BME Cancer Patient Information Survey

Research commissioned by BME Cancer Voice, part of the BHI charity

September 2012

Amended October 2013

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1 Executive Summary

Evaluation of Information Received

- The majority of patients (76%) received information throughout their cancer experience directly from NHS professionals (via spoken information) and from leaflets provided in hospitals (62%).
- These most frequently used channels (NHS professionals and leaflets in hospitals) were also the channels patients were most satisfied with; 98% found information from NHS professionals useful, 97% found leaflets in hospitals useful.
- 24% of patients reported that they did not receive information throughout their cancer experience from NHS healthcare professionals.
- 38% of patients reported that they did not receive information from leaflets in hospitals.
- 2% of patients stated they did not receive any information at all throughout their cancer experience.
- 11% of patients used NHS websites as a source of information, whereas 83% did not.
- 6% of patients used NHS direct as a source of information, 94% did not.
- 85% of patients found the information they received easy to understand, 73% felt they received a sufficient amount, and 75% received information at the time they needed it.
- 81% of patients agreed that the information provided was in the correct language, this figure was lower for patients from a Chinese ethnic group (73%).
- 53% felt the information they received was sensitive to their culture, whereas 37% were neutral or undecided. 10% felt the information they received was not sensitive to their culture.
- 36% of patients felt well informed regarding the advice or support available to them that was specific to their culture/religious beliefs during treatment, whereas 27% felt uninformed.
- After treatment only 28% felt informed regarding the advice or support specific to their culture/religious beliefs/spiritual needs, and 25% felt uninformed.

Patient Knowledge

- The majority of patients felt informed prior to diagnosis in terms of when tests would be carried out (83% extremely well or well informed), when to expect the results (83%).
- At diagnosis patients felt informed in terms of what type of cancer they had (86% extremely well or well informed), the options available to future management (81%).
- 82% of patients felt extremely well or well informed as to how effective treatment would be and 77% felt informed about how they would feel throughout treatment.
- Patients felt slightly less informed regarding how long recovery would take; 69% extremely well or well informed.
• Patients from a Mixed ethnic group were the most informed throughout their patient journey, with patients from a Chinese ethnic group the least informed.

• Breast cancer patients were better informed than other cancer patients across all aspects of their cancer journey.

• 69% of patients were extremely well or well informed regarding the role of the healthcare professional at diagnosis, and at treatment this figure increased to 78% extremely well or well informed.

• Two thirds (66%) of patients felt informed regarding their own role in the process at diagnosis and 68% felt informed at treatment.

• Post-treatment fewer patients felt informed about how to take care of themselves physically (62%).

• 53% of patients felt informed with information they received post treatment regarding the support and advice available to them.

• 20% of patients felt either extremely poorly or poorly informed with the information they received post treatment regarding the support and advice available to them.

• The majority (72%) of patients were well informed about who to contact with any further questions; patients from a Mixed ethnic group were significantly more informed than others (84%).

• 34% of patients felt extremely poorly or poorly informed about the emotional support groups and counselling available

• 41% of patients either did not receive any information on or felt poorly informed regarding how cancer might affect relationships and how to break the news of cancer to loved ones

• 36% of patients did not receive any information on how to access financial support or advice
Culturally Sensitive Services

- 23% of patients felt extremely poorly or poorly informed or received no information about needing and using a wig.
- 35% of patients felt extremely poorly or poorly informed or received no information regarding their diet needs and considerations.
- 58% of patients who required a prosthesis, were not offered one that was appropriate to their skin tone;
  - 67% of patients from a Chinese ethnic group and 66% of patients from an Asian ethnic group were not offered one that was appropriate to their skin tone.
- 48% of patients felt informed about the effect drug options had on different ethnic groups.
  - Patients from a Chinese ethnic group were significantly less informed (30% extremely well or well informed). One fifth (20%) of patients felt extremely poorly or poorly informed.
- 54% of patients were informed about the side effects of treatments on their skin type. 16% of patients felt uninformed.
- In 2 out of 5 cases where an interpreter was required, this service was not offered by the NHS

Key Insights in this Report:

- The majority of patients have not used online and telephone channels such as NHS direct to as a source of information during their cancer journey.
- Patients felt uninformed about their diet needs and considerations.
- A quarter of patients felt uninformed regarding advice or support specific to their culture/religious beliefs/spiritual needs.
- More than half of patients who required prosthesis were not offered one that was appropriate to their skin tone.
- Patients from a Chinese ethnic group were the least informed.
2 Research Design

2.1 Research Objectives

The main objectives of the survey were to uncover the information received by cancer patients and satisfaction with the information received at different points in their cancer journey:

- Prior to diagnosis
- At the point of diagnosis
- During treatment
- After treatment had finished

Further details are highlighted in section 2.3 Questionnaire design.

