could never get hold of her, so in the end my partner and myself had to deal with it. As well as dealing with me being told I had cancer”*
- *“The oncology nurse (specialist) who is supposed to support me has been useless, difficult to get hold of. On one occasion when I did manage to catch her, and I was particularly low, she told me she had*

been waiting for me to call. I had been far too "Gung Ho". Totally the wrong attitude. Needless to say, I have not contacted her since. I have been very positive throughout this horrible illness despite being told it is stage 4. I still say I will beat it and so far, so good. I do need financial advice but will not contact her"

Mental health support

What does the quantitative survey data tell us?

- 89% of patients within the most deprived subsample said staff provided them with relevant information about support or self-help groups, events or resources for people with cancer
- 77% of patients within the most deprived subsample said they definitely got the right level of support for their overall health and wellbeing from hospital staff
- 34% of patients within the most deprived subsample said after treatment, they definitely could get enough emotional support at home from community or voluntary services

A need for more information and access to mental health support was found in the subsample. Several comments pointed to a need for more proactivity to ensure patients are informed and offered the mental health support they need at varying stages of their experience of cancer care.

- *"Information on support groups as it felt like a lonely time at the time"*
- *"Information about counselling"*
- *"I really do need to know who my support worker is as I really do need to know when remedial work is being carried out"*
- *"IMHO they are amazing and did a fantastic job, but to highlight a possible improvement by expanding the team with a dedicated mental health professional/contact to help patients mentally cope with what they're facing"*
- *"Only thing maybe is support i.e., mental wise. I am a strong person, but I felt at times I needed a bit of support but saying that I never asked so works both ways I guess"*

- *“Just more interaction from my breast care nurse, she would have been able to see my mental health was deteriorating badly and maybe been able to help or give me advice”*
- *“I should have been offered more psychological support. Going through cancer at 18 was extremely hard and nobody at (name) or otherwise ever asked if I was okay. Now 24, and still living with cancer, I have sought my own therapy, counselling & support from charities”*
- *“I have been experiencing anxiety in the past couple of months (delayed reaction to the whole experience) and I had really hoped the follow up would help with this. I understand there are groups who could help me and perhaps I will look into this if I don't feel better soon”*

Macmillan support

Several respondents highlighted how their expectations for support from Macmillan, or professionals labelled as Macmillan professionals, were unmet. Examples spanned communications and access through to mental health and financial support.

- *“Macmillan visits/phone calls could be improved”*
- *“Only thing that would have helped more is for another MacMillan nurse to contact me and give me contact details if I needed support”*
- *“Yes, more contact from MacMillan nurse”*
- *“Communication with the Macmillan nurses was good to start with, I got a phone call a week from March to June and never had one since asking how I am coping”*
- *“Every time I rang the MacMillan number, I was told someone will ring me back. No phone call”*
- *“MacMillan nurses did not help at all. I was on my own from the first treatment until the last. I was suffering with PTSD over the whole cancer treatment”*
- *“Specialist nurse suggested financial help from MacMillan I wrote the application letter but was never contacted again”*

Sensitivity around diagnosis

What does the quantitative survey data tell us?

- 74% of patients within the most deprived subsample said they were definitely told sensitively that they had cancer

The language used to describe communication of diagnosis was emotive including words such as ‘blunt’, ‘brutal’ and ‘insensitive’. A call for improved sensitivity in confirming and communicating a diagnosis of cancer was made by several respondents in the subsample.

- *“When I asked the question ‘So have I got cancer?’ to the doctor who was taking a biopsy, her reply, matter of-fact, took me by surprise. She did apologise”*
- *“Yes - the way I was told about my diagnosis. I had an MRI scan as an outpatient. After the scan I was called into a side room by a doctor, I was on my own and not asked to be seated. As you can imagine I was in shock. It was very insensitive”*
- *“Informing me of the initial diagnosis should have been much better planned”*
- *“The way (name) told me I had breast cancer; I hadn't even sat down; in fact, her manner was quite brutal”*
- *“I know all the consultants are very busy, but I was frightened when he told me I had cancer as I only went in for my appendix. He just came out with ‘you do know you had cancer’ and that was soon afterwards. I do not know what I would have done. I've had panic attacks ever since”*
- *“I did feel I could have been told more sensitively as I didn't expect to be told bluntly - you need a mastectomy!”*

Quality of care

What does the quantitative survey data tell us?

- 89% of patients within the most deprived subsample said they were always treated with respect and dignity while in hospital

Within the subsample it was clear that for some respondents the care they received did not meet their expectations. The shared sentiment in the range of examples was a need for staff to take more ‘care’ with them as individuals. This presented in varying

ways from staff having caused additional experience of pain by being 'rough' through to closer monitoring regarding prevention of infection.

- *“Yes! More dressings for allergic skin like mine in bloods dept. To examine for infection more closely as I had yellowy crusty discharge on dressing and they just cleaned it and removed the picc line. The same day I had to be blue heightened into hospital. I had constant problems with painful picc line”*
- *“The A&E department must be equipped with these type of drain bottles and also the doctors must have knowledge on using the picco device. They told me to remove batteries as well. They made my blisters worse by covering them instead of removing the excess fluid then putting a dressing on. The blister became macerated and painful”*
- *“Dressings need to be changed regularly; it took 3 days for them to realise I was allergic to the wound dressings”*
- *“Some of the nurses are friendly and do not care about your pain especially when they want to find the vessel. I always have bruises in my hand after chemo and it really makes me upset”*
- *“There was a young doctor who saw me who seemed to be quite stressed. He asked to see my wound and he pulled where my stitches were and asked, ‘what is going on here? What is this?’ – he pulled my stitch and I replied, ‘be careful, it is where I had keyhole surgery’. He ripped my skin somewhat and left me in some pain”*
- *“The only thing I didn’t like was the way I was put to sleep - it was a bit rough”*

5

Subsample findings: people from ethnic minorities

Gratitude

When asked what could be improved about their cancer care, the overwhelming majority of respondents from the ethnic minorities subsamples made no suggestions and expressed gratitude for the care experienced.

Some examples are shared below of gratitude found in the subsample analysis:

- *"Everything was great"* (Ethnic minority group: Asian)
- *"No everything was perfect"* (Ethnic minority group: Asian)
- *"Not that I am aware of as I was treated with total duty of care"* (Ethnic minority group: Black)
- *"Keep up the good work thank you"* (Ethnic minority group: Black)
- *"[Hospital] were great - not sure what could be improved - admin on the desk to the surgeon were fantastic, helpful, caring, contactable warm and professional at all times"* (Ethnic minority group: Mixed)
- *"I don't think there is anything that needs improving. I was cared for and I was listened to and I can't ask for more than that!"* (Ethnic minority group: Mixed)
- *"Everything was brilliant and way exceeded my expectations!"* (Ethnic minority group: Other)
- *"I wouldn't change anything"* (Ethnic minority group: Other)

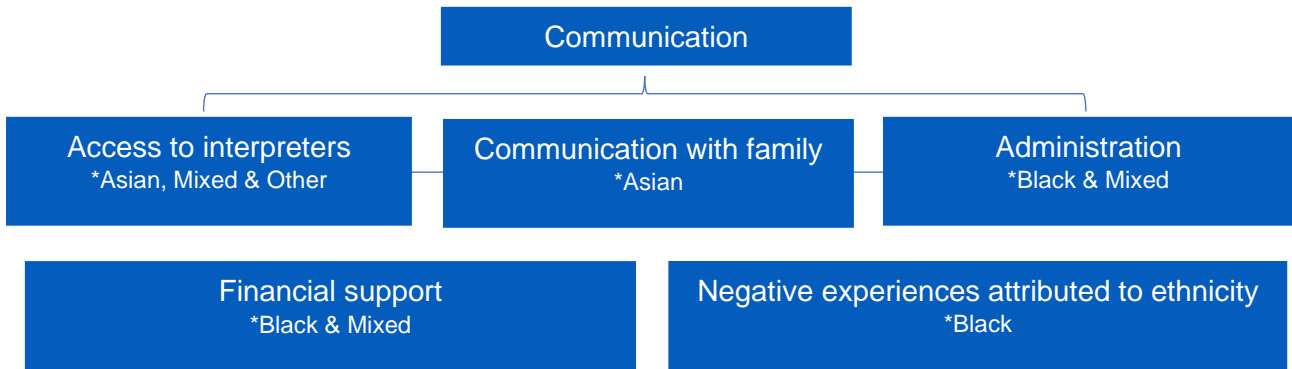
National parallels

Alongside 'gratitude' a number of insights for the subsample analyses of people in ethnic minority groups mirrored the national report as listed below:

- Negative experiences with the GP (delayed diagnosis described by Asian, Mixed and Other respondents)
- Communication for patients (more information needed on cancer type, treatment, side effects and dos and don'ts of surgery described by all; the need for a single point of contact described by Mixed respondents)
- Waiting times (physical waits while in hospital for appointments and procedures described by all; for test results described by Asian and Other respondents)
- Negative experiences with hospital staff (staff availability described by all; unprofessional attitudes described by Asian and Other respondents)
- Wider hospital issues (food quality described by Black respondents)

Unique insights

Five unique themes were found during thematic analysis of the ethnic minorities' subsamples, which highlighted a need for improvements to:



Communication is the common thread woven through the first three unique themes above regarding interpreters, family members and administration. It is also useful to note that the fourth theme of financial support also includes mentions of how signposting to what is available was found to be an unmet need. This could also be considered insight as to communication needs.

Access to interpreters

Comments were made across the Asian, Mixed, and Other ethnic minority subsamples regarding the need for interpreters / translators to assist and accommodate patients experiencing language barriers.

- *“The option for a translator service was not available. We could not get hold of information leaflets in another language (Bengali)”* (Ethnic minority group: Asian)
- *“More availability of interpreters”* (Ethnic minority group: Asian)
- *“English is not my first language and despite my family asking for interpreter for me. I never got one”* (Ethnic minority group: Asian)
- *“Some challenges as Punjabi is my first language which has been the biggest barrier, but family have been supportive which has made this easier”* (Ethnic minority group: Asian)
- *“The lack of means for people who do not speak English well, I did not always have an interpreter and communication was very bad”* (Ethnic minority group: Mixed)
- *“I would say if there were more staff to assist patients and/or leaflets which enclose information of their visit for patients who don't speak English as their first language”* (Ethnic minority group: Other)

Communication with family

What does the quantitative survey data tell us?

