

## **Unmet Needs of Minority Ethnic People with Blood Cancer**

### **A report for the Blood Cancer Alliance**

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## 1. Executive Summary

This report details the outcomes of a stand-alone piece of research that was funded by the Blood Cancer Alliance, and undertaken by researchers based in the School of Life and Medical Sciences at the University of Hertfordshire, with collaboration from a clinician based at Kings College Hospital. The aim of the commissioned work was to:

- Understand what can be gleaned from existing national datasets about minority ethnic people living with Blood Cancer
- Explore the experiences of healthcare professionals in providing culturally sensitive care in this setting

Two data sharing requests were made including to the National Cancer Registration and Analysis Service (NCRAS) the National Cancer Patient Experience Survey (NCPES). Further primary research was undertaken using 1-1 interviews with 4 healthcare professionals working in different job roles related to Blood Cancer care. The findings and recommendations based on the research are summarised below.

- Accurate data on the prevalence of Blood Cancer by ethnicity is not readily available for researchers. It is therefore difficult to know the true extent to which illness patterns vary by ethnicity, and factors such as the intersection of ethnicity and other patient socio-demographics
  - **Recommendation 1:** There should be an expanded request to the NCRAS to look at data completeness and what this shows about patterns in Blood Cancer types by patient demographics.
- Responses to the NCPES highlight many strengths of Blood Cancer care in England. There are however some key trends in responses that likely signal what matters most to patients from specific ethnic groups that could be explored further to drive quality improvement initiatives.
  - **Recommendation 2:** Qualitative inquiry with patients identifying with a range of ethnic heritage groups should help explore what matters most when rating aspects of care. This would provide depth of inquiry to plan specific quality improvement initiatives that result in meaningful changes in experience and satisfaction.
  - **Recommendation 3:** There should be a review of how the practice of the NCPES addresses recruitment for patients who may be 'easy to ignore' due to established barriers to participation in such quality improvement exercises.
  - **Recommendation 4:** For Blood Cancer specifically, there is limited evidence on care experiences by ethnicity as gleaned from different types of available published data. Taken with the overall sample limitations of the NCPES, it is recommended that the research community scales up effort to understand the care journey from the perspective of patients from different cultural backgrounds. This will inform targeted initiatives and interventions to address patient feedback.
- Professionals involved in Blood Cancer care recognise that culturally sensitive care 'fits individual needs'. What is lacking is a comprehensive understanding of how they achieve this to redress disparity that is partly signalled in Blood Cancer patient experiences from the CPES. This learning will be important to personalise care to the needs of patients and their families and to achieve the aspirations set out in the NHS Long Term ambition for Cancer care.
  - **Recommendation 5:** The Blood Cancer Alliance should consider how to mobilise learning from the healthcare workforce in relation to understanding and addressing health inequities.

## 2. Background

The many different types of Blood Cancer are categorised into three main groups; leukaemia, lymphoma and myeloma. Blood Cancer is the fifth most common form of cancer in the UK. Data suggest that 40,000 new cases are diagnosed each year and that over 250,000 people are living with blood cancer [1]. Available evidence also signals variations in prevalence by sex and ethnicity. For example, some types of blood cancer are more common in men, particularly those from White and Black heritage backgrounds [2]. Furthermore, people who identify as Black British are 2-2.5 times more likely to be diagnosed with myeloma than people identifying with a White ethnic group [3-4].

Patient experience is an essential part of excellent health care. Evidence from the National Cancer Patient Experience Survey (NNCPES) has highlighted that despite the NHS being built on core principles of equity, there are stark disparities in care experiences [5]. A review of existing evidence by the Blood Cancer Alliance has shown unmet needs in people with a Blood Cancer diagnosis compared to people with a solid tumour cancer diagnosis. For example, fewer Blood Cancer patients fully understand their condition and there are greater delays in diagnosis with 30% of cases in England being diagnosed after presenting as an emergency [6].

Whilst differences between tumour groups have been demonstrated, less is known about disparities in care experiences and outcomes between ethnic groups particularly for minority ethnic people diagnosed with Blood Cancer in England. Drawing on research conducted in America, individuals identifying as Black or Hispanic were found to have decreased survival for acute leukaemia in comparison to those identifying as non-Hispanic White [7]. These disparities may be partially explained by differences in treatment received by ethnic groups, such as reduced chemotherapy in individuals who identify with a Black heritage [8]. Data from the UK have also signalled reduced participation in cancer trials by minority ethnic people, a significant barrier to ensuring that research equally meets the needs of and benefits all patient communities [9].

Analysis of cancer care experiences has been conducted more broadly with results showing that patients from minority ethnic communities in particular rate their care as less optimal compared to White majority patients, even when controlling for the impact of factors such as socio-demographics [5]. The average number of visits to the GP before a referral is also significantly higher. Such variations can be seen as a form of health inequity with research across a range of health settings consistently evidencing that factors such as understanding how to navigate health systems, trust, systemic racism and lack of cultural sensitivity all contribute to unfair and avoidable differences in the wellbeing of minority ethnic people [10-12].

The aim of this report is to further understanding of unmet needs of minority ethnic people living with Blood Cancer in England by 1) exploring what can be learnt from existing national datasets on care experiences and outcomes and 2) exploring the perspectives of healthcare professionals including those in positions of leadership on the meaning of culturally responsive Blood Cancer care. The report aims to form part of a step change towards improving representativeness in Blood Cancer research, policy and patient care priorities.

### 3. Methodology

The research presented herein was funded by the Blood Cancer Alliance and is split into two work packages. Here we include in brief our methodology.

#### [3.1. Data from National Cancer Registries](#)

In order to understand what can be gleaned from existing national datasets about Blood Cancer in minority ethnic people, we made two requests for data sharing. The first was to the National Cancer Registration and Analysis Service (NCRAS) which collect data on all cases of cancer that occur in people living in England, formerly in partnership with Public Health England (PHE) and now NHS Digital [13,14]. Incidence, prevalence and survival data were requested from NCRAS, according to ethnicity group.

We also requested data from the National Cancer Patient Experience Survey (NCPES). The NCPES is an important part of the NHS Cancer Programme, designed to monitor national progress on cancer care, drive local quality improvements, assist commissioners and providers of cancer care and inform the work of the various charities/stakeholder groups supporting cancer patients [15]. Each year, a sample of patients are sent a paper survey, with the option of completing online. Due to the pandemic, 2020 participation was optional across centres. We requested results from the NCPES from 2019 therefore in order to explore any associations between reported care experience and patient ethnicity.

#### [3.2. Qualitative interviews with healthcare professionals](#)

Following University ethics approval (protocol number: LMS/SF/UH/04805), we invited, through multiple channels, healthcare professionals involved in Blood Cancer care to take part in 1-1 interviews about their experience of supporting patients from minority ethnic groups. An interview topic guide was developed following a desk top review of similar research in other health contexts and with additional refining based on the expertise of the research team. All interviews were via a digital platform, recorded and transcribed verbatim. Data were analysed using thematic analysis [16], and within a software package that supports qualitative analysis (NVivo).

## 4. Findings

### [4.1. Work package 1: Existing datasets](#)

**Headlines:** Although possible to obtain ethnicity-level data for people living with Blood Cancer in England from NCRAS, it is far from straightforward, with procedures in place restricting access. We therefore provide only a snapshot of the data that could be accessed and analysed with relevant permissions. Results from the NCPES showed some indication of disparity in patient experience of Blood Cancer care according to ethnicity. Further investigation and analysis is required to explore the drivers of disparity to enable the imbalance to be redressed.

#### [4.1.1. National Cancer Registration and Analysis Service](#)

NCRAS have a specific haematological team, with individual members responsible for various aspects of the data. Information is published on the NCRAS dashboard, with various filters which can be applied as needed. Table 1 provides an overview of the summary data available by type.