2.2 Fieldwork and sampling

A total of 661 BME cancer patients took part in the survey from the following sources:

1. BME Cancer Voice members – members of the BME Cancer Voice were contacted via their preferred contact method - either post, telephone or online, directly by Kadence.
   - The 1st stage of fieldwork, with a previous version of the survey, took place between 2009 and December 2011
   - In January 2012 an updated version of the survey was introduced, and all new members to the BME Cancer Voice were invited to take part.

2. Quality Health sample – 1400 BME cancer patients (sourced through a previous NHS survey) were invited to take part in the survey via post. Completed, anonymised surveys were sent back to Kadence International who were responsible for the data entry and analysis.
   - Fieldwork took place between Mid March 2012 – June 18th 2012

<table>
<thead>
<tr>
<th></th>
<th>PRE 2012 SURVEY</th>
<th>2012 SURVEY</th>
</tr>
</thead>
<tbody>
<tr>
<td>BME Cancer Voice members</td>
<td>47</td>
<td>10</td>
</tr>
<tr>
<td>Quality Health Sample</td>
<td>n/a</td>
<td>604</td>
</tr>
</tbody>
</table>

Table 1 – Overview of Information Survey respondents

Please note these results are for cancer patients only. Where appropriate ethnic group and cancer type splits have been included. Please see Figure 15 & 16 in Appendix 6.1 for further information.
2.3 Questionnaire design
A copy of the questionnaire is included in the Appendix of this report. It consisted of seven main sections, the first four specifically covering the different stages of the patients’ cancer experience:

Section A: Tests & Investigations - Respondents answered questions about how informed they felt during the testing phase and prior to their diagnosis.

Section B: Diagnosis – Questions in this section focused specifically on the type and quality of information patients had received at the time of diagnosis and prior to their treatment.

Section C: Treatment – Information the patient received during their treatment (both aimed to cure and manage the cancer).

Section D: Post Treatment – Information, guidance and support services post-treatment

Section E: Specific Needs – focus on particular information and other needs and how effectively these were addressed – for example needing an interpreter, skin-appropriate prostheses, information on diet, finance and relationships.

Section F: Overall Experience – Patients’ overall rating of their experience with the NHS with regards to cancer, as well as a detailed look at where and how they accessed this information and patients’ preferences. This section also provided the opportunity for open feedback from patients, whether positive or negative.

Section G: Demographics – Basic demographic information including cancer type, location, gender and ethnicity was collected in order to provide useful context for the analysis of the data.
3 Evaluation of Information Received

3.1 Information Channels

Results show there are two main channels by which patients remember receiving information throughout their cancer experience; spoken information from NHS healthcare professionals and leaflets provided in hospitals (Figure 1). Three quarters of patients (76%) received information directly through speaking with an NHS healthcare professional, and 62% of patients said they received leaflets which were provided in the hospital.

Information provision through Primary Care was less frequent. 11% of patients received leaflets provided at their GP surgery, and only 6% of patients received information via posters in GP surgeries, compared to 19% in hospitals.

Online or telephone channels of information were used less frequently throughout the patient’s journey. 11% used NHS websites and 6% used NHS Direct for information throughout their cancer experience.
3.2 Usefulness of Information Channels

The most frequently used channels were also perceived as the most useful (Figure 2).

Nearly all patients (98%) found information through NHS healthcare professionals useful, with a third of them (32%) stating that this information was extremely useful.

Leaflets provided at the hospital were considered more useful than leaflets provided in GP surgeries; 24% found hospital leaflets extremely useful compared to just 12% with regards to GP leaflets.

Patients were less satisfied with the usefulness of NHS websites and the NHS Direct Service (21% and 25% respectively found these services not useful).
3.3 Quality of Information Received

More than three quarters (85%) of all patients strongly or slightly agreed that the information they received was easy to understand (Figure 3), and this number is significantly higher for Breast cancer patients (92%).

73% of patients strongly or slightly agreed that they had enough information; however 12% believe they did not. A directionally higher proportion (82%) of those from a Mixed ethnic group strongly agreed that they received a sufficient amount.

The majority of patients (75%) strongly or slightly agreed that the information was provided at the right time in their cancer journey. Again this figure is significantly higher for Breast cancer patients (83%).

Fewer respondents agreed that the information they received was respectful to their culture (53% strongly or slightly agree), and a quarter (24%) stated it was neither respectful nor disrespectful.

81% of patients agreed that all the information they received was provided in the language they needed. Those from a Mixed ethnic group were more likely to agree with this statement (90%), however in the case of those from a Chinese ethnic group, this figure is directionally lower at just 73% who agree. Just 5% of patients disagreed that the information they
received was provided in the language they needed, but in the case of patients from a Chinese ethnic group, this number was directionally higher at 13%.

### 3.4 Cultural, Spiritual and Religious Information

Results show 40% of patients felt extremely well or well informed regarding the advice and support available to them that was specific to their culture or religious beliefs during their treatment. Significantly fewer patients from a Chinese ethnic group felt informed (22%), and over a quarter of patients (27%) felt poorly or extremely poorly informed (Figure 4).

Once treatment had finished, there were a similar number of patients who felt informed (28% extremely well or well informed) as those who felt uninformed (25% poorly or extremely poorly informed) with regards to support available to meet religious, spiritual or cultural needs.