- 62% of Asian respondents told us their family member or someone close to them were definitely able to talk to a member of the team looking after them in hospital

Within the Asian subsample, a small number of respondents commented that improvements could be made in relation to communication with family. The three comments shared below demonstrate that the reasons may vary patient to patient.

One example highlights a language barrier experienced by the patient to be the reason for family involvement; the other two briefly demonstrate an expectation for family involvement in receiving updates on their care relating to test results and an inpatient stay.

- *“Communication, relaying of results to family”* (Ethnic minority group: Asian)
- *“If staff were to communicate better with family while I was in hospital”* (Ethnic minority group: Asian)
- *“There was a language barrier whilst the stay in hospital, family member was communicating with the hospital staff and the patient. Had problems with communications with patient”* (Ethnic minority group: Asian)

Administration

What does the quantitative survey data tell us?

- 90% of Black respondents and 87% of Mixed respondents reported that administration of care (getting letters at the right time, doctors having the right notes/tests results, etc) was ‘very good’ or ‘good’

Respondents within the Black and Mixed subsamples highlighted the impact of administration errors. They explained that it can take a long time to receive letters and appointments were cancelled without any knowledge or at short notice.

On one occasion, the respondent had no knowledge of the cancellation until they attended hospital.

- *“My appointments were cancelled with me not knowing and I was sent a new appointment stating that I had cancelled when I did not receive the said first appointment”* (Ethnic minority group: Black)

- *“However, the administrative services, have been like incorrect & very late appointment letter; inaccuracies; letters referring you to call with queries, but no phone number provided; indifferent support when phone calls are made; very late letters after consultant reviews”* (Ethnic minority group: Black)
- *“Received letters relating to appointments were at times cancelled without due notification. I was only made aware of such cancellation upon arrival to the hospital”* (Ethnic minority group: Black)
- *“The administration at (name) is generally poor - letter come late, on with very little warming about appointments”* (Ethnic minority group: Mixed)
- *“Appointment letters often not received in time or appointments are not made - have had to chase many times - shouldn't someone be overseeing this?”* (Ethnic minority group: Mixed)

Financial support

What does the quantitative survey data tell us?

- 69% of Black respondents and 66% of Mixed respondents reported that they were offered information about how to get financial help or benefits

Experiences shared by Black and Mixed ethnic minority respondents drew attention to issues of financial support during the cancer journey. Respondents highlighted the financial impact of having cancer during an already stressful time and expressed unmet needs for support, e.g. costs of transportation. There was a desire for more information to be communicated as to what financial support was available.

- *“Trying to access help from consultants’ nursing/staff for forms with benefits etc.”* (Ethnic minority group: Black)
- *“People of colour need additional support as they might be isolated and not have the appropriate support. There needs to be more support services such as counselling, wellbeing staff, home visits, non-means tested support, prosthesis that are for people of colour”* (Ethnic minority group: Black)
- *“A little bit more information about benefits and financial support. I only found out I was entitled to free prescriptions 1 year later”* (Ethnic minority group: Black)
- *“Transport for treatment and the use of the Voluntary Service, not sure if we’re relying on this service when we should have a paid service where service level agreements have been signed and staff are paid for providing a professional service. I found it slightly worrying or disconcerting to be told that I should call this number to arrange transport myself when in the throes of using a service that by its very definition means that the individual is in crisis,*

you shouldn't be thinking about finance at that point, the State should be looking after you" (Ethnic minority group: Black)

- *"Knowing what I know now, it would be to set out the financial impact it will have on you and that even if you don't want to claim any benefits you should do so as soon as possible. The stress of having a cancer diagnosis and worrying about finances is one thing that needs to be off the table as you concentrate on getting well. You must get your teeth seen to by a dentist, as you don't want any issues to arise in regard to your teeth while you are going through treatment. Silly but practical things, like making sure you get the best rates on heating as you will need to use a lot of it"* (Ethnic minority group: Black)
- *"More information about financial support"* (Ethnic minority group: Mixed)

Negative experiences attributed to ethnicity

Within the Black subsample, two respondents highlighted that a negative experience of care they had was directly attributed to their ethnicity.

One felt that they received lack of care from African doctors, highlighting that they felt this was a result of being a fellow African. They mentioned a perception that doctors from other nationalities had given them more help.

- *"Yes. Please train the African staff to be helpful and caring to us fellow Africans. I found most of them unhelpful compared to other nationalities. I am a Nigerian myself and it seems once you are Nigerian, a fellow Nigerian treats you with less detail, less concern, less empathy, less care"* (Ethnic minority group: Black)

Another respondent discussed issues that emerged from the tattoo markings given during radiotherapy treatment. They were not offered a tattoo colour that would be visible on their skin, leaving the respondent feeling embarrassed and unable to clean themselves for a considerable amount of time.

- *"In (name) I had to get temporary tattoos to the areas I was to receive the radiotherapy. I am black skinned, and they had to ask me to wear clear medical tape over the tattoos as this was the same colour of my skin & they didn't seem to be able to see the marks on my skin. In this age of technology, it was quite embarrassing I was not offered white tattoos so it could be seen. I couldn't bath for weeks & weeks as they said the black tattoo would come off"* (Ethnic minority group: Black)

6

Subsample findings: people reporting a mental health condition

Gratitude

When asked what could be improved about their cancer care, the overwhelming majority of respondents reporting a mental health condition made no suggestions and expressed gratitude for the care experienced.

Some described their overall experience as ‘excellent’ and ‘brilliant’, with staff members praised in the same way as was found in the national sample.

Some examples are shared below of gratitude found in the subsample analysis:

- *“No one could have done anything any better than them all”*
- *“Nothing everything was quickly sorted for myself thank you”*
- *“I found all my treatments dealt with in the highest standard”*
- *“Not a thing happy with my care treatment”*
- *“No everyone was amazing in the hospital. Hospital very respectable”*
- *“No. For a service that is FREE, I have nothing to complain about, nothing that has gone wrong and nothing I would change”*
- *“Nothing I am very happy, excellent service. My cancer nurse [name] was wonderful always at the end of the phone. I cannot say anything about my consultant so amazingly brilliant and kind”*

National parallels

Alongside ‘gratitude’ a number of insights for the subsample analysis of people reporting a mental health condition mirrored the national report as listed below:

- Negative experiences with the GP (lack of follow-up)
- Communication for patients (more information needed on cancer type, treatment and side effects; the need for a single point of contact; more communication and information needed after discharge as an in-patient)
- The co-ordination of cancer care (within the hospital)
- Waiting times (physical waits while in hospital for appointments and procedures)
- Negative experiences with hospital staff (staff availability; unprofessional attitudes)

Unique insights

Three unique themes were found during thematic analysis of the mental health condition subsample, which highlighted a need for improvements to:



Administration

What does the quantitative survey data tell us?

- 83% of patients who reported having a mental health condition reported that administration of care (getting letters at the right time, doctors having the right notes/tests results, etc) was very good or good

The experience and impact of administration errors when communicating with patients was highlighted within the subsample. Administration errors included: delayed letters, mix-ups with appointment bookings, delayed appointments, treatment cancellations, over reliance on text messages and incorrect information being shared. As an example, one respondent described how they had chased for copies of letters sent to their GP for multiple years.

- *“Fewer admin mistakes - major treatment cancellations, checked to see if they were correct”*
- *“There was one admin mix-up that meant an appointment with a consultant was delayed by 3/4 weeks”*
- *“Administration needs improving e.g. I rarely get copies of my letters to GP and I have been asking for these for over 6 years”*
- *“Appointment letters often not received in time or appointments are not made - have had to chase many times - shouldn't someone be overseeing this?”*
- *“Appointments and letters not being sent in time”*
- *“General administration & appointments seem to be a little chaotic & not always supported with a letter (too much reliance on text messages)”*
- *“If one could nit-pick, formal letters could arrive before texts that allude to 'see appointment letter' when there hasn't been one”*

Delivering sensitive news

What does the quantitative survey data tell us?

- 67% of patients who reported having a mental health condition reported they were definitely told they had cancer in a sensitive way
- 55% of patients who reported having a mental health condition reported they were always able to discuss worries and fears with hospital staff
- 67% of patients who reported having a mental health condition reported they were always able to discuss worries and fears with hospital staff while being treated as an outpatient or day case

Respondents reported a wish for more consideration when staff delivered sensitive news to them in terms of diagnosis, treatment plans and results. Several respondents wished for communication to be face-to-face, in a private room. There was also a need expressed by some to have the opportunity to ask questions.

As an example of impact, one of the comments shared below mentions that they have PTSD from the way in which they were told they had cancer.

- *“First mention of cancer, the junior doctor announced 'sorry' you have a massive [condition]”*
- *“I was disappointed by the contact with the oncologist, (name). He phoned me, unannounced, whilst I was at work to tell me about and discuss my treatment. Other phone calls from the breast cancer team were planned and I was able to have someone with me. He did not even check that I was in an appropriate place to talk about the treatment. I know that face to face appointments were not possible at this time, but I would have much preferred an appointment time for this call”*
- *“I was told I had [condition] in a corridor 11.30pm in A&E after more than 10 hours. I was very tired and unwell for 3 months”*
- *“The way the surgeon told me I had cancer as I had no family or friends around me, and the surgeon showed no sympathy. I spoke to someone from cancer survivorship, and they said I have PTSD from the way I was told”*
- *“My tumours were initially found via a scan at A&E - I was told in front of a busy room of patients that I had `a large growth, possibly a cyst' on my kidney and needed an urgent referral. Whilst I accept that no diagnosis could be given at this stage, I do not think this was acceptable”*
- *“Some staff deliver life changing news in an insensitive way & do not allow you to ask questions (e.g. very abrupt & rush you out)”*

- *“Not being told I had cancer, in the A&E department, on my own!”*
- *“Things could have been improved regarding my care post-surgery in particular the communication concerning my chemotherapy. I had not been told I would be having chemotherapy and I found out from a phone call asking me to go for a blood test! This was an absolute shock and more upsetting than if I had been told in a proper setting/appropriate manner i.e., at a face-to-face appointment with someone from the oncology team”*

Mental health support

What does the quantitative survey data tell us?