*Table 1: Summary of data readily available from NCRAS*

Data Type	Years Available	Information Held	Sub-groups Available	Notes
Incidence	2001-2019	3- or 5-year rolling incidence Age standardised or non-standardised	Regional, sex, age groups, ICD-10 codes	Blood cancer by ethnicity unavailable
Prevalence	2018	People diagnosed with a cancer (1995-2018) alive on 31/12/2018 Time series 2010-2018	Sex, age, ethnicity, stage, deprivation, time since diagnosis, cancer type	Blood Cancer info available by demographics, including ethnicity
Survival	2001-2019	3- or 5-year rolling incidence Age standardised or non-standardised	Regional, sex, age groups, ICD-10 codes	Blood cancer by ethnicity unavailable. Blood cancer separately listed (e.g., leukaemia, lymphoma)

Although possible to obtain more detailed information about people living with Blood Cancer according to their ethnicity group, this would require detailed bespoke application, alongside ethical approval, with a clear purpose needed in order for the data to be released. Information is recorded at individual level and submitted to NCRAS by regional cancer registries. Pseudo-anonymised data can be requested, albeit with strict governance to ensure data protection rules are upheld and patient confidentiality is maintained.

#### [4.1.2. National Cancer Patient Experience Survey](#)

The Cancer Patient Experience Survey (NCPES) asks current patients living with cancer to answer 61 questions enquiring about their care experience from seeking a diagnosis to the treatment received.

#### [Accessing the report](#)

The Cancer Patient Experience Survey (NCPES) from NHS England for haematological cancer was requested in October 2021 and received on 7<sup>th</sup> February 2022. Whilst the 2020 report was

originally requested as participation by trusts was voluntary due to the impact of the COVID-19 pandemic, there was not enough data to split the responses into ethnic groups for solely haematological cancer. Therefore, the 2019 NCPES was analysed for this report.

## Results

All questions required a multiple-choice response and 52 out of the 61 questions are scored for analysis. For the scored questions, each response is identified as either positive, negative or neutral. The percentages presented are the percent of positive responses for each question.

The 2019 national NCPES collected data from 143 NHS trusts and yielded a response rate of 61%. The haematological cancers, including non-Hodgkin’s lymphoma, multiple myeloma, leukaemia and Hodgkin’s lymphoma, data was extracted from the national NCPES report and analysed in this report. Sub-group comparisons will be made across the six predetermined ethnic groups; White, Mixed, Asian, Black, or other ethnicity type. These ethnic groups are broader than the UK census, which aims to be more granular.

*Table 2: Ethnicity profile of NCPES respondents in 2019*

Ethnic group	NCPES response rate (2019)	Prevalence (2018) <sup>#</sup>
Asian	288 (2.7%)	8,474 (4.3%)
Black	188 (1.7%)	5,018 (2.5%)
Mixed	99 (0.9%)	1,445 (0.7%)
Other	21 (0.2%)	3057 (1.5%)
Unknown	667 (6.2%)	8,769 (4.4%)
White	9,553 (88.3%)	170,740 (86.4%)
<b>Total</b>	<b>10,816</b>	<b>197,503</b>

<sup>#</sup>From NCRAS dashboard <https://www.cancerdata.nhs.uk/prevalence>

As shown in Table 2, individuals of minority ethnic heritage were under-represented in the NCPES according to 2018 prevalence data (Asian 2.7% vs 4.3%, Black 1.7% vs 2.5% and Other 0.2% vs 1.5%). However, 6.2% of patients were unwilling to disclose their ethnicity when participating in the survey and so this data can only be used with this caveat in mind.

*Figure 1: Results of NCPES Question 61 by Ethnicity for People with Blood Cancer*

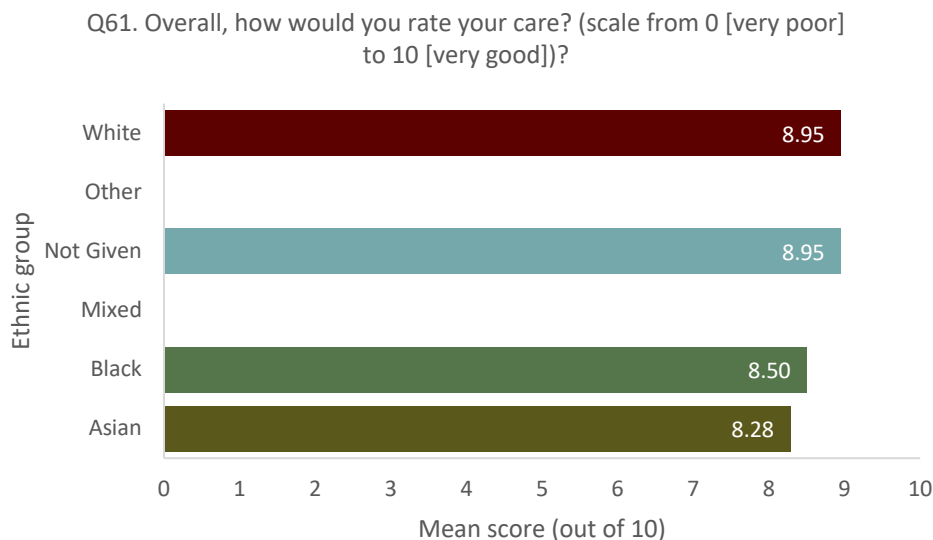


Figure 1 shows results for question 61: “overall how would you rate your care?”, with possible scores from 0 (very poor) to 10 (very good). Asian Blood Cancer respondents scored lowest on average (8.28 out of 10), those of Black heritage slightly higher (8.50 out of 10) and patients identifying with a White heritage the highest (8.95 out of 10). Each question requires a minimum response from 21 individuals to produce a score. When exploring sub-group comparisons, if there is a group with less than 21 responses then this would be suppressed along with the group with the next lowest number of respondents. Therefore, the missing means for Other and Mixed ethnicity groups are due to the Other category not meeting the minimum response requirements. A detailed analysis of the remaining NCPES questions, with available data, can be found in Appendix A. This data is drawn on in the summary below also.

### Summary of NCPES for haematology patients according to ethnicity

- NCPES data is more readily available by ethnicity for people living in England compared to the NCRAS data.
- For the NCPES, there was a lack of data for ‘Mixed’ and ‘Other’ ethnic groups due to the minimum response rate requirements.
- Blood Cancer patients signal a number of key areas of satisfaction with care in the main.
- Less than half of respondents in all the four minority ethnic groups, with available data in the NCPES, felt that they were however given enough care and support from health or social services after their cancer treatment.
- Regarding the overall care experience, the lowest score was recorded for Asian respondents in comparison to respondents from other ethnic groups.
- Asian respondents in particular rated care lower in a number of domains such as time to first appointment with a hospital doctor, waiting times for clinic appointments, involvement in treatment decision making, understanding responses to questions from Nurse Specialists as selected examples.
- It is noteworthy that patients from a Black heritage reported more often being informed about opportunities to participate in research though under-representation in cancer research is still evident.
- Based on existing data, we cannot fully understand the drivers of disparity.

#### [4.2. Interviews with healthcare professionals](#)

**Headlines: Blood Cancer is complex and communicating with patients about it is not straightforward. Considering the impact of ethnicity and culture is part of providing patient centred care from the perspective of healthcare professionals. This is essential to helping all patients feel equally comfortable in healthcare settings. How this is achieved is less clear and warrants further exploration.**

Four London-based healthcare professionals including a clinical nurse specialist, psychological therapy lead, haematologist and honouree haemato-oncologist (two males and two females;  $M = 46$  y [ $SD = 6.65$ ]) were interviewed about their understanding and perceptions of providing culturally appropriate care for people living with Blood Cancer. Analysis of interview data identified **two themes**:

1. Language and communication
2. Clustering of disadvantage

#### 4.2.1. Theme 1: Language and communication

All healthcare professionals commented on language as a major factor in a patient accessing and understanding their care. This theme encapsulated both health literacy and explicit language barriers. Language can influence care in multiple ways; professionals expressed that the nature of Blood Cancer is very complex, and the terminology is difficult to understand if you are an individual from a non-medical background.