![Cultural, Spiritual and Religious Information](image)

**Figure 4**

Just over half of patients (53%) strongly or slightly agree that the information (as opposed to the support) they received was sensitive and respectful of their culture —9% disagreed. Respondents from a Chinese ethnic group gave a significantly lower rating (32% strongly or slightly agree).
As shown in Figure 4 around a quarter of patients stated that they did not have an opinion regarding the cultural, spiritual and/or religious information they received (neither positive nor negative – shown by the yellow box). Open-ended comments indicate that some patients simply did not expect culture or religion to be part of the service – either because they didn’t feel they needed it or because they felt it wasn’t relevant.

“I don’t think culture has anything to do with the information I received. I was grateful for all information received irrespective of culture. All information should be medical and not culture oriented.”

“I do not believe that consideration needs to be given to culture and ethnic matters, other than providing interpreter services if necessary. Priority should be given to providing patients with diagnostic and treatment options that are best for them.”

“I had complete faith in all medical staff with whom I came in contact. My life is not defined by any religion or cultures, I was unwell, the doctors and staff explained the best in treatment in their opinion for my individual needs.”
4 Patient Knowledge

4.1 Patient Knowledge from Diagnosis to Treatment

Figure 5 summarises how well informed patients felt during different points of their cancer treatment; from the tests carried out prior to diagnosis, the diagnosis itself, through to treatment and recovery.

Prior to diagnosis, 83% of patients felt either extremely well or well informed about which tests would be carried out, and when to expect their results. Only a small minority felt uninformed prior to diagnosis (5% poorly or extremely poorly informed on the tests carried out, and 6% with regards to when to expect the results).

86% of patients felt either extremely well or well informed about the type of cancer they had, and 6% felt uniformed regarding this. A further 81% felt informed with regards to the options available to them for managing their cancer and treatment, and again just 6% felt uninformed regarding this.

![Patient Knowledge from Diagnosis to Treatment](image_url)

Figure 5
At the point of treatment, 82% of patients felt informed regarding the effectiveness of their treatment. 77% felt informed regarding how they would feel throughout treatment; with 7% stating they felt uninformed regarding this.

In terms of recovery time, fewer patients felt well informed at this point in their cancer journey (69% extremely well or well informed) compared to at other points of their journey. Furthermore a higher number of patients stated they felt uninformed at this time (10% poorly or extremely poorly informed), than at any other time during their cancer journey.

*Figure 6* displays the percentage stating they felt extremely well or well informed (top 2 box) split by different subgroups.

<table>
<thead>
<tr>
<th>QA1, A2, B1, B2, C1, C2 &amp; C6</th>
</tr>
</thead>
<tbody>
<tr>
<td>How well informed did you feel about...</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TOP 2 BOX % of Patients*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asian</td>
</tr>
<tr>
<td>Which tests would be carried out</td>
</tr>
<tr>
<td>When results should be expected</td>
</tr>
<tr>
<td>Which type of cancer you had</td>
</tr>
<tr>
<td>Options available for managing your cancer &amp; treatment</td>
</tr>
<tr>
<td>How effective treatment may be</td>
</tr>
<tr>
<td>How you would feel throughout the treatment</td>
</tr>
<tr>
<td>How long recovery may take</td>
</tr>
</tbody>
</table>

*Top 2 box is the percentage of respondents who selected ‘extremely well’ or ‘well informed’ for each statement

**Significant difference at the 50% confidence level

Overall it is those from a Mixed ethnic group who are the most informed; 92% were informed regarding the tested carried out, and 89% were informed on the options available to them in the management of their cancer, significantly more than the total result (78%). This is followed closely by those from a Black ethnic origin; 89% were informed on type of cancer they had, 87% were informed on tested carried out and when results should be expected prior to diagnosis.

Patients from a Chinese ethnic group were the least informed; 70% informed on what their options were for managing their cancer, and 72% informed on what tests would be carried out.
On the whole Breast cancer patients were more informed throughout their cancer journey than other cancer patients were. Breast cancer patients were significantly better informed in terms of when results should be expected (89%), the options available for managing their cancer (86%) and how they would feel throughout treatment (83%).

4.2 Patient Knowledge of Roles

Results show that at diagnosis, 69% of patients were extremely well or well informed regarding the role of different healthcare professionals in the management and treatment of their cancer (Figure 7), whereas 11% felt extremely poorly or poorly informed. Patients from a Mixed ethnic group felt significantly more informed (85% extremely well or well informed).

During treatment, an increased number of patients felt informed with regards to the role of the healthcare professionals undertaking their treatment (78% extremely well or well informed). Patients who felt uninformed decreased to 6% (poorly or extremely poorly informed).

The majority of patients felt they had a good understanding of their own role throughout their cancer journey. At diagnosis stage 66% felt extremely or well informed, and once again those from a Mixed ethnic group were the most informed (70% extremely well or well informed). Only 10% of patients felt uninformed at this point.
This number remains similar for patients during treatment; 68% of patients felt extremely or well informed, and just 9% who felt uninformed.