- 63% of patients who reported having a mental health condition reported they received the right level of support for their overall health and wellbeing from hospital staff
- 27% of patients who reported having a mental health condition reported that after treatment, they definitely could get enough emotional support at home from community or voluntary services

Respondents highlighted the need for improved access to mental health services. Some respondents said that they were not offered any mental health support. Others mentioned that wait times to be able to access mental health services were too long.

As well as emotional support to help respondents living with cancer, needs extended to living beyond cancer, including support with returning to work and ongoing isolation as examples.

- *“There has been zero after care. I had to refer myself to the mental health team following the treatment delayed shock”*
- *“It took a while to get counselling support”*
- *“Mental health support before the operation would be good and more follow up regularly after hormone therapy”*
- *“Just some support from mental health services after treatment”*
- *“I thought that very little explanation was given to me about the backup services that were available for people who have a cancer diagnosis. I was left with numbers I could ring from the hospital if I had any physical problems with the cancer, but no contact numbers were left so I could cope with the emotional side to cancer. I was alone in the house for a quite a long period after the diagnosis due to Covid”*

- *“More access and little waiting times for emotional support, more counselling for patients”*
- *“Emotional care and support beyond cancer treatment (going back to work etc)”*
- *“I have not been offered any psychological treatment despite the fact I believe I am suffering from PTSD”*
- *“Not enough mental support to deal with my anxieties & fears. No support offered to deal with isolation, no wellbeing support. Total isolation from other cancer sufferers & no support offered going forward”*

7

Subsample findings: people with Learning Disabilities

Gratitude

When asked what could be improved about their cancer care, the overwhelming majority of respondents with a learning disability made no suggestions and expressed gratitude for the care experienced.

Some described their overall experience as 'excellent', and staff were praised in the same way as was found in thematic analysis of the national sample.

Some examples are shared below of gratitude found in the subsample analysis:

- *“Everything was spot on - without these amazing people I would not be here today!!!”*
- *“Everything was just fine. Could not have wished for more”*
- *“I am pretty happy with the way that I was cared for by the medical staff. No complaints at all. Personally speaking, they were absolutely great with me”*
- *“No they all did a fantastic job & anything I needed from doctors to surgeons did an amazing job top class cannot fault the whole team”*

National parallels

Alongside 'gratitude' a number of insights for the subsample analysis of people with a learning disability mirrored the national report as listed below:

- Negative experiences with the GP (delayed diagnosis; poor access)
- Communication for patients (more information needed on cancer type, treatment and side-effects; the need for a single point of contact; more communication and information needed after discharge as an in-patient)
- The co-ordination of cancer care (within the hospital)
- Waiting times (to start treatment; for test results; physical waits while in hospital for appointments and procedures)
- Negative experiences with hospital staff (unprofessional attitudes)
- Wider hospital issues (choice of food available)

It should be noted that the sample size for the learning disability subsample is much smaller than the national sample. This is helpful context as unique themes which follow were identified by a small number of respondents.

Unique insights

Two unique themes were found during thematic analysis of the learning disability subsample, which highlighted a need for improvements to:



Sensitivity around diagnosis

What does the quantitative survey data tell us?

- 71% of patients with a Learning Disability said they were definitely told sensitively that they had cancer
- 77% of patients with a Learning Disability said they were told they could have a family member, carer or friend with them when told diagnosis
- 81% of patients with a Learning Disability said that they were definitely told about their diagnosis in an appropriate place

Respondents within the learning disability subsample highlighted the need for more consideration and sensitivity to be provided when a cancer diagnosis was delivered.

Some patients described experiencing a lack of sympathy or understanding from staff when the news was shared.

- *“The way the surgeon told me I had cancer as I had no family or friends around me and the surgeon showed no sympathy. I spoke to someone from cancer survivorship and they said I have PTSD from the way I was told”*
- *“First mention of cancer, the junior doctor announced 'sorry' you have a massive [condition]”*
- *“The hospital should have informed me I had cancer as my GP told me a couple of weeks later”*
- *“I was told I had [condition] in a corridor 11.30pm in A&E after more than 10 hours”*

Reasonable adjustments

What does the quantitative survey data tell us?

- 61% of patients with a Learning Disability said diagnostic test results were explained in a way they could completely understand
- 70% of patients with a Learning Disability said that treatment options were explained in a way they could completely understand

The common thread across the insights detailed within this theme is that care was not reasonably adjusted to better meet the individual needs of patients with a learning disability.

Within this theme there was inference of the requirement for staff to be trained to better support patients with learning disabilities and their families/carers. The quotation below is shared as an explicit call for comprehensive staff training to result in improved care for patients with learning disabilities including autism.

- *“Staff need autism training!!!! Focus needs to be on: presuming competence, sensory issues, communication differences, need for additional support person”*

A range of examples were shared both by patients and their parents/carers which highlighted that a negative experience of care was attributed to the patient having a learning disability and/or autism, i.e. this experience would not have happened if the patient did not have a learning disability and/or autism and/or reasonable adjustments had been put in place.

What is common across these examples is a need to tailor and adjust care for individual needs. Importantly, these needs may vary from patient to patient as learning disabilities present and impact in a multitude of ways.

- *“On the day of the operation when we arrived the ward has changed. [name] has LD limited understanding, he was placed next to a gentleman that was screaming and shouting. [name] didn't understand and became frightened. No reasonable adjustments made at the hospital”*
- *“I was only allowed 1 hour visits per day when admitted to the hospital, despite having two carers at home. As the ward staff is busy with other patients, this led to a significant drop in my healthcare. As a result of the drop in my care, I suffered a fall and my mental condition has worsened. I still have not recovered from my inpatient stay and do not wish what I experienced on anyone”*

- *“Autism support should be made available to anyone who has to navigate through hospital stays, particularly for someone who has to visit multiple different departments/specialities”*
- *“Listening to us as parents. Better communication and not writing my son off as if he didn’t matter because of his learning disability. He didn’t care. Then when I was upset not throwing his hands up and saying don’t blame me he has cancer exploring other treatment options listening to us not ignoring us. Allowing us to leave the hospital with no hope and extremely frightened as to what was going to happen. Even the learning disability nurse said nothing when we left expect am so sorry and that was as the lift doors closed !! Not making me feel as though am being difficult because I wanted treatment for my son not making us feel as a family that we were worthless and so was my son and not worth saving”*
- *“I’m a support worker & felt the decision of chemo was taken out of [name] hands by [name] as because [name] has a mental illness & learning difficulties she felt [name] would not cope”*

It was also highlighted that it is important to ensure communication methods used are appropriate and consideration is given as to what will be most suitable for each individual patient. Again, a range of examples were shared demonstrating the way communication needs vary for individual patients with learning disabilities and/or autism and how one method is unlikely to be accessible for all patients equally.

- *“There was some difficulty in communicating. But this is partly down to my own disability, having been recently diagnosed with Autism”*
- *“More easy reading for people with learning disabilities”*
- *“Not having face to face reading with the consultant on review was difficult because of my communication issue”*
- *“I would have liked a one to one with a nurse/volunteer about financial help or just a cup of tea and an informal chat as I did not read the many booklets that were given to me due to my own difficulties. My daughter helped a lot”*
- *“All of my communication is done through my nephew, but when he is busy, the Big Word system does not work effectively. All staff should be trained on how to use Big Word to improve access to healthcare”*

8

Subsample findings: people aged 16 to 44

Gratitude

When asked what could be improved about their cancer care, a vast number of respondents aged 16 to 44 made no suggestions and expressed gratitude for the care experienced. While significant to note, compared to the national qualitative sample, gratitude was not expressed by the overwhelming majority of those in this subsample.

Some described their overall experience as ‘excellent’, and staff were praised in the same way as was found in thematic analysis of the national sample. While not an overwhelming majority for this subsample, it remains important context to keep in mind as the unique insights for the subsample are explored within this chapter.

Some examples are shared below of gratitude found in the subsample analysis:

- *“Nothing at all - everything was excellent”* (Aged 16 to 24)
- *“Nothing at all. It was an excellent experience in all areas. {Name} and all the staff I interacted with were amazing!”* (Aged 16 to 24)
- *“Everything they have done was perfect”* (Aged 16 to 24)
- *“Excellent, first class, compassionate care following diagnosis”* (Aged 25 to 44)
- *“I couldn’t think of anything to improve. The service was excellent! Hats off to all the people who work for the NHS!”* (Aged 25 to 44)
- *“Once I was referred, I cannot fault the care I received! My specialist nurse has been exceptional as well as the consultants I have seen”* (Aged 25 to 44)

National parallels

Alongside ‘gratitude’ a number of insights for the subsample analysis of people aged 25 to 44 mirrored the national report as listed below:

- Negative experiences with the GP (delayed diagnosis and lack of follow-up described by all)
- Communication for patients (more information needed on cancer type, treatment, side effects and dos and don’ts of surgery; the need for a single point of contact; more communication and information needed after discharge as an in-patient described by all; preference for face-to-face communication described by respondents 25 to 44)
- Co-ordination of cancer care (between and within different hospitals and departments described by all)

- Waiting times (to start treatment; for test results; physical waits while in hospital for appointments and procedures described by all; to be discharged and transported described by respondents aged 25 to 44)
- Negative experiences with hospital staff (staff availability; unprofessional attitudes; more specialist staff training described by all)
- Wider hospital issues (noise levels; a need for privacy described by all; parking and drop-off areas and food issues described by respondents aged 25 to 44)

Unique insights

Six unique themes were found during thematic analysis of the respondents aged 25 to 44 subsample, which highlighted a need for improvements to:

Involvement in treatment decisions	Menopause support	Financial support
Access to Clinical Nurse Specialists	Administration	Mental health support

Apart from ‘mental health support’, all other themes were found only in the analysis of data collected from respondents aged 25 to 44. This perhaps reflects the low volume of written feedback collected for those aged 16 to 24, keeping in mind that every comment shared by this age group in response to QB was included in the analysis.

Involvement in treatment decisions

What does the quantitative survey data tell us?

- 75% of patients aged 25 to 44 said treatment options were explained in a way they could completely understand
- 68% of patients aged 25 to 44 said they were definitely involved as much as they wanted to be in decisions about their treatment
- 51% of patients aged 25 to 44 said they could get further advice or a second opinion before making decisions about their treatment options

Amongst those aged 25 to 44, there was desire for improvement regarding their

involvement in treatment decision making. The quotes shared below illustrate that several respondents would have liked to have been provided with different options for their treatment, including alternative therapies.