*“The disease is complex, the treatment is complex, the terminology is complex.”*

For some individuals from minority ethnic backgrounds, their first language is not English therefore adding another layer of difficulty in making informed decisions. Professionals identified some practical issues and solutions. For example, the language in which information is printed is limited. The NHS does have translators available for clinical settings, however, unless this has been “flagged in advance”, reliance on a dial-up service is necessary. Telephone services are however becoming more frequent due to the Covid-19 pandemic restrictions. There is also frequent use of asking colleagues to assist and/or the patient’s family who are of course not always trained in communication in such settings. It was acknowledged that such barriers can impact patient experience and limit health engagement.

*“I think sort of the system generally can feel quite complex and even oppressive for even if you're white British and your first language is English and let alone if you're not, you know if you're not in that category.”*

If the translator is not independent of the patient, there were concerns regarding what the patient is being told by their family member, with professionals acknowledging this can, at times, lead to challenges with their priority of putting the patient at the centre of the care provided.

*“If your partner is acting as a translator, questions are going to be asked ...I mean I recall one lady, in particular, to a specific blood condition diagnosed during pregnancy and not a really medically complicated pregnancy and what we were trying to communicate with her and her husband was there should be no more pregnancy and you know, there was. Well, I had the perception that he wasn't translating verbatim.”*

#### 4.2.2. Theme 2: Clustering of disadvantage

Ethnicity is only one part of an individual patient identity and there are other known factors that can affect care, including education and religious beliefs. Professionals noted education in relation to a patient’s ability to advocate for themselves and saw this as more important than ethnicity in and of itself.

*“My impression is stuff that's more related to education than it is to ethnicity. So if you have someone from an ethnic minority background, who has had A Level education, they will advocate for themselves. From a white background, who left school at 14 they will have fewer questions.”*

Professionals also described how religious beliefs from their experience can impact patients accepting treatment options available. Some examples included:



- Jehovah's witness and treatment options that may involve blood transfusions.
- Individual from a Zimbabwean background believed they were possessed, and illness was caused by the devil (wanted exorcism, not medical intervention).
- Women of Islamic faith often observe modesty, signified in wearing a hijab and this require cultural understanding and accommodation in settings where there may be multiple patients, medical staff, cleaning staff e.g. inpatient care. This empowers patients to feel at ease in care settings.

Culturally appropriate care in relation to such factors was therefore described as:

*“Making sure that the patient understands and is kind of able to understand and that the care that is provided fits them as an individual.”*

There was consensus amongst professionals recognising the individual patient at the centre of culturally appropriate care.

Professionals did note that trust was a factor that they believed took time to achieve with minority ethnic patients more often than for those from a White heritage but an important aspect of addressing equity in experience.

*“For the majority of my white patients they walk in the door and I don't need to earn their trust, because the label of Dr is sufficient to earn their trust you know they assume I'm going to be trustworthy cause I'm a doctor, whereas I think some people from an ethnic minority background don't...they walk in the door, with their guards up.”*

## 5. Conclusion

This report has considered what data is already available nationally to help further understand the experience and outcomes of patients identifying with a minority ethnic heritage with Blood Cancer. It has also provided primary data on what culturally sensitive care means for professionals working in Blood Cancer care settings, across different professional job roles. Whilst there is a range of national data available, a full request for permissions is needed with a detailed underlying analysis plan to the NCRAS to be able to answer questions that can drive the priorities of policy makers, commissioners and researchers working to address health inequities. Further, there is a need for qualitative inquiry with patients directly to explore some of the variations in question ratings in the NPES for Blood Cancer patients specifically. Though limitations of the sample size for professional interviews are acknowledged, on the basis of the evidence provided, there is value in gaining broader healthcare faculty input to answer whether they feel empowered to provide culturally responsive care, their successes and challenges in doing so, and case study examples of change within individual trusts that has led to demonstrable patient benefit.

## 6. References

1. What is Blood Cancer? Blood Cancer UK. Available from: <https://bloodcancer.org.uk/understanding-blood-cancer/what-is-blood-cancer/>
2. Blood Cancers. Cancer Research UK. Available from: <https://www.cancerresearchuk.org/aboutcancer/blood-cancers>
3. Forman, D. (2009) *Cancer Incidence and Survival by Major Ethnic Group, England, 2002–2006*. National Cancer Intelligence Network, London.
4. Shirley, M. H. et al. (2013) Incidence of haematological malignancies by ethnic group in England, 2001-7, *British Journal of Haematology*, 163(4), 465–477.
5. Pinder R. J., Ferguson J., Møller H. (2016). Minority ethnicity patient satisfaction and experience: results of the National Cancer Patient Experience Survey in England. *BMJ Open*, e011938. doi:10.1136/bmjopen-2016-011938
6. The unmet needs of people with blood cancer across the United Kingdom. Available from: <https://static1.squarespace.com/static/5b98cdc612b13fdd2982129d/t/619664793014f77536aeaf5d/1637246073957/The+Forgotten+Fifth+Evidence+Review.pdf>
7. Patel, M. I., Ma, Y., Mitchell, B. S., & Rhoads, K. F. (2012). Understanding disparities in leukemia: a national study. *Cancer Causes & Control*, 23(11), 1831-1837.
8. Patel, M. I., Ma, Y., Mitchell, B., & Rhoads, K. F. (2015). How do differences in treatment impact racial and ethnic disparities in acute myeloid leukaemia?. *Cancer Epidemiology and Prevention Biomarkers*, 24(2), 344-349.
9. Popat, R., Craig, Z., Davies, F. E., Cairns, D., Olivier, C., Child, J. A., ... & Jackson, G. H. (2021). Enrolment and Outcomes of Ethnic Minorities with Multiple Myeloma Treated in UK Myeloma Research Alliance (UK-MRA) Clinical Trials over 18 Years. *Blood*, 138, 4118.
10. Sharma, S., King, M., Mooney, R., Davenport, A., Day, C., Duncan, N., Modi, K., Da Silva-Gane, M., Wellsted, D. and Farrington, K. 2019. How do patients from South Asian backgrounds experience life on haemodialysis in the UK? A multicentre qualitative study. *BMJ Open*, 9(5), e024739.
11. Vydelingum, V., 2006. Nurses' experiences of caring for South Asian minority ethnic patients in a general hospital in England. *Nursing Inquiry*, 13(1), 23-32.
12. Licqurish, S., Phillipson, L., Chiang, P., Walker, J., Walter, F. and Emery, J., 2017. Cancer beliefs in ethnic minority populations: a review and meta-synthesis of qualitative studies. *European Journal of Cancer Care*, 26(1), e12556.
13. About the National Cancer Registration and Analysis Service. Available from: [http://www.ncin.org.uk/about\\_ncin/](http://www.ncin.org.uk/about_ncin/)
14. National Cancer Registration and Analysis Service (NCRAS). Available from: <https://www.gov.uk/guidance/national-cancer-registration-and-analysis-service-ncras>
15. National Cancer Patient Experience Survey. Available from: <https://www.ncpes.co.uk/>
16. Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. Sage.