After their treatment this figure drops; 62% of patients stated they felt informed regarding how to take care of themselves physically, and those who felt uniformed increases (14% extremely poorly or poorly informed).

### 4.3 Emotional, Relationship and Other Support Information

Just over half (53%) of patients were either extremely well or well informed with the information on the psychological and emotional support available to them post-treatment (Figure 8), whilst 1 in 5 (20%) felt uninformed.

![Emotional, Relationship & Other Support Information](image)

When considering how informed patients felt regarding the emotional support through counselling and support groups at any given point in their cancer journey 45% felt extremely well or well informed. 11% of patients felt uninformed, and 23% of patients did not receive any information. In the case of Breast cancer patients, the number of those who did not receive this information was significantly lower than other cancer patients (13%).
With regards to receiving information on the effects of cancer on relationships, and how to break the news of the diagnosis to loved ones, a quarter of patients did not receive any information regarding either of these (28% and 25% respectively). Of those who did receive this information, 13% and 12% respectively felt uninformed. Those from a Chinese ethnic group felt less informed than others and a higher number received no information on these matters; 40% received no information about how cancer might affect relationships and 36% received no information on how to break the news to loved ones.

The majority of patients felt well informed about who they should contact with any further questions regarding their care (72% extremely well or well informed). Patients from a Mixed ethnic group were significantly more informed (84%). 11% of patients felt uninformed (poorly or extremely poorly informed) regarding who to contact with further questions.

Patients were less well informed with regards to information on financial support and advice available. 28% felt informed (extremely well or well informed), and over a third (36%) of patients did not receive any information regarding this. This result is mirrored across each of the different ethnic subgroups.
5 Culturally Sensitive Services

5.1 Specific Patient Needs and Services

Of those to which it was applicable, half of patients (50%) felt either extremely well or well informed with regards to information on needing and using a prosthesis (Figure 9). Breast cancer patients were significantly more informed (62%) than other cancer patients. 14% of patients did not receive any information on prostheses.

The majority of patients felt well informed regarding needing and using a wig (62% extremely well or well informed). 16% did not receive any of this information, but for Breast cancer patients this number was significantly lower (6%).

Patients felt less informed with regards to dietary needs and considerations, with 40% who felt extremely well or well informed. Patients from a Chinese ethnic group felt significantly less informed (22% extremely well or well informed) with regards to diet. Just over a fifth (23%) of patients in total did not receive any information on this.
Of those who required prosthesis, 42% were offered one which was appropriate to their skin tone, however over half did were not (Figure 10). 67% of patients from a Chinese ethnic group, and 66% from an Asian ethnic group were not offered prosthesis appropriate to their skin tone.

The open-ended comments below show issues patients commented on with regard to specific needs and services:

“I could not find a suitable match for a wig and the length was important as most wigs used short hair. For some women who do not cut their hair due to religious beliefs this is difficult.”

“I was told I would have to pay to have a wig to match my hair. The alternative was to have a short European type wig. I also had very little info provided on prosthesis to colour match my skin”

“The only issue I had was the choice of wigs. My hair was natural before I was sick, however although there was a choice of wigs it was only for people that had straightened hair beforehand, so nothing to match the natural afro hair texture.”

“Dietary information totally lacking, especially in relation to best foods to eat during chemotherapy”
“I did not receive dietary tips specific to my needs or culture, all information showed food which I only rarely ate. I think there should be more leaflets or information on ethnic food to avoid”

5.2 Drug Options and Side Effects

Less than half (48%) of patients felt informed about the effect of different drug options on people from different ethnic groups (Figure 11). One in five (20%) patients felt either poorly or extremely poorly informed. A similar pattern can be seen with regards to knowledge of side effects on different skin types; 54% felt informed, and 16% felt uninformed. Patients from a Chinese ethnic group felt significantly less informed (30%) with regards to the effect drug options have on people from different ethnic groups.

**Figure 11**

**Significant differences at the 95% confidence level**
5.3 Interpretation Services

Results show that 1 in 10 (9%) patients required an interpreter at some point during their cancer journey (Figure12). This proportion was 1 in 5 among patients from a Chinese ethnic group (20%), and 1 in 7 among patients from an Asian ethnic group (14%).

Of those who required an interpreter, 3 in 5 were offered one by the NHS, and in the majority of cases (80%) this interpreter was used. In 2 in 5 cases however, an interpreter was not offered by the NHS. Of those who were not offered an interpreter by the NHS two thirds relied on friend or family member and in a third of cases the patient did not have an interpreter at all.

Of those who were offered and used an NHS interpreter, the vast majority of them (19 out of 24) found the service either very or extremely useful.