Other quotes refer to being 'dismissed' on having raised alternative therapies for consideration. In this context the respondent is positioned as not having had expectations met as to their influence and therein involvement in the treatment decisions made.

- *“More info complementary / holistic treatments would be good, such as cancer specific meditation, nutrition etc. Staff very dismissive so I had to find info & groups myself. This is time consuming and high risk as you have to work out which sources / specialists are good” (Aged 25 to 44)*
- *“I would have liked to be informed about potential clinical trials & alternative therapies & nutrition. Alongside my treatment” (Aged 25 to 44)*
- *“A more open mind should be adopted by the NHS and its Oncologists regarding other Holistic, alternative or integrative approaches that may be complementary and/or beneficial to the aggressive conventional therapies of chemotherapy, radiotherapy and surgery that are generally offered” (Aged 25 to 44)*
- *“Other treatment options, taking a holistic view, supplements, trials, immunotherapy etc.” (Aged 25 to 44)*
- *“To let us know all the meds & options available” (Aged 25 to 44)*

Menopause support

Menopause can be either a consequence of cancer treatment amongst pre-menopausal women or can be induced as a measure to reduce recurrence risk amongst some cancers. For those who found themselves experiencing menopause during their cancer care journey, providing support and information regarding menopause was a key way in which their experience could be improved.

- *“Providing more information about the long-term side effects of the menopause. I was told that my treatment may put me into menopause but as a younger person I wasn't really aware of the impact menopause would have on my body and these side effects were assumed to be side effects of the chemotherapy. It wasn't until after my treatment had ended and my body recovered and I was still left with side effects that, after quite a lot of research & self-diagnosis, I worked out were caused by the menopause.” (Aged 25 to 44)*
- *“Talk about sex, the menopause (I got it at 33). No one even asked and I didn't know.” (Aged 25 to 44)*
- *“Have had no 'end' appointment to see about my mental wellbeing and effect of the menopause etc.” (Aged 25 to 44)*

Financial support

What does the quantitative survey data tell us?

- 71% of patients aged 25 to 44 said they were offered information about how to get financial help or benefits

A further theme identified amongst the 25 to 44 age group was the need for financial support and information.

- *“More support with day to day and finances”* (Aged 25 to 44)
- *“More information about financial support”* (Aged 25 to 44)
- *“Cancer was such a horrible experience & and having to worry about money was really bad”* (Aged 25 to 44)
- *“I claimed P.I.P on my own behalf but not sure if was entitled to anything else?”* (Aged 25 to 44)

Access to Clinical Nurse Specialists

What does the quantitative survey data tell us?

- 85% of patients aged 25 to 44 said they had a Clinical Nurse Specialist (CNS) as their main contact person within the care team
- Of those aged 25 to 44 that had a CNS as the main contact, 81% said they found it very or quite easy to contact them and 94% said they found advice very or quite helpful
- Of those aged 25 to 44 that did not have a CNS as the main contact, 60% said they found it very or quite easy to contact the main contact and 87% said they found advice from the main contact very or quite helpful

One of the most prevalent themes amongst respondents aged 25 to 44 was a lack of contact with clinical nurse specialists both generally and from breast cancer nurses specifically.

Some respondents found their breast cancer nurse difficult to get hold of; some felt their allocated breast cancer nurse should make more proactive contact; and others felt that they did not see their nurse often enough.

There were also some comments about clinical nurse specialists not being available regularly or being as easy to contact as respondents would like. Importantly, whilst many of the comments within this theme were from breast cancer patients, there were also comments from patients receiving treatment for other cancer types.

- *“Perhaps more spontaneous contact with the breast cancer specialist nurse during treatment - e.g. a phone call every couple of weeks to check in during chemo.... I must stress, that I didn’t *need* to speak to her about anything, and I gave no cause for concern, but it’s nice to have a check in perhaps a little more frequently.” (Aged 25 to 44)*
- *“The breast care nurse at {name} really needs to be a bit more motivated. She once took almost a month to get back to me. I was 3 sessions into chemo and my question was relevant prior to starting chemo. It was at this point I decided there was no point asking her for further support. It caused more stress than anything else.” (Aged 25 to 44)*
- *“Just more interaction from my breast care nurse, she would have been able to see my mental health was deteriorating badly and maybe been able to help or give me advice” (Aged 25 to 44)*
- *“Contact from the allocated breast nurse. I didn’t have any contact with her unless I contacted them. From that point of view, I didn’t feel like I had support from this team proactively to me, but when I contacted them they were very supportive” (Aged 25 to 44)*
- *“Support from clinical nurse specialist. Visits from the nurses when attending first chemotherapy or treatment, when you are most scared and need support” (Aged 25 to 44)*
- *“I felt at times the clinical nurse that was looking after my care was not always available when I needed advice or support” (Aged 25 to 44)*

Administration

What does the quantitative survey data tell us?

- 84% of patients aged 25 to 44 said that administration of care (getting letters at the right time, doctors having the right notes/test results etc) was very good or good

The need for improved administration, particularly in relation to appointments, was highlighted amongst the 25 to 44 age group in the subsample. Examples shared

spanned a range of issues including timeliness, volume and accuracy of communication through to consistency between different communication methods.

- *“Taking care to ensure that all medical details in any letters sent are correct. I received a copy of a letter sent to my GP indicating ‘results’ from my biopsy. This information did not match what I had understood from face-to-face meetings. When I enquired about these details, I was informed that the information in the letter had been incorrect! Receiving this incorrect information had caused me great stress and hopefully won’t be repeated again” (Aged 25 to 44)*
- *“All administration, letters etc. had the wrong information from {name} and lots of misleading information - wrong dates, wrong locations which is appalling service considering my illness” (Aged 25 to 44)*
- *“Administration: I received two letters & a phone call about my appointment - no one called. I was told that it was cancelled and should never have been booked” (Aged 25 to 44)*
- *“Admin was at times dreadful. Being sent letters to ask to attend a specific hospital 45 mins away, only to find out that it should have been a phone consultation. I received phone consultations without prior knowledge. Admin errors occurred at least 50% of the time” (Aged 25 to 44)*
- *“Missing letters despite requesting copies from the Oncologists secretary 3 times” (Aged 25 to 44)*
- *“More clarity on whether I needed to attend appointments or if they are phone calls, as quite often I had letters saying to attend and text messages saying not to attend. So had to phone my specialist nurse to see if I was supposed to attend or not as I found this very confusing” (Aged 25 to 44)*

Mental health support

What does the quantitative survey data tell us?

- 73% of patients aged 16 to 24 and 62% of patients aged 25 to 44 said they definitely got the right level of support for their overall health and wellbeing from hospital staff
- 42% of patients aged 16 to 24 and 30% of patients aged 25 to 44 reported that they definitely could get enough emotional support at home from community or voluntary services

It was identified across both age groups in the subsample, that a greater emphasis needed to be placed on the mental health of cancer patients with support offered from diagnosis through to treatment and living with and beyond cancer.

Many respondents felt that their mental health was overlooked and should be made a higher priority, with mental health and psychological support offered to all patients.

- *“More access and less waiting time for emotional support, more counselling for patients”* (Aged 25 to 44)
- *“Awareness of the impact on mental health is very overlooked, they only seem to focus on the physical side effects”* (Aged 25 to 44)
- *“I think information on resources and help for the psychological impact of the diagnosis could be more forthcoming. There is very little/no counselling offered/available”* (Aged 25 to 44)
- *“I think during treatment and post treatment if more resources or ideas about mental health could have been available to me then I think that the experience might of been different”* (Aged 25 to 44)
- *“More information on how cancer/treatment can affect you mentally, as I struggled more mentally than physically, and I wasn't really prepared for that”* (Aged 25 to 44)
- *“I should have been offered more psychological support. Going through cancer at 18 was extremely hard and nobody at {name} or otherwise ever asked if I was okay. Now 24, and still living with cancer, I have sought my own therapy, counselling & support from charities”* (Aged 16 to 24)
- *“I think mental health support needs to be available for everyone diagnosed with cancer”* (Aged 16 to 24)

9

Conclusions

Conclusions

The analysis identified several unique insights and variations in experience of care for the chosen subsamples which did not emerge in the national sample and analysis. These unique insights point to additional areas for improvement to consider alongside those informed by national insights which as shown, are largely mirrored for the subsamples and would be beneficial also to these populations.