## Appendix A: Responses to each NCPES question for haematology patients according to ethnicity.

### Overall NHS care

Forty-four percent of respondents from Asian and Black ethnic groups recorded that they had been given a care plan in comparison to 34.6% of respondents who identified as White. Similar positive ratings of the overall administration of care were recorded across White (90.9%), Mixed (92.7%), Asian (89.7%), Black (91.8%), Other (90.5%) and Not Given (91.3%) ethnic groups. Figures 2 and 3 show the percentage of positive responses to healthcare professionals providing care, and wait times.

Figure 2.

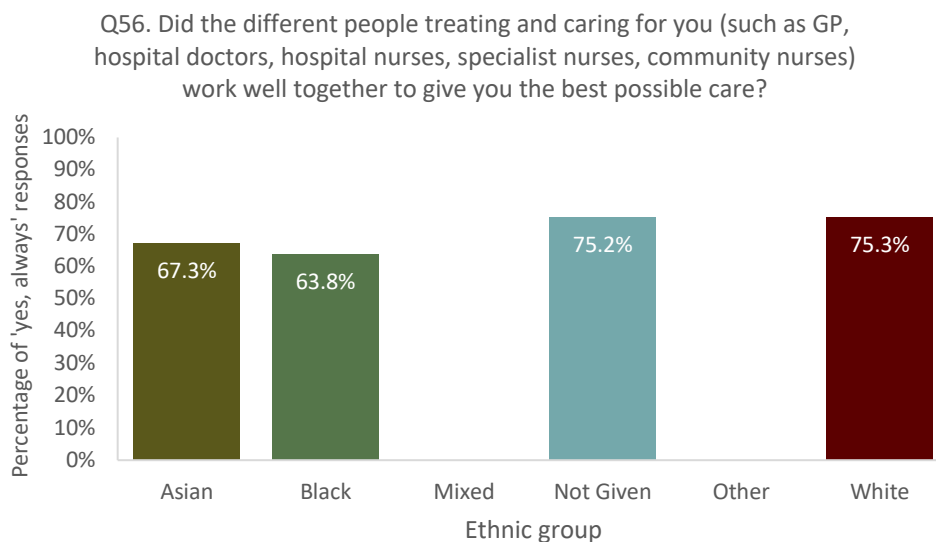
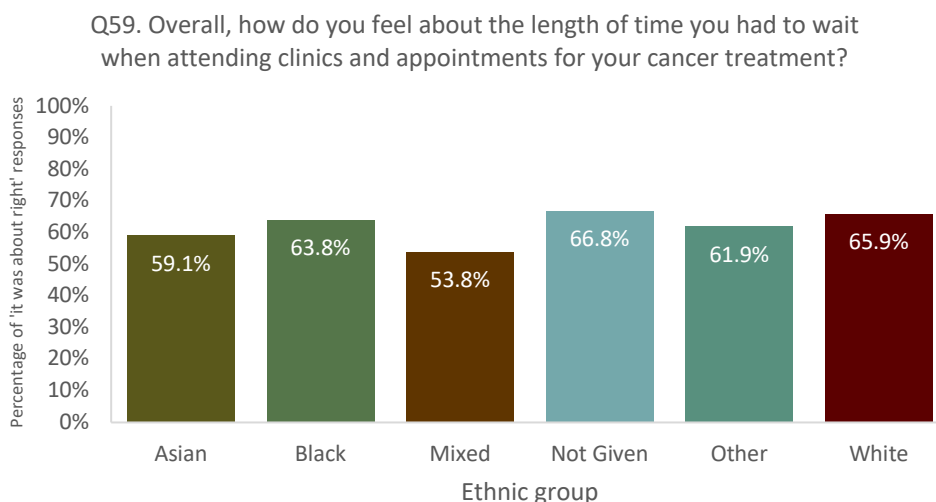


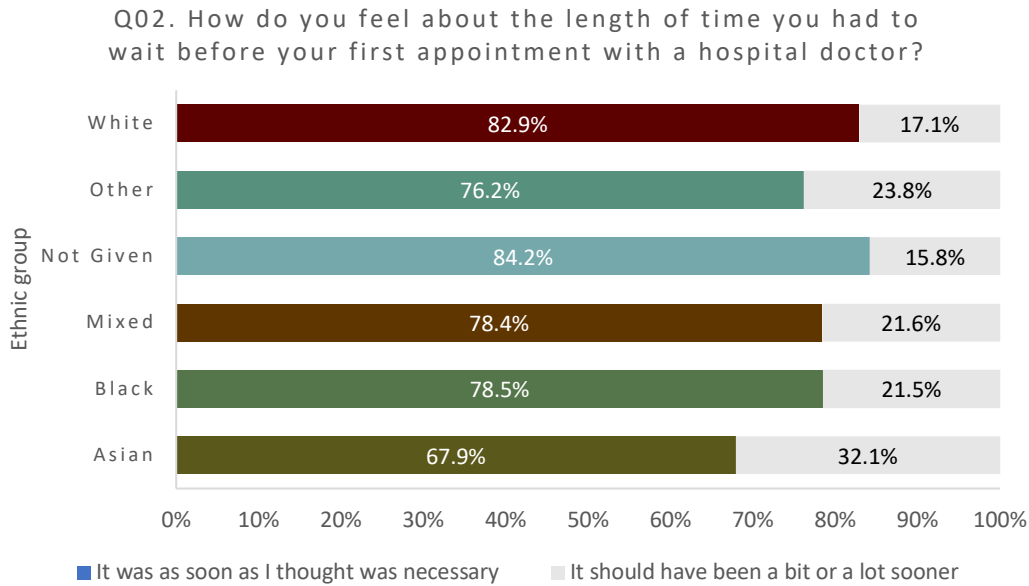
Figure 3.



Seeing their GP

Noteworthy, 32.1% of respondents who identify as Asian felt that the wait before their first appointment with a hospital doctor could have been a bit or a lot sooner which is nearly double the percentage compared to White respondents (as shown in Figure 4).

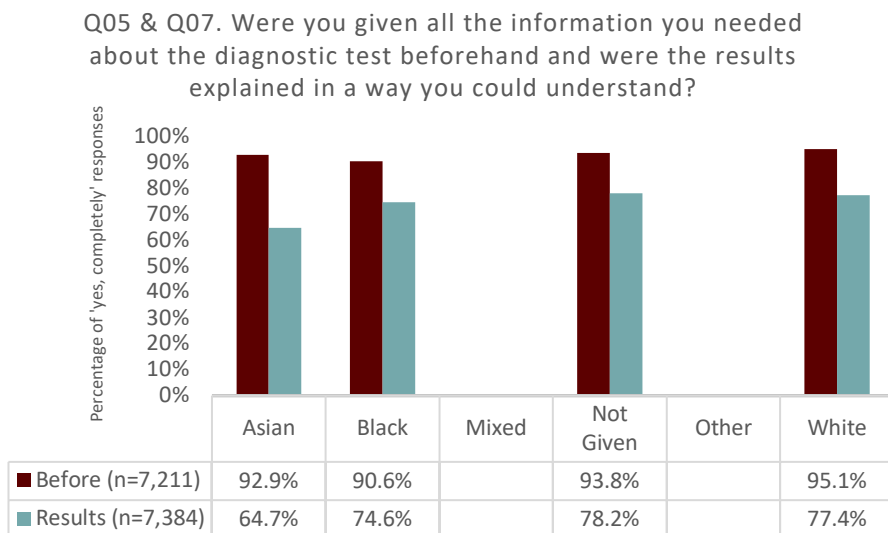
Figure 4.



Diagnostic tests

Just over 72 percent of respondents who identify as Asian felt that the length of time they had to wait for a diagnostic test to be done was 'about right'. This percentage is considerably lower compared to the Other ethnic groups (White=89.9%, Black=88.6%, Not Given=88.3%). Across all ethnic groups, the respondents were more likely to feel that they had all the necessary information before the diagnostic test than agree that the results were explained in a way that they could understand (as shown in Figure 5). Only 64.7% of Asian respondents (n=200) reported that their test results were completely explained in a way that they could understand.