![Interpretation Services](image)

Figure 12
6 APPENDIX

6.1 Respondent profile

Respondent Profile

Q 1 What form of cancer were you first diagnosed with?*

(! rows of percentages)

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>% of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast Cancer</td>
<td>39%</td>
</tr>
<tr>
<td>Prostate Cancer</td>
<td>12%</td>
</tr>
<tr>
<td>Lymphoma / Hodgkin’s Lymphoma</td>
<td>10%</td>
</tr>
<tr>
<td>Other</td>
<td>10%</td>
</tr>
<tr>
<td>Bowel / Colon Cancer</td>
<td>9%</td>
</tr>
<tr>
<td>Cancer of the Bladder</td>
<td>4%</td>
</tr>
<tr>
<td>Thyroid Cancer</td>
<td>3%</td>
</tr>
<tr>
<td>Colon / Rectal Cancer</td>
<td>3%</td>
</tr>
<tr>
<td>Ovarian Cancer</td>
<td>3%</td>
</tr>
<tr>
<td>(Multiple) Myeloma</td>
<td>2%</td>
</tr>
<tr>
<td>Lung Cancer</td>
<td>2%</td>
</tr>
<tr>
<td>Leukaemia</td>
<td>2%</td>
</tr>
<tr>
<td>Kidney Cancer</td>
<td>1%</td>
</tr>
<tr>
<td>Stomach Cancer</td>
<td>1%</td>
</tr>
<tr>
<td>Testicular Cancer</td>
<td>1%</td>
</tr>
<tr>
<td>Cancer of the Uterus</td>
<td>1%</td>
</tr>
<tr>
<td>Liver Cancer</td>
<td>1%</td>
</tr>
<tr>
<td>Cervical Cancer</td>
<td>1%</td>
</tr>
<tr>
<td>Throat Cancer</td>
<td>1%</td>
</tr>
<tr>
<td>Cancer of the womb</td>
<td>1%</td>
</tr>
<tr>
<td>Brain Tumour</td>
<td>1%</td>
</tr>
</tbody>
</table>

n = 554

* Quality Health Sample only

Respondent Profile

Q 5 To which of the following ethnic groups would you say you belong?*

(! rows of percentages)

<table>
<thead>
<tr>
<th>Ethnic Group</th>
<th>% of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indian</td>
<td>23%</td>
</tr>
<tr>
<td>Caribbean</td>
<td>18%</td>
</tr>
<tr>
<td>African</td>
<td>16%</td>
</tr>
<tr>
<td>Other Asian background</td>
<td>8%</td>
</tr>
<tr>
<td>Chinese</td>
<td>7%</td>
</tr>
<tr>
<td>Pakistani</td>
<td>7%</td>
</tr>
<tr>
<td>White and Black Caribbean</td>
<td>4%</td>
</tr>
<tr>
<td>Any other ethnic group</td>
<td>4%</td>
</tr>
<tr>
<td>White and Asian</td>
<td>3%</td>
</tr>
<tr>
<td>White and Black African</td>
<td>2%</td>
</tr>
<tr>
<td>Other Mixed background</td>
<td>2%</td>
</tr>
<tr>
<td>Bangladeshi</td>
<td>2%</td>
</tr>
<tr>
<td>White and Chinese</td>
<td>1%</td>
</tr>
<tr>
<td>Other Black background</td>
<td>1%</td>
</tr>
<tr>
<td>Other White background</td>
<td>1%</td>
</tr>
</tbody>
</table>

n = 586

* Quality Health Sample only

Figure 13

Figure 14

Page 24 of 38
**Respondent Profile**

**G 2 Which area do you live in?**

<table>
<thead>
<tr>
<th>Region</th>
<th>% of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>North East</td>
<td>1%</td>
</tr>
<tr>
<td>North West</td>
<td>7%</td>
</tr>
<tr>
<td>Yorkshire &amp; the Humber</td>
<td>5%</td>
</tr>
<tr>
<td>East Midlands</td>
<td>7%</td>
</tr>
<tr>
<td>West Midlands</td>
<td>8%</td>
</tr>
<tr>
<td>East of England</td>
<td>10%</td>
</tr>
<tr>
<td>South East</td>
<td>18%</td>
</tr>
<tr>
<td>South West</td>
<td>1%</td>
</tr>
<tr>
<td>North East</td>
<td>7%</td>
</tr>
<tr>
<td>London</td>
<td>31%</td>
</tr>
<tr>
<td>7% - Not stated</td>
<td>1%</td>
</tr>
</tbody>
</table>

*Quality Health Sample only*

**G 3 What age are you?**

<table>
<thead>
<tr>
<th>Age Range</th>
<th>% of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 - 25</td>
<td>1%</td>
</tr>
<tr>
<td>26 - 35</td>
<td>4%</td>
</tr>
<tr>
<td>36 - 45</td>
<td>10%</td>
</tr>
<tr>
<td>46 - 55</td>
<td>28%</td>
</tr>
<tr>
<td>56 - 65</td>
<td>26%</td>
</tr>
<tr>
<td>66 - 75</td>
<td>20%</td>
</tr>
<tr>
<td>76 - 85</td>
<td>10%</td>
</tr>
<tr>
<td>86+</td>
<td>1%</td>
</tr>
</tbody>
</table>

*Quality Health Sample only*

**G 4 Are you male or female?**

<table>
<thead>
<tr>
<th>Gender</th>
<th>% of Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>36%</td>
</tr>
<tr>
<td>Female</td>
<td>64%</td>
</tr>
</tbody>
</table>

*Quality Health Sample only*

---

*Figure 15*

*Figure 16*
Patient Information Survey

Thank you for agreeing to be contacted again following the National Cancer Patient Experience Survey. We would like you to consider taking part in this questionnaire which is focused around the written and verbal information needs you may have had whilst using NHS cancer services.