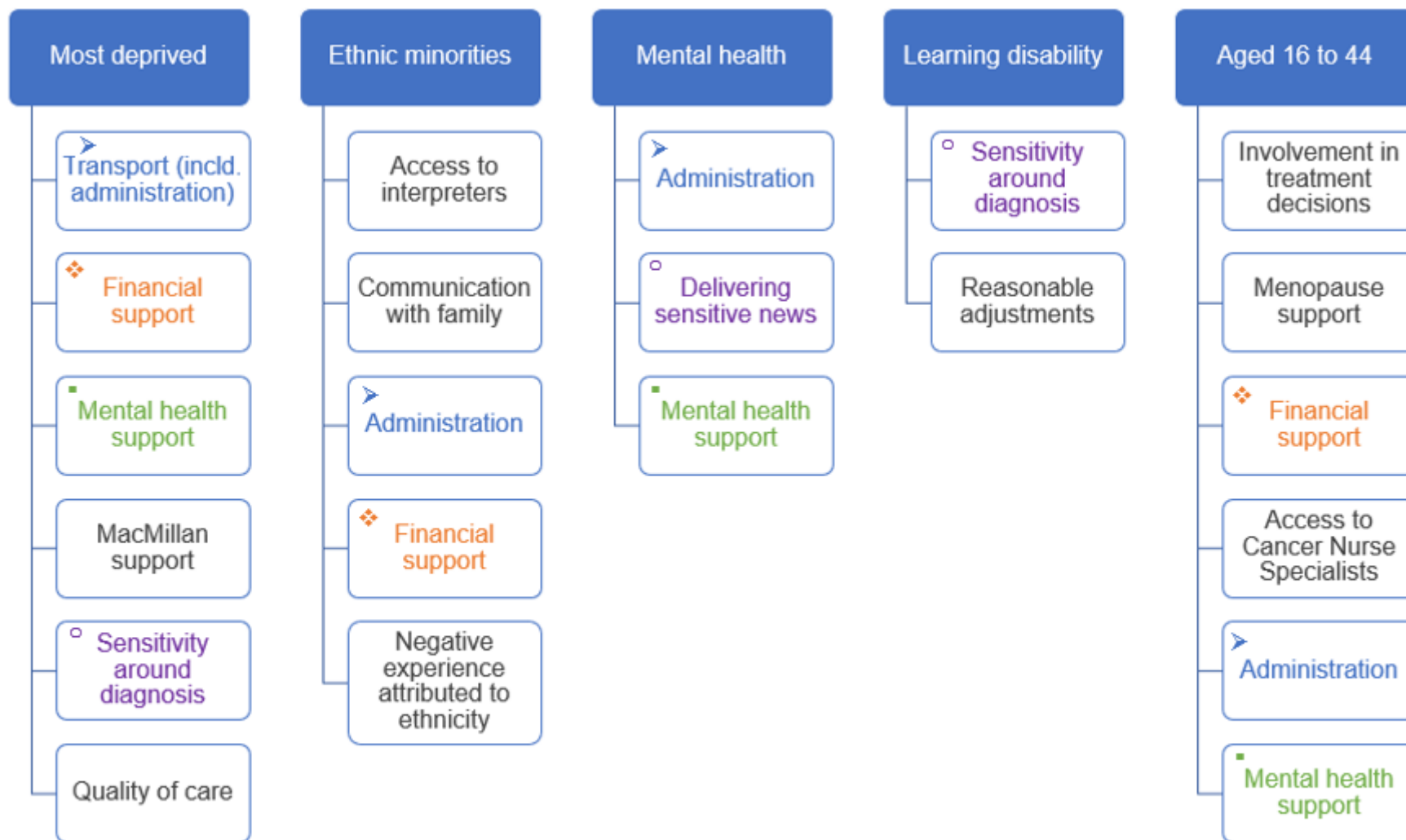
A visual summary of the unique insights for each subsample is shown on the page which follows. As highlighted earlier in the report, there are four themes which have overlapped, and this is visually displayed using colour and a key below. This includes the themes around **administration**, **mental health support**, **financial support**, and **sensitivity in communications**.

While described as unique insights, it is important to be clear that it does not mean the experience described is necessarily exclusive only to the specific subsample of focus. As detailed in the sampling section, respondents may be included in several subsamples reflecting the reality that these can overlap. For example an individual may have a learning disability and be aged under 45. Improvements which could be informed by this report are anticipated to have wider benefit with this in mind. Take administration as a good example of this.

It is highly unlikely administration errors which impacted on experiences of cancer care for several subsamples is happening only to these populations. The next steps recommended would be to further explore and consider **why** administration has emerged prominently in the thematic analysis for the subsamples and not for the national sample. It could indicate a different sense of importance placed on administration; a different level of impact when administration does not go well; or a different standard or set of expectations around administration, as examples. Without further exploration we simply will not know.

One drawback of qualitative data collected through survey methods is that the approach does not allow for further detail to be elicited through prompting, probing and deeper discussion as is the case for qualitative collection methods such as interviews and focus groups. The deep dive analyses make a strong case for triangulation with other existing evidence and/or additional primary data collection that is qualitative, to understand in greater depth **how** and **why** there is variation in cancer care to build further on what has been learnt through this exercise.

The findings as detailed within this report, while having exhausted the value of the qualitative data captured, arguably points only to **what** has varied for the subsamples. The insight has shed little light on **how** and **why** due to the lack of detail captured in the data which can best be described as 'thin'. It is with this in mind that the conclusion of this report is to encourage use of the findings alongside other insight from cancer patient experience data and engagement of lived experience partners, with the aim of meaningful listening and enacting coproduced improvements which matter most to cancer patients/families/carers and will deliver the greatest benefits.



❖ Financial support

▪ Mental health support

➤ Administration

○ Sensitivity in communications

10

Appendix: sampling information

This appendix details how the demographic characteristics of the subsamples of respondents included in the five ‘deep dive’ thematic analyses compare to the sample of ‘overall qualitative’ respondents for that population, i.e. only those that provided comments to QB asked in the survey. Numbers therefore differ to those within the overall quantitative sample because only those who answered QB are included for comparison. For information about how sub-groups were defined, please see the technical documents available at www.ncpes.co.uk.

As noted in the report, where there was a low volume of qualitative data for a specific population this rendered a sampling approach unnecessary and the whole dataset was included in thematic analysis. Of those who provided a comment to QB in the survey, the whole dataset was analysed for people with learning disabilities, the ‘other’ ethnic minority group, and those aged 16 to 24. A demographic breakdown has been provided for these populations.

Sampling information: people most deprived

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

Age	Overall sample of most deprived qualitative respondents (7,192)	Sample for thematic analysis (932)
16-24	0.4%	0.4%
25-34	1.5%	1.6%
35-44	4.1%	3.6%
45-54	10.5%	9.8%
55-64	25.6%	26.7%
65-74	33.6%	33.3%
75-84	20.7%	20.9%
85+	3.6%	3.6%

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

Gender	Overall sample of most deprived qualitative respondents (7,192)	Sample for thematic sample (932)
Female	51.8%	51.7%
Male	42.7%	43.0%
Not given	5.4%	4.9%
Non-binary	0.01%	0.1%
Prefer not to say	0.1%	0.1%
Prefer to self-describe	0.03%	0.1%

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

Ethnicity	Overall sample of most deprived qualitative respondents (7,192)	Sample for thematic sample (932)
Asian	4.7%	4.5%
Black	3.5%	2.9%
Missing / Not known	7.7%	6.9%
Mixed	1.5%	1.3%
Other*	0.6%	0.6%
White	82.0%	83.8%

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

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

Tumour Group*	Overall sample of most deprived qualitative respondents (7,192)	Sample for thematic sample (932)
Brain / CNS	0.6%	0.4%
Breast	21.9%	22.3%
Colorectal / LGT	13.2%	14.6%
Gynaecological	5.4%	4.4%
Haematological	12.1%	11.7%
Head and Neck	4.0%	4.1%
Lung	9.5%	9.4%
Other	9.9%	10.3%
Prostate	7.3%	7.4%
Sarcoma	1%	0.8%
Skin	2.3%	2.0%
Upper Gastro	4.8%	4.8%
Urological	8%	7.7%

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

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

Sexual orientation	Overall sample of most deprived qualitative respondents (7,192)	Sample for thematic sample (932)
Bisexual	0.5%	0.5%
Don't know / not sure	0.2%	0.1%
Gay or Lesbian	1.1%	0.9%
Heterosexual or straight	88.6%	90.6%
Not given	7.6%	6.4%
Other	0.4%	0.3%
Prefer not to say	1.7%	1.2%

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

ICS name	Overall sample of most deprived qualitative respondents (7,192)	Sample for thematic sample (932)
Bath and Northeast Somerset, Swindon and Wiltshire	0.8%	1.3%
Bedfordshire, Luton and Milton Keynes	1.1%	1%
Birmingham and Solihull	2.9%	2.8%
Bristol, North Somerset and South Gloucestershire	1.3%	1.2%
Buckinghamshire, Oxfordshire and Berkshire West	0.4%	0.5%
Cambridgeshire and Peterborough	1.0%	1.1%
Cheshire and Merseyside	4.7%	5.5%
Cornwall and the Isles of Scilly Health and Social Care Partnership	1.5%	1.9%
Coventry and Warwickshire	1.1%	1.1%
Cumbria and North East	11.7%	9.9%
Devon	2.7%	1.9%
Dorset	0.5%	0.4%
East London Health and Care Partnership	2.7%	2.7%
Frimley Health and Care ICS	0.2%	0.2%
Gloucestershire	0.5%	1.3%
Greater Manchester Health and Social Care Partnership	7.9%	7.9%
Hampshire and the Isle of Wight	1.8%	1.7%
Healthier Lancashire and South Cumbria	5.4%	7%
Herefordshire and Worcestershire	1.3%	1.2%
Hertfordshire and West Essex	0.3%	0.4%
Humber, Coast and Vale	3.8%	3.8%
Joined Up Care Derbyshire	1.7%	1.5%
Kent and Medway	3.2%	4.0%
Leicester, Leicestershire and Rutland	1.1%	1.1%
Lincolnshire	1.6%	0.8%
Mid and South Essex	0.6%	0.4%
Norfolk and Waveney Health and Care Partnership	1.9%	1.8%
North London Partners in Health and Care	3.2%	2.8%

ICS name	Overall sample of most deprived qualitative respondents (7,192)	Sample for thematic sample (932)
North West London Health and Care Partnership	2.4%	2.1%
Northamptonshire	1.2%	1.3%
Nottingham and Nottinghamshire Health and Care	1.4%	1.9%
Our Healthier South East London	2.3%	2.5%
Shropshire and Telford and Wrekin	0.8%	0.5%
Somerset	0.4%	0.3%
South West London Health and Care Partnership	1.0%	0.9%
South Yorkshire and Bassetlaw	3.9%	4%
Staffordshire and Stoke on Trent	2.8%	2.8%
Suffolk and North East Essex	0.8%	0.5%
Surrey Heartlands Health and Care Partnership	0.04%	0%
Sussex Health and Care Partnership	1.7%	2.6%
The Black Country and West Birmingham	5.7%	6.5%
West Yorkshire and Harrogate (Health and Care Partnership)	8.3%	7%

Sampling information: people from ethnic minorities

Table 1: Age (% in overall ethnic minority qualitative sample vs thematic samples)