Figure 5.



### Finding out what was wrong with them

A high proportion (90.6%) of respondents were told that they had cancer at least 6 months before completing the survey and were informed about their cancer diagnosis by a specialist doctor or consultant at a hospital (see Table 3).

Table 3. The frequency of responses to 'Who told you that you had cancer?'

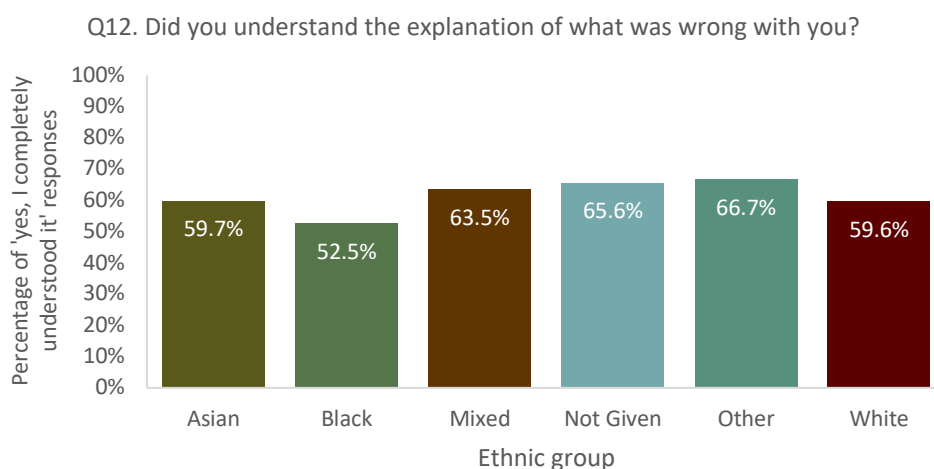
	A specialist doctor or consultant	My GP	A Clinical Nurse Specialist	Someone else	Don't know/can't remember
Asian	261	38	14	6	1
Black	-	-	-	-	-
Mixed	-	-	-	-	-
Not Given	585	90	38	10	10
Other	-	-	-	-	-
White	8,490	1,360	562	182	35

- No data was available

Seventy-one percent of White respondents, 73.4% of Asian, 74.9% of Black respondents were told that they could bring a family member or friend with them when they were first told that they had cancer. The majority of White (84.1%), Mixed (88.8%), Asian (79.6%), and Black (85.4%) respondents felt that they were told about the cancer diagnosis sensitively.

When asked whether they were given written information about the type of cancer they had when first told, 76.5% of White respondents answered they had, and it was easy to understand. The same response was given by 71.3% of Asian respondents, 70% of Black respondents and 76.8% of respondents who did not disclose their ethnicity. Of the 181 Black respondents, 52.5% said that they completely understood the explanation of what was wrong with them (see Figure 6).

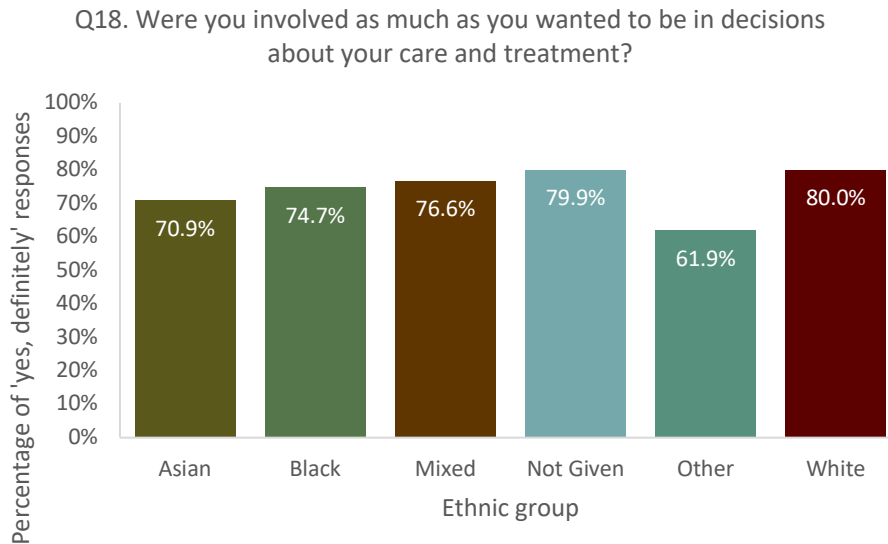
Figure 6.



### Deciding the best treatment for them

The following percent of respondents according to their ethnic group answered 'yes completely' when asked whether their treatment options were explained to them before cancer treatment started: 82% White, 74.4% Asian, 80% Black and 83.7% ethnicity not disclosed. Respondents identifying with a White ethnicity, more often than any other ethnic group, stated that they were involved as much as they wanted in decisions about their care and treatment (figure 7).

Figure 7.



Positive ratings for being told about how side effects of their treatment could affect them in the future rather than straight away were found for respondents who identified as Asian (54.2%), Black (55.5%) and those who did not disclose their ethnicity (55.9%) compared to a lower positive rating given by White respondents (50.4%).

Similar ratings for definite agreement to being offered practical advice and support in dealing with the side effects of treatment were found for respondents who identified as White (65.4%), Black (66.1%) and those who did not disclose their ethnicity (65.1%) compared to a lower positive rating given by Asian respondents (61.9%).

### Clinical nurse specialist

Respondents were asked three questions regarding the care experience provided by their Clinical Nurse Specialist (see Figures 8-10). The data signal disparity that points to ability to contact a Nurse Specialist and gaining answers that can be understood for some ethnic groups in particular. It is also notable more generally that a number of patients across all ethnic groups reported not receiving the name of their Clinical Nurse Specialist.

Figure 8.

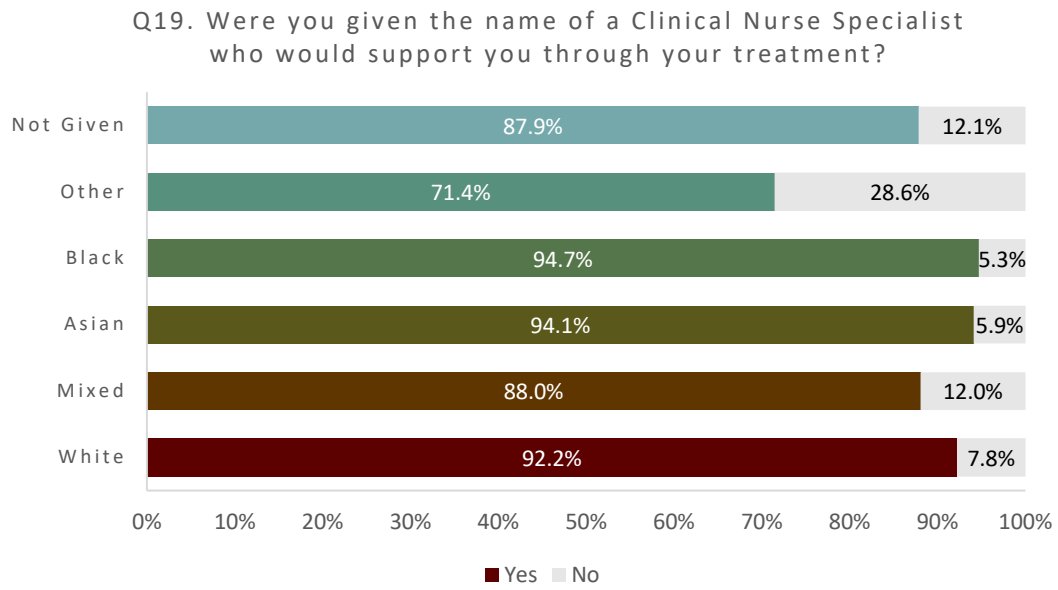


Figure 9.