This questionnaire has been developed specifically to understand more fully the views of patients from black and minority ethnic communities so that we can work to ensure that cancer services meet the needs of all cancer patients across England.

To help improve cancer services, the National Black and Minority Ethnic (BME) Cancer Voice has been established to provide an opportunity for people to give feedback.

At the end of this questionnaire there will be an opportunity for you to become a member of the National BME Cancer Voice, which will give you further opportunities to have your say about NHS cancer services.

Taking part in this survey is voluntary, as is becoming a member of the National BME Cancer Voice. Non-participation will not affect you in anyway; all of your answers will be treated in confidence.

Completing the questionnaire
For each question please tick clearly inside one box using a black or blue pen.

Don’t worry if you make a mistake; simply cross out the mistake and put a tick in the correct box.

Taking part in this survey is voluntary.

All of your answers will be treated in confidence.
Section A
Your Tests and Investigations

We would like you to think about the first time you were told you needed to go for tests to investigate cancer.

We would like to know how well informed you felt by the NHS professionals who carried out your tests before you had your diagnosis.

1. How well informed were you regarding which tests would be carried out?
   - [ ] Extremely well informed
   - [ ] Well informed
   - [ ] Neither poorly nor well informed
   - [ ] Poorly informed
   - [ ] Extremely poorly informed
   - [ ] Don’t Know

2. How well informed were you about when you should expect the results?
   - [ ] Extremely well informed
   - [ ] Well informed
   - [ ] Neither poorly nor well informed
   - [ ] Poorly informed
   - [ ] Extremely poorly informed
   - [ ] Don’t Know
Section B

Your Diagnosis

The following questions focus on the time when you were diagnosed, before you started your treatment.

1. How well informed were you regarding which type of cancer you had?
   - Extremely well informed
   - Well informed
   - Neither poorly nor well informed
   - Poorly informed
   - Extremely poorly informed
   - Don’t Know

2. How well informed were you regarding the variety of options available in terms of managing your cancer and your treatment?
   - Extremely well informed
   - Well informed
   - Neither poorly nor well informed
   - Poorly informed
   - Extremely poorly informed
   - Don’t Know

3. How well informed were you regarding the effect that the drug options can have on people from different ethnic groups?
   - Extremely well informed
   - Well informed
   - Neither poorly nor well informed
   - Poorly informed
   - Extremely poorly informed
   - Don’t Know
   - This does not apply to me

4. How well informed were you regarding the role of different healthcare professionals in the management and treatment of your cancer?
   - Extremely well informed
   - Well informed
   - Neither poorly nor well informed
   - Poorly informed
   - Extremely poorly informed
   - Don’t Know

5. How well informed were you regarding your own role and responsibility in the future management of your cancer?
   - Extremely well informed
   - Well informed
   - Neither poorly nor well informed
   - Poorly informed
   - Extremely poorly informed
   - Don’t Know
Section C
Your Treatment

The next set of questions focus specifically on the time of your treatment. (Please remember, in treatment, we are talking both about treatments aimed to cure, as well as manage cancer)

1. How well informed were you regarding how effective the treatment may be?
   - [ ] Extremely well informed
   - [ ] Well informed
   - [ ] Neither poorly nor well informed
   - [ ] Poorly informed
   - [ ] Extremely poorly informed
   - [ ] Don’t Know

2. How well informed were you regarding how you would feel throughout the course of treatment?
   - [ ] Extremely well informed
   - [ ] Well informed
   - [ ] Neither poorly nor well informed
   - [ ] Poorly informed
   - [ ] Extremely poorly informed
   - [ ] Don’t Know

3. How well informed were you regarding the role of the healthcare professionals undertaking your treatment?
   - [ ] Extremely well informed
   - [ ] Well informed
   - [ ] Neither poorly nor well informed
   - [ ] Poorly informed
   - [ ] Extremely poorly informed
   - [ ] Don’t Know

4. How well informed were you regarding what your own role should be in your treatment?
   - [ ] Extremely well informed
   - [ ] Well informed
   - [ ] Neither poorly nor well informed
   - [ ] Poorly informed
   - [ ] Extremely poorly informed
   - [ ] Don’t Know

5. How well informed were you about what the likely side effects of your treatment might be for your particular skin type?
   - [ ] Extremely well informed
   - [ ] Well informed
   - [ ] Neither poorly nor well informed
   - [ ] Poorly informed
   - [ ] Extremely poorly informed
   - [ ] Don’t Know
   - [ ] This does not apply to me