Age	Overall sample of 'Asian' ethnic minority respondents (913)	Asian sample for thematic analysis (200)	Overall sample of 'Black' ethnic minority respondents (574)	Black sample for thematic analysis (200)	Overall sample of 'Mixed' ethnic minority respondents (318)	Mixed sample for thematic analysis (200)	Overall sample of 'Other' ethnic minority respondents (125)	Other sample for thematic analysis (125)
16-24	1.4%	2.0%	0.3%	0.5%	0.6%	0.5%	2.4%	2.4%
25-34	3.6%	1.0%	1.0%	0.5%	5.3%	6.0%	2.4%	2.4%
35-44	9.2%	7.0%	7.5%	7.0%	7.2%	6.5%	13.6%	13.6%
45-54	20.4%	17.5%	20.6%	20.5%	21.4%	20.5%	21.6%	21.6%
55-64	25.8%	27.5%	35.4%	38.0%	26.7%	25.5%	22.4%	22.4%
65-74	27.2%	31.5%	20.2%	22.0%	25.5%	27.0%	26.4%	26.4%
75-84	10.6%	12.0%	12.9%	9.0%	11.3%	11.5%	10.4%	10.4%
85+	1.8%	1.5%	2.1%	2.5%	1.9%	2.5%	0.8%	0.8%

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

Gender	Overall sample of 'Asian' ethnic minority respondents (913)	Asian sample for thematic analysis (200)	Overall sample of 'Black' ethnic minority respondents (574)	Black sample for thematic analysis (200)	Overall sample of 'Mixed' ethnic minority respondents (318)	Mixed sample for thematic analysis (200)	Overall sample of 'Other' ethnic minority respondents (125)	Other sample for thematic analysis (125)
Female	61.9%	60.0%	57.1%	57.0%	61.9%	62.0%	52.0%	52.0%
Male	35.0%	37.5%	40.8%	41.0%	36.2%	36.5%	44.8%	44.8%
Not given	2.7%	2.0%	1.9%	1.5%	1.3%	1.0%	3.2%	3.2%
Non-binary	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%
Prefer not to say	0.3%	0.5%	0.2%	0.5%	0.3%	0.0%	0.0%	0.0%
Prefer to self-describe	0.0%	0.0%	0.0%	0.0%	0.3%	0.5%	0.0%	0.0%

Table 3: IMD quintile (deprivation) (% in overall ethnic minority qualitative sample vs thematic samples)

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

IMD deprivation*	Overall sample of 'Asian' ethnic minority respondents (913)	Asian sample for thematic analysis (200)	Overall sample of 'Black' ethnic minority respondents (574)	Black sample for thematic analysis (200)	Overall sample of 'Mixed' ethnic minority respondents (318)	Mixed sample for thematic analysis (200)	Overall sample of 'Other' ethnic minority respondents (125)	Other sample for thematic analysis (125)
1 (most deprived)	20.0%	20.5%	27.2%	26.0%	20.8%	21.5%	22.4%	22.4%
2	23.5%	30.0%	33.8%	33.5%	23.6%	25.0%	31.2%	31.2%
3	20.8%	19.0%	19.5%	19.0%	20.4%	15.0%	18.4%	18.4%
4	18.7%	16.5%	12.2%	12.5%	17.0%	18.0%	16.8%	16.8%
5 (least deprived)	16.8%	14.0%	7.3%	9.0%	18.2%	20.5%	11.2%	11.2%

Table 4: Tumour Group (% in overall ethnic minority qualitative sample vs thematic samples)

Tumour group*	Overall sample of 'Asian' ethnic minority respondents (913)	Asian sample for thematic analysis (200)	Overall sample of 'Black' ethnic minority respondents (574)	Black sample for thematic analysis (200)	Overall sample of 'Mixed' ethnic minority respondents (318)	Mixed sample for thematic analysis (200)	Overall sample of 'Other' ethnic minority respondents (125)	Other sample for thematic analysis (125)
Brain /CNS	0.7%	0.5%	0.2%	0.5%	0.6%	0.5%	0.0%	0.0%
Breast	33.1%	36.0%	31.9%	34.0%	32.1%	33.5%	26.4%	26.4%
Colorectal / LGT	8.8%	8.5%	9.8%	12.0%	11.0%	12.0%	12.0%	12.0%
Gynaecological	5.9%	5.5%	4.7%	3.0%	6.0%	4.0%	2.4%	2.4%
Haematological	15.7%	15.5%	18.3%	17.0%	15.7%	14.0%	16.8%	16.8%
Head and Neck	3.5%	2.5%	1.9%	1.5%	2.2%	2.0%	3.2%	3.2%
Lung	4.5%	4.5%	2.3%	1.5%	6.0%	6.5%	5.6%	5.6%
Other	11.5%	10.5%	6.6%	6.5%	9.1%	9.0%	11.2%	11.2%
Prostate	5.9%	6.0%	16.7%	17.5%	5.0%	6.0%	12.8%	12.8%
Sarcoma	1.6%	1.5%	0.9%	0.5%	1.3%	1.0%	0.8%	0.8%
Skin	0.2%	0.5%	0.5%	0.5%	1.6%	2.0%	1.6%	1.6%
Upper Gastro	3.2%	4.0%	3.0%	3.5%	3.5%	3.0%	4.0%	4.0%
Urological	5.5%	4.5%	3.3%	2.0%	6.0%	6.5%	3.2%	3.2%

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

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

Sexual Orientation	Overall sample of 'Asian' ethnic minority respondents (913)	Asian sample for thematic analysis (200)	Overall sample of 'Black' ethnic minority respondents (574)	Black sample for thematic analysis (200)	Overall sample of 'Mixed' ethnic minority respondents (318)	Mixed sample for thematic analysis (200)	Overall sample of 'Other' ethnic minority respondents (125)	Other sample for thematic analysis (125)
Bisexual	0.8%	1.0%	0.9%	1.0%	2.5%	3.0%	0.0%	0.0%
Don't know	1.4%	0.0%	0.3%	0.5%	0.3%	0.5%	0.8%	0.8%
Gay or lesbian	0.4%	0.5%	0.2%	0.5%	1.9%	2.0%	1.6%	1.6%
Heterosexual/straight	85.4%	84.0%	90.2%	89.5%	89.9%	89.5%	84.8%	84.8%
Not given	5.4%	4.5%	4.4%	2.5%	1.9%	2.0%	7.2%	7.2%
Other	1.1%	2.0%	0.5%	0.5%	0.9%	1.5%	0.0%	0.0%
Prefer not to say	5.5%	8.0%	3.5%	5.5%	2.5%	1.5%	5.6%	5.6%

Table 6: ICS name (in overall ethnic minority qualitative sample vs thematic samples)

ICS name	Overall sample of 'Asian' ethnic minority respondents (913)	Asian sample for thematic analysis (200)	Overall sample of 'Black' ethnic minority respondents (574)	Black sample for thematic analysis (200)	Overall sample of 'Mixed' ethnic minority respondents (318)	Mixed sample for thematic analysis (200)	Overall sample of 'Other' ethnic minority respondents (125)	Other sample for thematic analysis (125)
Bath and Northeast Somerset, Swindon and Wiltshire	1.0%	0.5%	0.2%	0.5%	1.6%	1.5%	0.8%	0.8%
Bedfordshire, Luton and Milton Keynes	3.2%	4.5%	4.0%	5.0%	0.9%	0.5%	0.8%	0.8%
Birmingham and Solihull	2.0%	2.5%	2.4%	1.5%	1.9%	1.5%	2.4%	2.4%
Bristol, North Somerset and South Gloucestershire	0.2%	0.5%	0.5%	1.0%	1.6%	2.5%	0%	0%
Buckinghamshire, Oxfordshire and Berkshire West	3.3%	3.0%	1.9%	1.5%	2.5%	2.5%	0.8%	0.8%
Cambridgeshire and Peterborough	1.8%	2.5%	0.7%	0.5%	2.2%	2.0%	1.6%	1.6%
Cheshire and Merseyside	1.4%	1.5%	0.7%	1.0%	3.8%	2.0%	3.2%	3.2%
Cornwall and the Isles of Scilly Health and Social Care Partnership	0.4%	0%	0.3%	0.5%	0.6%	1.0%	0.8%	0.8%
Coventry and Warwickshire	2.1%	1.5%	1.2%	1.0%	1.9%	1.0%	1.6%	1.6%
Cumbria and North East	1.5%	1.5%	1.4%	2.0%	3.1%	3.5%	3.2%	3.2%
Devon	0.7%	0%	0.7%	0.5%	4.1%	3.0%	0%	0%
Dorset	0.2%	0.5%	0.3%	0.5%	1.3%	2.0%	0.8%	0.8%
East London Health and Care Partnership	8.2%	10.0%	10.8%	13.5%	3.5%	3.0%	9.6%	9.6%
Frimley Health and Care ICS	3.1%	1.5%	2.1%	1.0%	1.9%	2.0%	0%	0%

ICS name	Overall sample of 'Asian' ethnic minority respondents (913)	Asian sample for thematic analysis (200)	Overall sample of 'Black' ethnic minority respondents (574)	Black sample for thematic analysis (200)	Overall sample of 'Mixed' ethnic minority respondents (318)	Mixed sample for thematic analysis (200)	Overall sample of 'Other' ethnic minority respondents (125)	Other sample for thematic analysis (125)
Gloucestershire	0.3%	0%	0%	0%	0.3%	0.5%	0%	0%
Greater Manchester Health and Social Care Partnership	4.6%	4.5%	3.8%	4.0%	5.0%	5.0%	6.4%	6.4%
Hampshire and the Isle of Wight	1.3%	2.5%	1.0%	1.5%	2.8%	1.5%	0.8%	0.8%
Healthier Lancashire and South Cumbria	1.8%	2.0%	0.5%	0.5%	1.3%	1.5%	0.8%	0.8%
Herefordshire and Worcestershire	0%	0%	0.3%	0%	1.6%	1.5%	0.8%	0.8%
Hertfordshire and West Essex	2.3%	1.5%	2.1%	3.0%	2.5%	3.5%	3.2%	3.2%
Humber, Coast and Vale	0.7%	1.0%	0.9%	0.5%	0.9%	1.0%	2.4%	2.4%
Joined Up Care Derbyshire	0.9%	1.0%	1.0%	1.0%	0.3%	0.5%	0.8%	0.8%
Kent and Medway	2.5%	2.5%	1.7%	1.5%	4.1%	4.0%	1.6%	1.6%
Leicester, Leicestershire and Rutland	4.2%	4.5%	0.7%	1.0%	1.6%	2.5%	0.8%	0.8%
Lincolnshire	0.8%	0.5%	0.2%	0.5%	0.6%	1.0%	0%	0%
Mid and South Essex	0.4%	0%	0.9%	0%	0.6%	0.5%	1.6%	1.6%
Norfolk and Waveney Health and Care Partnership	0.4%	0.5%	0.2%	0.5%	2.5%	2.5%	0%	0%
North London Partners in Health and Care	6.1%	3.5%	12.9%	10%	9.1%	10.0%	12.8%	12.8%
North West London Health and Care Partnership	16.4%	19.0%	9.4%	9.5%	6.6%	7.0%	17.6%	17.6%
Northamptonshire	1.0%	0.5%	1.7%	2.5%	1.3%	1.0%	0%	0%