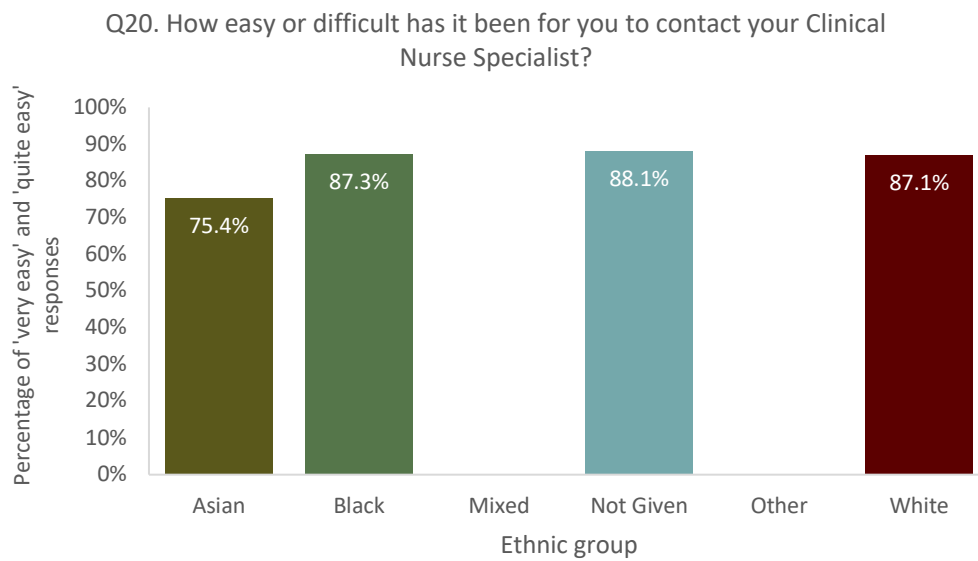
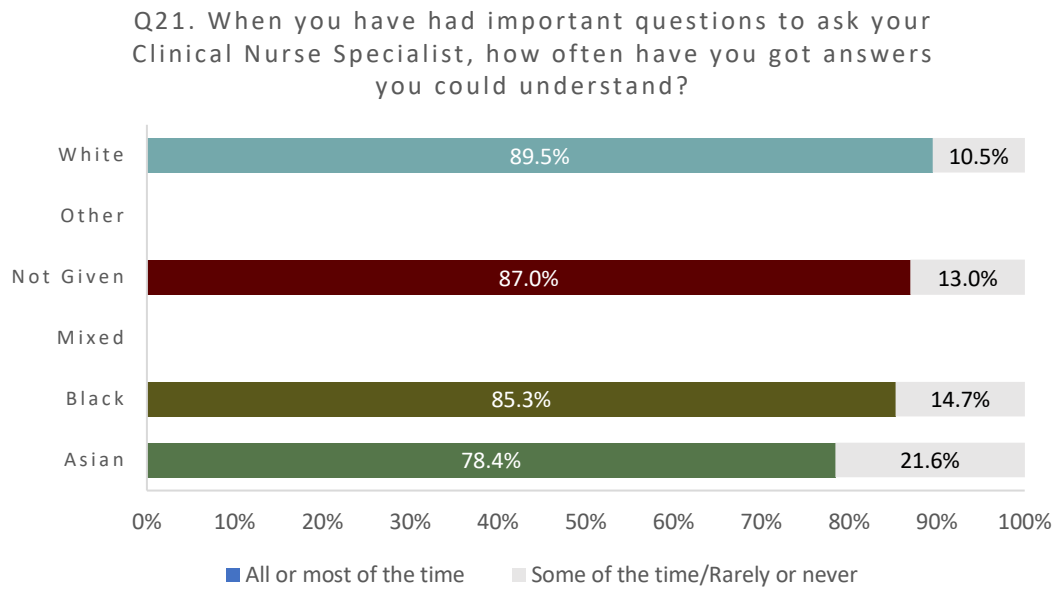


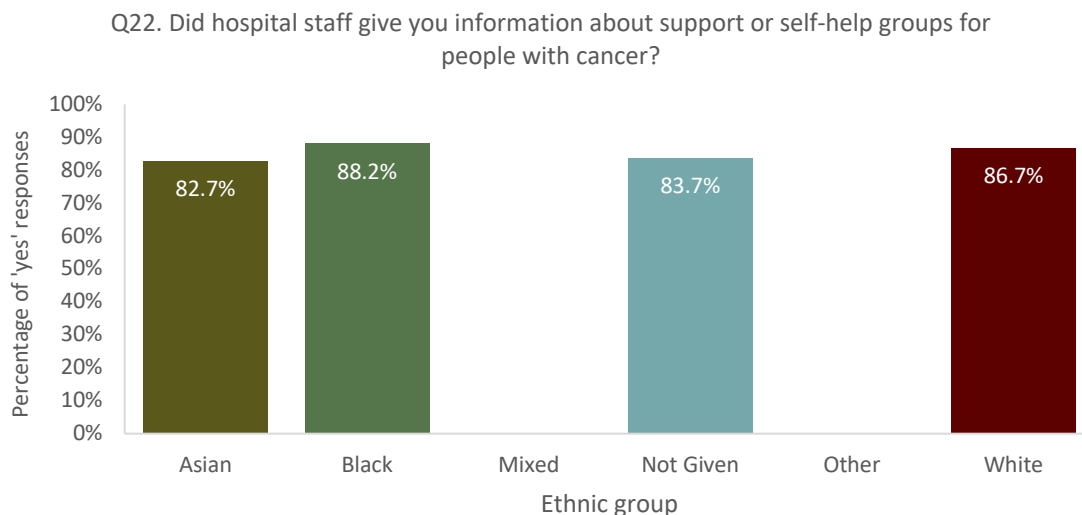
Figure 10.



Support for people with cancer

The following percent of respondents according to their ethnic group answered yes when asked whether hospital staff discussed or gave information about the impact that cancer could have on your day-to-day activities: 61.6% White, 59.6% Asian, 64.3% Black and 57.3% ethnicity not disclosed. Positive ratings for whether respondents were given support information from hospital staff are presented in Figure 11.

Figure 11.



When asked whether or not hospital staff gave them information about financial help or any benefits they might be entitled to, 61.2% of White respondents, 59.2% of Asian respondents,



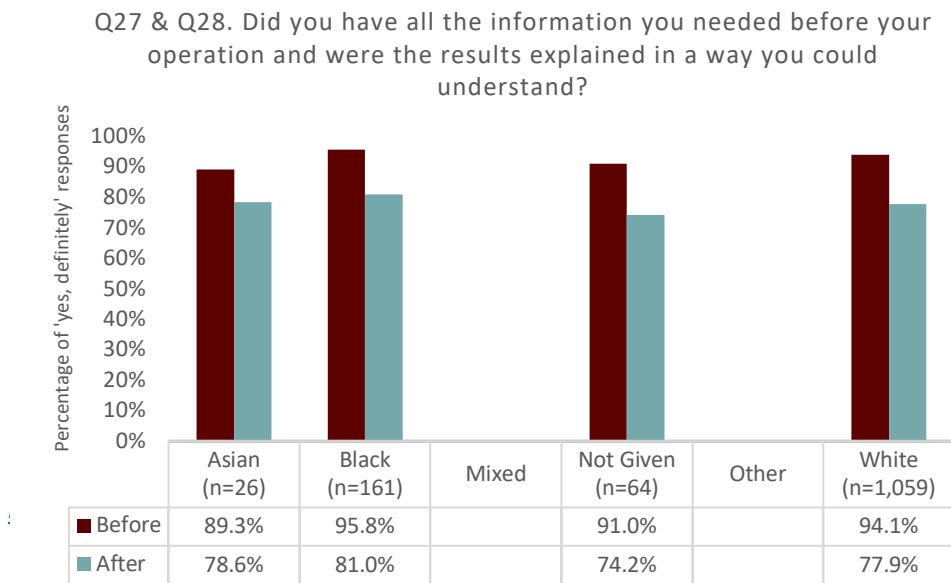
64.3% of Black respondents and 57.3% of respondents who did not give their ethnicity responded yes.