6. How well informed were you regarding how long recovery might take?
   - [ ] Extremely well informed
   - [ ] Well informed
   - [ ] Neither poorly nor well informed
   - [ ] Poorly informed
   - [ ] Extremely poorly informed
   - [ ] Don’t Know
   - [ ] This does not apply to me

7. How well informed were you about any particular advice or support which may be available to you that is specific to your culture and/or religious beliefs?
   - [ ] Extremely well informed
   - [ ] Well informed
   - [ ] Neither poorly nor well informed
   - [ ] Poorly informed
   - [ ] Extremely poorly informed
   - [ ] Don’t Know
   - [ ] This does not apply to me
Section D

After Your Treatment Finished

The following questions focus on your experience after you had finished your treatment.

1. How well informed were you regarding **how to take care of yourself physically post-treatment**?
   - [ ] Extremely well informed
   - [ ] Well informed
   - [ ] Neither poorly nor well informed
   - [ ] Poorly informed
   - [ ] Extremely poorly informed
   - [ ] Don’t Know

2. How well informed were you regarding **the psychological and emotional support available to you post-treatment**?
   - [ ] Extremely well informed
   - [ ] Well informed
   - [ ] Neither poorly nor well informed
   - [ ] Poorly informed
   - [ ] Extremely poorly informed
   - [ ] Don’t Know

3. How well informed were you regarding **the support available to meet your religious, spiritual and/or cultural needs**?
   - [ ] Extremely well informed
   - [ ] Well informed
   - [ ] Neither poorly nor well informed
   - [ ] Poorly informed
   - [ ] Extremely poorly informed
   - [ ] Don’t Know

4. How well informed were you about **who to contact should you have further questions about your care**?
   - [ ] Extremely well informed
   - [ ] Well informed
   - [ ] Neither poorly nor well informed
   - [ ] Poorly informed
   - [ ] Extremely poorly informed
   - [ ] Don’t Know
Section E
About other needs you may have had

This section focuses on any other specific needs you may have had.

1. Did you feel, at any point during your experience, that you required an interpreter, regardless of whether or not this was provided?
   1. Yes ➔ Go to Q1a
   2. No ➔ Go to Q2

1a. Was an interpreter offered to you by the NHS?
   1. Yes ➔ Go to Q1b
   2. No ➔ Go to Q1d

1b. Did you use that interpreter?
   1. Yes ➔ Go to Q1c
   2. No ➔ Go to Q1d

1c. How useful did you find the service provided by the interpreter?
   1. Extremely useful
   2. Very useful
   3. Quite useful
   4. Not useful ➔ Go to Q2

1d. Did a family member or friend interpret on your behalf?
   1. Yes
   2. No

2. We would now like you to think about how well informed you felt regarding other needs you may have had. Please note that we are focusing specifically on the information the NHS provided, rather than any information you may have found yourself.

2a. How well informed, by the NHS, did you feel about needing and using a prosthesis?
   1. Extremely well informed
   2. Well informed
   3. Neither poorly nor well informed
   4. Poorly informed
   5. Extremely poorly informed
   6. I did not receive any information from the NHS about this
   7. Don’t Know
   8. This does not apply to me

2b. Were you offered a prosthesis that was appropriate for your skin tone?
   1. Yes
   2. No
   3. This does not apply to me

2c. How well informed did you feel, by the NHS, about your diet needs and considerations?
   1. Extremely well informed
   2. Well informed
   3. Neither poorly nor well informed
   4. Poorly informed
   5. Extremely poorly informed
   6. I did not receive any information from the NHS about this
   7. Don’t Know
2d. How well informed, by the NHS, did you feel about accessing financial support or advice?

- Extremely well informed
- Well informed
- Neither poorly nor well informed
- Poorly informed
- Extremely poorly informed
- I did not receive any information from the NHS about this
- Don’t Know

2e. How well informed, by the NHS, did you feel about any emotional support you could receive through counselling, support groups etc?

- Extremely well informed
- Well informed
- Neither poorly nor well informed
- Poorly informed
- Extremely poorly informed
- I did not receive any information from the NHS about this
- Don’t Know

2f. How well informed, by the NHS, did you feel about how to tell those you care about that you have been diagnosed with cancer?

- Extremely well informed
- Well informed
- Neither poorly nor well informed
- Poorly informed
- Extremely poorly informed
- I did not receive any information from the NHS about this
- Don’t Know

2g. How well informed, by the NHS, did you feel about how cancer might affect your relationships?

- Extremely well informed
- Well informed
- Neither poorly nor well informed
- Poorly informed
- Extremely poorly informed
- I did not receive any information from the NHS about this
- Don’t Know

2h. How well informed, by the NHS, did you feel about needing and using a wig?

- Extremely well informed
- Well informed
- Neither poorly nor well informed
- Poorly informed
- Extremely poorly informed
- I did not receive any information from the NHS about this
- Don’t Know
- This does not apply to me
Section F
Your Overall Experience

This section focuses on your overall experience as a cancer patient.