ICS name	Overall sample of 'Asian' ethnic minority respondents (913)	Asian sample for thematic analysis (200)	Overall sample of 'Black' ethnic minority respondents (574)	Black sample for thematic analysis (200)	Overall sample of 'Mixed' ethnic minority respondents (318)	Mixed sample for thematic analysis (200)	Overall sample of 'Other' ethnic minority respondents (125)	Other sample for thematic analysis (125)
Nottingham and Nottinghamshire Health and Care	0.8%	1.0%	0.5%	0%	1.3%	1.5%	0.8%	0.8%
Our Healthier South East London	3.4%	2.5%	13.4%	13.5%	5.7%	4.0%	4.8%	4.8%
Shropshire and Telford and Wrekin	0.3%	0.5%	0.3%	1.0%	0.9%	0.5%	0%	0%
Somerset	0%	0%	0.3%	0%	0.3%	0.5%	0%	0%
South West London Health and Care Partnership	6.3%	6.0%	10.5%	10.0%	7.9%	9.5%	6.4%	6.4%
South Yorkshire and Bassetlaw	1%	2.5%	1.2%	1.0%	2.5%	3.0%	1.6%	1.6%
Staffordshire and Stoke on Trent	0.7%	1.5%	0.5%	0%	1.6%	2.0%	0.8%	0.8%
Suffolk and North East Essex	0.3%	0%	0.3%	0%	0.6%	0%	0%	0%
Surrey Heartlands Health and Care Partnership	2.2%	1.5%	1.4%	1.0%	0.9%	0.5%	1.6%	1.6%
Sussex Health and Care Partnership	1.9%	2.5%	0.7%	0.5%	2.2%	3.0%	2.4%	2.4%
The Black Country and West Birmingham	5.0%	4.0%	3.7%	3.5%	1.6%	1.0%	1.6%	1.6%
West Yorkshire and Harrogate (Health and Care Partnership)	5.0%	4.5%	2.3%	3.5%	2.5%	3.0%	4.8%	4.8%

Sampling information: people reporting a mental health condition

Table 1: Age (% in overall mental health condition qualitative sample vs thematic sample)

Age	Overall sample of respondents reporting mental health conditions (1750)	Sample for thematic analysis (700)
16-24	1.2%	1.6%
25-34	3.5%	3.3%
35-44	8.0%	8.4%
45-54	19.9%	19.9%
55-64	33.4%	33.3%
65-74	24.2%	23.7%
75-84	9.0%	9.0%
85+	0.8%	0.9%

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

Gender	Overall sample of respondents reporting mental health conditions (1750)	Sample for thematic analysis (700)
Female	65.5%	66.3%
Male	33.7%	32.9%
Not given	0.1%	0.1%
Non-binary	0.3%	0.3%
Prefer not to say	0.2%	0.1%
Prefer to self-describe	0.1%	0.3%

Table 3: Ethnicity (% in overall mental health condition sample vs thematic sample)

Ethnicity	Overall sample of respondents reporting mental health conditions (1750)	Sample for thematic sample (700)
Asian	3.1%	3.0%
Black	1.4%	1.4%
Missing / Not known	2.4%	2.7%
Mixed	1.4%	1.7%
Other*	0.6%	0.6%
White	91.0%	90.6%

Table 4: IMD quintile (deprivation) (% in overall mental health condition qualitative sample vs thematic sample)

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

IMD	Overall sample of respondents reporting mental health conditions (1750)	Sample for thematic analysis (700)
1 (most deprived)	19.1%	19.4%
2	22.6%	21.7%
3	18.7%	17.7%
4	20.6%	22.1%
5 (least deprived)	18.5%	18.1%
Non-England	0.6%	0.9%

Table 5: Tumour Group (% in overall mental health condition qualitative sample vs thematic sample)

Tumour Group*	Overall sample of respondents reporting mental health conditions (1750)	Sample for thematic analysis (700)
Brain / CNS	0.7%	1.0%
Breast	33.4%	33.7%
Colorectal / LGT	9.8%	10.0%
Gynaecological	6.3%	6.9%
Haematological	12.6%	13.1%
Head and Neck	3.8%	3.7%
Lung	5.0%	4.4%
Other	8.9%	8.3%
Prostate	6.6%	6.0%
Sarcoma	1.0%	1.1%
Skin	2.4%	2.6%
Upper Gastro	2.9%	3.1%
Urological	6.5%	6.0%

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

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

Sexual orientation	Overall sample of respondents reporting mental health conditions (1750)	Sample for thematic analysis (700)
Bisexual	1.4%	1.4%
Don't know / not sure	0.4%	0.4%
Gay or Lesbian	2.6%	3.0%
Heterosexual or straight	92.1%	91.7%
Not given	1.1%	0.7%
Other	0.3%	0.6%
Prefer not to say	2.1%	2.1%

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

ICS name	Overall sample of respondents reporting mental health conditions (1750)	Sample for thematic analysis (700)
Bath and Northeast Somerset, Swindon and Wiltshire	1.4%	1.6%
Bedfordshire, Luton and Milton Keynes	1.6%	1.2%
Birmingham and Solihull	1.3%	1.0%
Bristol, North Somerset and South Gloucestershire	1.6%	2.3%
Buckinghamshire, Oxfordshire and Berkshire West	3.3%	2.6%
Cambridgeshire and Peterborough	1.3%	0.9%
Cheshire and Merseyside	2.9%	3.3%
Cornwall and the Isles of Scilly Health and Social Care Partnership	2.1%	1.2%
Coventry and Warwickshire	2.4%	1.6%
Cumbria and North East	8.2%	9.5%
Devon	4.0%	4.6%
Dorset	1.2%	1.0%
East London Health and Care Partnership	1.6%	1.6%
Frimley Health and Care ICS	1.3%	1.6%
Gloucestershire	0.7%	0.9%
Greater Manchester Health and Social Care Partnership	3.9%	3.7%
Hampshire and the Isle of Wight	4.3%	3.7%
Healthier Lancashire and South Cumbria	3.3%	2.9%
Herefordshire and Worcestershire	1.9%	2.3%
Hertfordshire and West Essex	2.6%	1.9%
Humber, Coast and Vale	3.5%	3.0%
Joined Up Care Derbyshire	2.0%	1.9%
Kent and Medway	3.2%	4.0%
Leicester, Leicestershire and Rutland	1.8%	2.4%

ICS name	Overall sample of respondents reporting mental health conditions (1750)	Sample for thematic analysis (700)
Lincolnshire	1.7%	2.2%
Mid and South Essex	1.1%	0.6%
Norfolk and Waveney Health and Care Partnership	2.4%	1.7%
North London Partners in Health and Care	2.6%	2.2%
North West London Health and Care Partnership	2.8%	3.0%
Northamptonshire	2.0%	2.4%
Nottingham and Nottinghamshire Health and Care	1.1%	1.3%
Our Healthier South East London	2.5%	3.3%
Shropshire and Telford and Wrekin	1.4%	1.3%
Somerset	1.0%	1.2%
South West London Health and Care Partnership	2.4%	2.9%
South Yorkshire and Bassetlaw	2.3%	2.2%
Staffordshire and Stoke on Trent	2.6%	2.6%
Suffolk and North East Essex	1.3%	1.9%
Surrey Heartlands Health and Care Partnership	1.7%	1.6%
Sussex Health and Care Partnership	2.8%	2.2%
The Black Country and West Birmingham	2.4%	2.6%
West Yorkshire and Harrogate (Health and Care Partnership)	4.5%	4.3%

Sampling information: people with learning disabilities

Table 1: Age

Age	% in Learning Disability sample
16-24	3.14%
25-34	6.81%
35-44	9.95%
45-54	14.14%
55-64	27.23%
65-74	20.94%
75-84	14.14%
85+	3.66%

Table 2: Gender

Gender	% in Learning Disability sample
Female	54.45%
Male	43.46%
Not given	0.52%
Non-binary	0.52%
Prefer not to say	0.52%
Prefer to self-describe	0.52%

Table 3: Ethnicity

Ethnicity	% in Learning Disability sample
Asian	8.90%
Black	3.66%
Missing / Not known	6.81%
Mixed	2.09%
Other*	1.57%
White	76.96%

Table 4: IMD quintile (deprivation)

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

IMD	% in Learning Disability sample)
1 (most deprived)	28.80%
2	27.75%
3	15.71%
4	18.85%
5 (least deprived)	8.90%

Table 5: Tumour Group

Tumour Group*	% in Learning Disability sample
Brain / CNS	2.09%
Breast	25.13%
Colorectal / LGT	10.99%
Gynaecological	7.85%
Haematological	12.57%
Head and Neck	3.66%
Lung	6.81%
Other	9.42%
Prostate	5.76%
Sarcoma	0.52%
Skin	1.57%
Upper Gastro	5.76%
Urological	7.85%

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

Table 5: Sexual orientation

Sexual orientation	% in Learning Disability sample
Bisexual	2.09%
Don't know / not sure	3.14%
Gay or Lesbian	3.66%
Heterosexual or straight	82.72%
Not given	2.62%
Prefer not to say	5.76%