The majority of respondents reported that they were told that they could get free prescriptions (White=87.2%, Asian=83.1%, Black=79.8%, Not Given=86.5%).

Operations

Figure 2 shows the proportion of positive ratings in terms of information before an operation and a clear explanation of the operation outcome across the ethnic groups. The most positive rating is from patients identifying with a Black heritage overall.

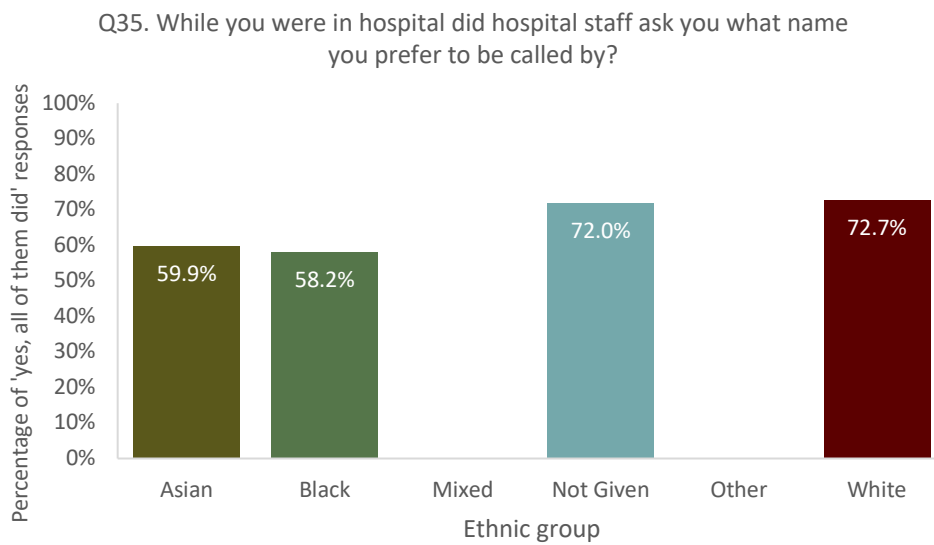
Figure 12.



Note. n = number of respondents who reported having an operation in the 12 months prior to completing the NCPES.

stayed in a s (n=3,683) considerably percentage of respondents who belong to Asian and Black ethnic groups were asked what name they prefer to be called by hospital staff in comparison to White respondents (see Figure 13).

Figure 13.



When asked whether they thought the hospital staff did everything they could to help control their pain, 82.6% of White, 75.4% of Asian, 77.5% of Black respondents and 84% of respondents who did not disclose their ethnicity selected 'yes, definitely'.

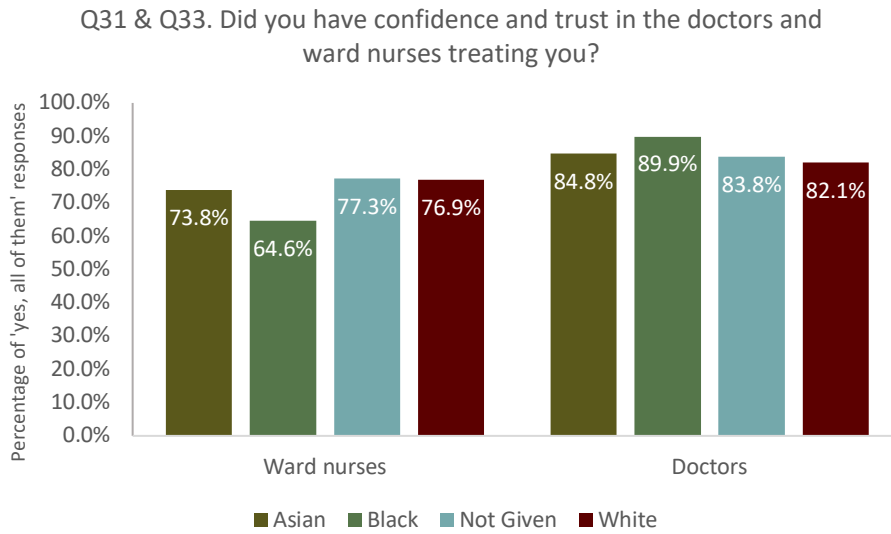
Of the 3,327 responses recorded, similar percentages from 56.7% White, 56.7% Black and 55.8% Not Given respondents said that they definitely found someone on the hospital staff to talk to about their worries and fears; however, ≈6% fewer respondents of Asian ethnicity recorded this positive experience (50.7%).

The following percent of respondents according to their ethnic group answered yes when asked whether their family or someone else close was able to talk to a doctor if they wanted to: 73.9% White, 75.0% Asian, 68.5% Black and 78% ethnicity not disclosed.

Along with being asked about trust in the ward nurses (see Figure 14), respondents were asked whether there were enough nurses on duty to care for them whilst they were in the hospital. According to ethnic group, 63.2% of White respondents said that there were always or nearly

always enough nurses compared to 59.5% of Asian respondents, 62.8% of Black respondents and 58.4% of respondents who did not disclose their ethnicity.

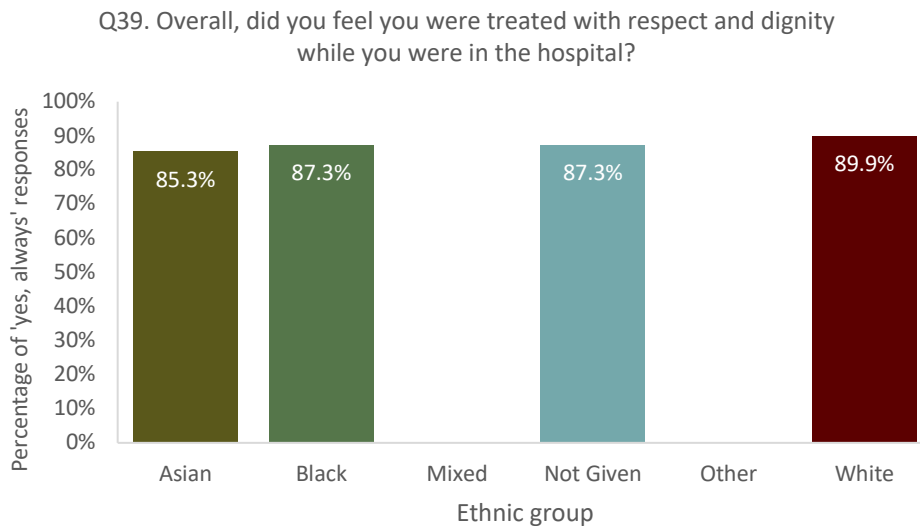
Figure 14.



Of 78 respondents of Black ethnicity, 78.2% felt that they were always given enough privacy when discussing their condition or treatment. This was in comparison to 86.4% of White respondents, 85.7% of Asian respondents and 89.4% of respondents who did not give their ethnicity.

As shown in Figure 15.5, the majority of respondents from all ethnic groups, with data available, reported that they always were treated with respect and dignity while they were in the hospital.