1. In which of the following ways do you remember receiving information from NHS professionals, throughout your experience as a cancer patient? (please tick all that apply)

☐ Spoken information from NHS healthcare professionals
☐ NHS Direct – the telephone information and advisory service from the NHS
☐ NHS websites
☐ Leaflets provided in the GP’s surgery
☐ Leaflets provided in hospital
☐ Posters up in the GP’s surgery
☐ Posters up in the hospital
☐ Other (please write below)

☐ Received no information

2. We would now like you to think in general about all of the information you have received from healthcare professionals throughout your experience as a cancer patient.

Below is a list of statements, and for each statement, please tick how strongly you agree or disagree

2a. The information received was easy to understand
☐ Agree strongly
☐ Agree slightly
☐ Neither agree nor disagree
☐ Disagree slightly
☐ Disagree strongly
☐ Don’t Know

2b. The amount of information was sufficient
☐ Agree strongly
☐ Agree slightly
☐ Neither agree nor disagree
☐ Disagree slightly
☐ Disagree strongly
☐ Don’t Know

2c. The information given was sufficiently sensitive to and respectful of your culture
☐ Agree strongly
☐ Agree slightly
☐ Neither agree nor disagree
☐ Disagree slightly
☐ Disagree strongly
☐ Don’t Know

2d. The information provided was given at the time when you needed it
☐ Agree strongly
☐ Agree slightly
☐ Neither agree nor disagree
☐ Disagree slightly
☐ Disagree strongly
☐ Don’t Know

2e. The information was provided in the language you needed
☐ Agree strongly
☐ Agree slightly
☐ Neither agree nor disagree
☐ Disagree slightly
☐ Disagree strongly
☐ Don’t Know
3. How useful did you find the following sources of information? (please only tick those which you have used)

3a. NHS healthcare professionals (nurses, doctors etc)
- [ ] Not useful
- [ ] Quite useful
- [ ] Very useful
- [ ] Extremely useful

3b. NHS Direct – the telephone information and advisory service from the NHS
- [ ] Not useful
- [ ] Quite useful
- [ ] Very useful
- [ ] Extremely useful

3c. NHS websites
- [ ] Not useful
- [ ] Quite useful
- [ ] Very useful
- [ ] Extremely useful

3d. Leaflets provided by the GP
- [ ] Not useful
- [ ] Quite useful
- [ ] Very useful
- [ ] Extremely useful

3e. Leaflets provided by the hospital
- [ ] Not useful
- [ ] Quite useful
- [ ] Very useful
- [ ] Extremely useful

3f. Posters up in hospital
- [ ] Not useful
- [ ] Quite useful

3g. Other
(Please write in________________________)
- [ ] Not useful
- [ ] Quite useful
- [ ] Very useful
- [ ] Extremely useful

3h. Other
(Please write in________________________)
- [ ] Not useful
- [ ] Quite useful
- [ ] Very useful
- [ ] Extremely useful

3i. Other
(Please write in________________________)
- [ ] Not useful
- [ ] Quite useful
- [ ] Very useful
- [ ] Extremely useful
4. You may feel that some of the information you received was delivered in a way that was particularly sensitive to, or respectful of your culture. Please tell us about this in the space below.
5. You may feel that some of the information you received was not delivered in a way that was sufficiently sensitive to, or respectful of your culture. Please tell us about this in the space below.
6. In your opinion, how can the NHS improve their provision of information about cancer for BME patients like yourself? Please tell us in the space below.
Section G – About You

In this section we need to collect some basic information about you. Please be assured that this information is completely anonymous and will not be distributed to any other party. However, it is important for us to collect it so that the opinions you have provided in the survey can be used to improve NHS cancer services.

1. What form of cancer were you first diagnosed with?


2. Which area do you live in?
   (Please complete the first part of your postcode only in the box below)


3. What year were you born?


4. Are you male or female?
   - Male
   - Female

5. To which of these ethnic groups would you say you belong? (Tick ONE only)
   a. WHITE
      - Please indicate your ethnicity e.g. Polish, Turkish etc
         (Please write in box)

   b. MIXED
      - White and Black Caribbean
      - White and Black African
      - White and Asian
      - White and Chinese
      - Any other Mixed background
         (Please write in box)

   c. ASIAN OR ASIAN BRITISH
      - Indian
      - Pakistani
      - Bangladeshi
      - Any other Asian background
         (Please write in box)

   d. BLACK OR BLACK BRITISH
      - Caribbean
      - African
      - Any other Black background
         (Please write in box)

   e. CHINESE
      - Chinese
      - Any other Chinese background
         (Please write in box)

   f. OTHER ETHNIC BACKGROUND
      - Any other ethnic group
         (Please write in box)

Thank You

Thank you for taking part. All your answers will be treated in confidence.

This survey is being conducted by an independent market research company called Kadence International on behalf of the BME Cancer Voice and BHI.
Acknowledgement and thank you to both One Medical Group and www.sanedesign.co.uk for supporting the printing of this report