Table 6: ICS name

ICS name	% in Learning Disability sample
Bath and Northeast Somerset, Swindon and Wiltshire	1.05%
Bedfordshire, Luton and Milton Keynes	2.62%
Birmingham and Solihull	1.05%
Bristol, North Somerset and South Gloucestershire	1.05%
Buckinghamshire, Oxfordshire and Berkshire West	1.05%
Cambridgeshire and Peterborough	1.57%
Cheshire and Merseyside	2.09%
Cornwall and the Isles of Scilly Health and Social Care Partnership	0.52%
Coventry and Warwickshire	1.05%
Cumbria and North East	5.76%
Devon	2.09%
Dorset	0.52%
East London Health and Care Partnership	4.71%
Frimley Health and Care ICS	1.05%
Gloucestershire	0.52%
Greater Manchester Health and Social Care Partnership	6.28%
Hampshire and the Isle of Wight	2.62%
Healthier Lancashire and South Cumbria	5.24%
Herefordshire and Worcestershire	2.09%
Hertfordshire and West Essex	1.05%
Humber, Coast and Vale	2.09%
Joined Up Care Derbyshire	2.62%
Kent and Medway	4.71%
Leicester, Leicestershire and Rutland	2.09%
Lincolnshire	1.05%
Mid and South Essex	0.52%
Norfolk and Waveney Health and Care Partnership	1.57%
North London Partners in Health and Care	5.76%
North West London Health and Care Partnership	5.76%
Northamptonshire	3.14%
Nottingham and Nottinghamshire Health and Care	1.57%
Our Healthier South East London	6.81%
Shropshire and Telford and Wrekin	1.57%
Somerset	0.52%
South West London Health and Care Partnership	3.66%
South Yorkshire and Bassetlaw	2.09%
Staffordshire and Stoke on Trent	3.14%

ICS name	% in Learning Disability sample
Suffolk and North East Essex	1.05%
Surrey Heartlands Health and Care Partnership	0.52%
Sussex Health and Care Partnership	1.57%
The Black Country and West Birmingham	2.62%
West Yorkshire and Harrogate (Health and Care Partnership)	1.57%

Sampling information: people aged 16 to 44

Table 1: Gender (% in overall younger sample vs thematic sample)

Gender	Overall sample of respondents aged 25 to 44 (1565)	Sample for thematic analysis aged 25 to 44 (736)	Overall sample of respondents aged 16 to 24 (122)
Female	75.46%	73.78%	53.28%
Male	21.79%	23.37%	43.44%
Not given	2.17%	2.31%	1.64%
Non-binary	0.38%	0.27%	0.00%
Prefer not to say	0.19%	0.27%	0.00%
Prefer to self-describe	0.00%	0.00%	1.64%

Table 2: Ethnicity (% in overall younger sample vs thematic sample)

Ethnicity	Overall sample of respondents aged 25 to 44 (1565)	Sample for thematic analysis aged 25 to 44 (736)	Overall sample of respondents aged 16 to 24 (122)
Asian	7.48%	7.61%	10.66%
Black	3.13%	2.85%	1.64%
Missing / Not known	4.66%	4.76%	5.74%
Mixed	2.56%	2.04%	1.64%
Other*	1.28%	1.49%	2.46%
White	80.89%	81.25%	77.87%

Table 3: IMD quintile (deprivation) (% in overall younger sample vs thematic sample)

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

IMD	Overall sample of respondents reporting mental health conditions (1565)	Sample for thematic analysis aged 25 to 44 (736)	Overall sample of respondents aged 16 to 24 (122)
1 (most deprived)	16.10%	16.30%	13.93%
2	18.98%	18.07%	15.57%
3	22.11%	19.84%	25.41%
4	20.83%	22.42%	18.85%

5 (least deprived)	21.41%	22.28%	24.59%
Non-England	0.58%	1.09%	1.64%

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

Tumour Group*	Overall sample of respondents aged 24 to 44 (1565)	Sample for thematic analysis aged 25 to 44 (736)	Overall sample of respondents aged 16 to 24 (122)
Brain / CNS	1.85%	1.90%	6.56%
Breast	42.56%	41.71%	2.46%
Colorectal / LGT	9.52%	9.78%	1.64%
Gynaecological	5.75%	6.52%	3.28%
Haematological	13.99%	14.40%	54.92%
Head and Neck	4.73%	4.35%	5.74%
Lung	0.89%	0.68%	0.00%
Prostate	0.19%	0.27%	0.00%
Sarcoma	1.73%	1.63%	9.02%
Skin	4.03%	4.35%	4.92%
Upper Gastro	1.28%	0.95%	0.82%
Urological	4.35%	4.89%	3.28%
Other	9.14%	8.56%	7.38%

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

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

Sexual orientation	Overall sample of respondents aged 25 to 44 (1565)	Sample for thematic analysis aged 25 to 44 (736)	Overall sample of respondents aged 16 to 24 (122)
Bisexual	2.62%	2.72%	4.10%
Don't know / not sure	0.19%	0.41%	1.64%
Gay or Lesbian	2.17%	2.45%	5.74%
Heterosexual or straight	89.52%	88.45%	76.23%
Not given	2.94%	2.85%	2.46%
Other	0.64%	1.09%	1.64%
Prefer not to say	1.92%	2.04%	8.20%

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

ICS name	Overall sample of respondents aged 25 to 44 (1565)	Sample for thematic analysis aged 25 to 44 (736)	Overall sample of respondents aged 16 to 24 (122)
Bath and Northeast Somerset, Swindon and Wiltshire	1.47%	1.36%	3.28%
Bedfordshire, Luton and Milton Keynes	2.24%	1.90%	4.92%
Birmingham and Solihull	0.89%	0.82%	0.82%
Bristol, North Somerset and South Gloucestershire	2.43%	2.72%	1.64%
Buckinghamshire, Oxfordshire and Berkshire West	3.51%	3.26%	4.92%
Cambridgeshire and Peterborough	1.92%	2.31%	2.46%
Cheshire and Merseyside	2.24%	2.04%	1.64%
Cornwall and the Isles of Scilly Health and Social Care Partnership	1.73%	1.77%	2.46%
Coventry and Warwickshire	1.98%	1.63%	1.64%
Cumbria and North East	5.69%	7.07%	3.28%
Devon	3.45%	3.26%	3.28%
Dorset	0.64%	0.68%	0.82%
East London Health and Care Partnership	3.39%	2.72%	1.64%
Frimley Health and Care ICS	1.79%	2.31%	2.46%
Gloucestershire	0.77%	0.68%	0.82%
Greater Manchester Health and Social Care Partnership	3.07%	2.99%	1.64%
Hampshire and the Isle of Wight	3.64%	3.26%	0.82%
Healthier Lancashire and South Cumbria	2.30%	2.72%	4.10%
Herefordshire and Worcestershire	1.15%	1.22%	1.64%
Hertfordshire and West Essex	3.19%	2.99%	6.56%
Humber, Coast and Vale	3.45%	3.26%	3.28%
Joined Up Care Derbyshire	1.47%	1.63%	2.46%
Kent and Medway	2.62%	2.31%	1.64%
Leicester, Leicestershire and Rutland	1.79%	1.77%	0.82%
Lincolnshire	1.47%	1.77%	2.46%
Mid and South Essex	1.66%	2.45%	4.10%
Norfolk and Waveney Health and Care Partnership	2.30%	1.90%	0.82%
North London Partners in Health and Care	2.94%	2.85%	3.28%

North West London Health and Care Partnership	4.22%	3.80%	4.92%
Northamptonshire	1.09%	1.09%	0.82%
Nottingham and Nottinghamshire Health and Care	1.15%	1.09%	0.82%
Our Healthier South East London	3.51%	3.67%	0.82%
Shropshire and Telford and Wrekin	0.51%	0.68%	0.82%
Somerset	1.53%	1.09%	0.00%
South West London Health and Care Partnership	3.96%	3.94%	1.64%
South Yorkshire and Bassetlaw	1.85%	1.49%	1.64%
Staffordshire and Stoke on Trent	2.88%	3.26%	4.10%
Suffolk and North East Essex	1.15%	0.95%	1.64%
Surrey Heartlands Health and Care Partnership	2.68%	2.58%	2.46%
Sussex Health and Care Partnership	1.98%	1.90%	2.46%
The Black Country and West Birmingham	2.04%	2.17%	0.82%
West Yorkshire and Harrogate (Health and Care Partnership)	5.69%	5.57%	5.74%

11

Appendix: summary of national parallels

This appendix provides a visual summary of themes found to be mirrored in the comparisons drawn between each subsample and the national qualitative sample, referred to as ‘national parallels.’ The blue colouring indicates presence of the theme.

	Negative experiences with General Practice		
	Delayed diagnosis	No of follow up	Access to appts
National			
People most deprived			
People from ethnic minorities: mixed			
People from ethnic minorities: black			
People from ethnic minorities: asian			
People from ethnic minorities: other			
People reporting a mental health condition			
People with learning disabilities			
People aged 16-24			
People aged 25-44			

	Communication for patients			
	More info needed	Follow up lacking/ infrequent	Single point of contact	Method of contact (e.g. f2f)
National				
People most deprived				
People from ethnic minorities: mixed				
People from ethnic minorities: black				
People from ethnic minorities: asian				
People from ethnic minorities: other				
People reporting a mental health condition				
People with learning disabilities				
People aged 16-24				
People aged 25-44				

	Co-ordination of care	
	Between departments within the hospital	Between hospitals
National		
People most deprived		
People from ethnic minorities: mixed		
People from ethnic minorities: black		
People from ethnic minorities: asian		
People from ethnic minorities: other		
People reporting a mental health condition		
People with learning disabilities		
People aged 16-24		
People aged 25-44		

	Wait times			
	Lengthy waits (wide range; emphasis on treatment to begin)	Physical waits within hospital/ delays with appt times	Waits for test results	Waits for prescriptions and medicines
National				
People most deprived				
People from ethnic minorities: mixed				
People from ethnic minorities: black				
People from ethnic minorities: asian				
People from ethnic minorities: other				
People reporting a mental health condition				
People with learning disabilities				
People aged 16-24				
People aged 25-44				

	Negative experiences with hospital staff		
	Staff availability/ shortages	Unprofessional attitudes – isolated examples	Training needs e.g. delivering bad news
National			
People most deprived			
People from ethnic minorities: mixed			
People from ethnic minorities: black			
People from ethnic minorities: asian			
People from ethnic minorities: other			
People reporting a mental health condition			
People with learning disabilities			
People aged 16-24			
People aged 25-44			

	Wider issues		
	Wards (privacy; décor; visiting; Covid19; beds/chairs)	Parking/drop offs (cost and availability)	Food & drinks (quality, choice, cancer needs)
National			
People most deprived			
People from ethnic minorities: mixed			
People from ethnic minorities: black			
People from ethnic minorities: asian			
People from ethnic minorities: other			
People reporting a mental health condition			
People with learning disabilities			
People aged 16-24			
People aged 25-44			