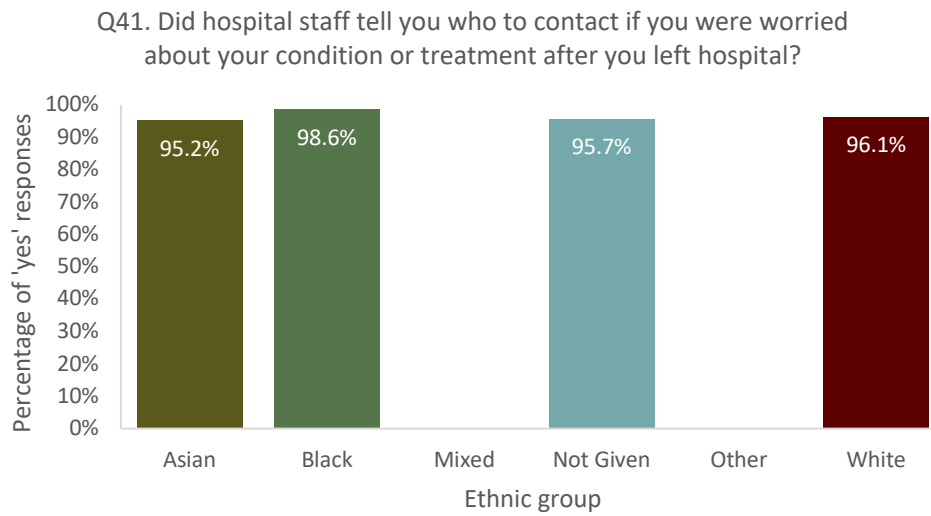
Figure 15.



A high proportion of respondents from the ethnic groups, with available data, reported that they did know whom to contact if they were worried about their condition or treatment after they left the hospital (see Figure 16.6). Similar positive ratings were given in agreement on if respondents were provided with clear written information about what they should or should not do after leaving the

hospital for respondents who identified as White (82.6%), Asian (82.4%), or Black (78.6%) or did not disclose their ethnicity (82.3%).

Figure 16.



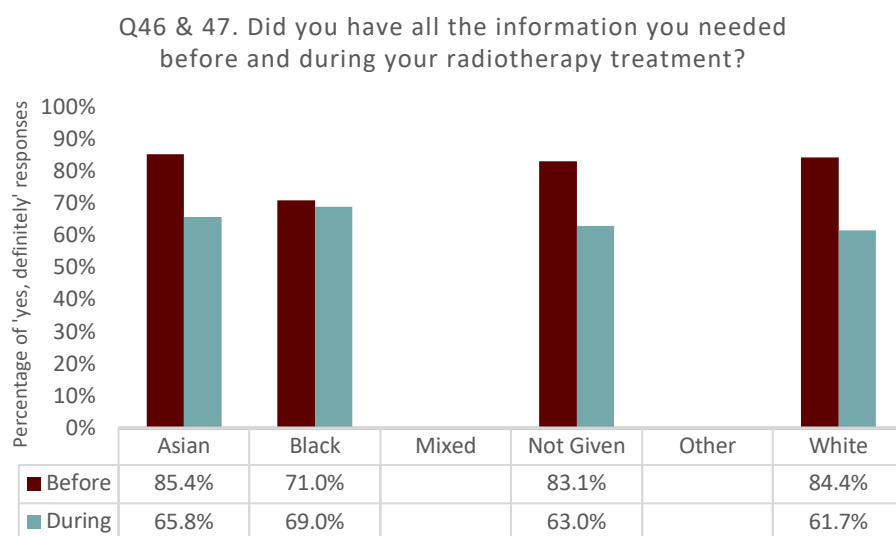
#### Hospital care as a day patient/outpatient

In the 12 months before completing the survey, 10,011 respondents had been treated as an outpatient or day cases for cancer care. Of the 3,327 responses recorded, similar percentages from 73.8% (n=7,223) of White respondents and 73.5% (n=476) respondents who did not give their ethnicity said that they definitely found someone on the hospital staff to talk to about their worries and fears when being treated as an outpatient or day case; however, ≈10% fewer respondents of Asian (63.3%; n=237) and Black (64.7%; n=136) ethnicity heritage recorded this positive experience.

Equal to or greater than 95.6% of respondents from all ethnic groups with scored data notes that during their last outpatient appointment with a cancer doctor that they had the right medical documents. Mixed and Other categories had no scored data for this question.

In the 12 months before completing the survey, 1,139 respondents had received radiotherapy treatment. A breakdown of positive ratings of respondents in terms of having enough information before and during radiotherapy treatment can be seen in Figure 17.

Figure 17.



Of the respondents who had received chemotherapy in the 12 months before completing the NCPES (n=7,406), similar proportions across White, Asian, Black and ethnicity Not Given respondents (75.2%, 75.7%, 75%, 76.9% respectively) recorded that they were given enough information about whether their chemotherapy was working in a way they could understand. Prior to treatment, 85% of White respondents stated that they definitely had all the information they needed about their chemotherapy treatment compared to 83.1% of Asian, 80.2% of Black and 87.1% of ethnicity not disclosed respondents.

#### Home care and support

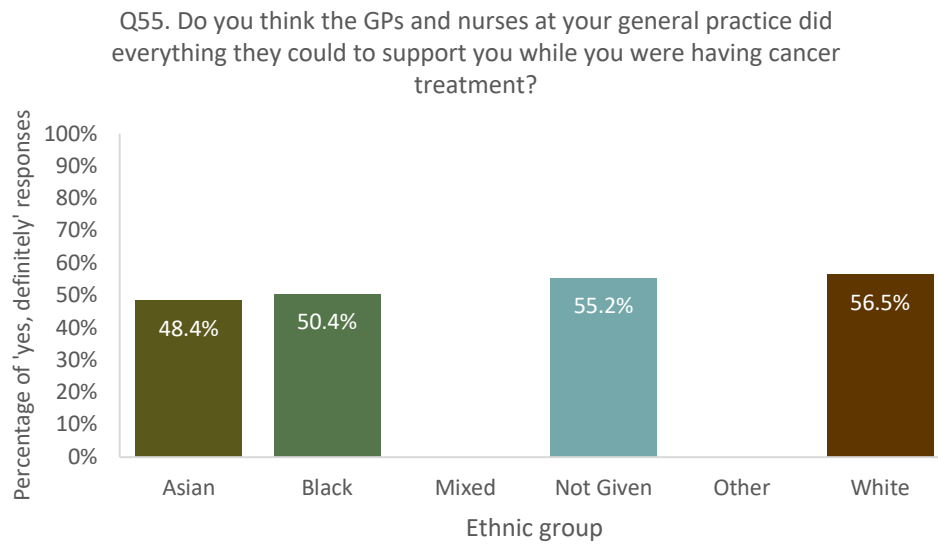
When asked if the doctors or nurses gave their family or someone close to them all the information they needed to help care for them at home, 61.9% of White respondents ticked 'yes, definitely' compared to 59.2% of Asian respondents and 59.3% of Black respondents.

Less than half of respondents in all the four minority ethnic groups with available data felt that they were given enough care and support from health or social services after their cancer treatment.

#### Care from their general practice

Ninety-six percent of White respondents said as far as they knew, their GP was given enough information about their condition and the treatment they had at the hospital. In comparison, this response was recorded by 87.2% of respondents who identify as Asian, 94.6% of respondents who identify as Black and 94.3% of respondents who did not disclose their ethnicity. Comparing results across ethnic groups, respondents who identified as Asian reported the lowest percentage of confidence that the healthcare staff at their general practice did everything they could during their cancer treatment (see Figure 18).

Figure 18.



Research

Just over 50 percent of respondents who identified with a Black background stated that someone has discussed possible participation in cancer research. This percentage was considerably higher than White respondents (32.2%).