

VBME-T

Voice of BME - Trafford



**Cancer
Outreach
Project**

**Experience of cancer amongst
Asian & African-Caribbean Communities
in the Borough of Trafford**

MAJOR FINDINGS

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Index

Executive Summary

1. Preface
 2. Introduction
 3. Methodology
 4. Experience of the Carer
 5. Experience of the Patient
 6. Experience of the Professional
 7. Recommendations
 8. Acknowledgements
 9. Conclusion
 10. References
- ## Appendices
- A.1 Case Studies
 - A.2 Data
 - A.3 VBME-T Aims and Objects

Executive Summary

This pilot research project was funded by the National Cancer Action Team and it was undertaken in the Borough of Trafford to find out the impact of cancer amongst the Asian and African-Caribbean communities. The study took place during the year 2011 with some follow-up work during 2012.

Throughout this study common themes were identified. Results were consistent whether they participants contributed through one to one interview and questionnaire, focus group or through workshop discussion. Some of the major findings are:

Cancer Awareness

There is a distinct lack of cancer awareness in the black and minority ethnic community in Trafford. Participants confirmed that they would have benefited from cancer awareness sessions. They displayed a clearer understanding of services and the importance of routine screening leading to their diagnosis. Lack of awareness made patients frightened.

"I thought I was going to die. I did not even know that you could get cancer of parts of the body. I thought you had it everywhere. I was preparing to say good bye to my family and wondering how they would cope. The 'big c' destroyed me. Then I had surgery and the cancer of my throat is now gone. I did not know that you could get better."

Quoted from a 58 year old male from Pakistan

Support Service & Pathway Awareness

There is a lack of knowledge about procedures and pathways. Half of interviewed participants were not aware of their right to a second opinion. Just under a third of participants attended a GP appointment three or more times before a referral was made for further investigation. Also, that there was a lack of awareness of cancer support services. Popular belief amongst participants was that during their cancer journey they have been misinformed in relation to treatment, and contradictions made by cancer staff in relation to diagnosis and information. They felt strongly about the lack of support available or offered for family and children of patients. Often services are not culturally appropriate and some staff are not culturally aware.

"My husband had difficulty coming to terms with my diagnosis at the time. My best friend helped me to communicate with him and I found out he was frightened and thought I was going to die. Support for partners and family members is crucial to enable them to explore their fears. They are often more frightened than the person who has been diagnosed. This should be looked into. Cancer support provided must include the whole family of the diagnosed person"

Quoted from a 56 year old African-Caribbean female

GP and Health Professional Interaction

When interacting with health professionals, most of the issues and negative experiences arise during contact with GPs. A recurring theme throughout the study was people feeling they are not being listened to when approaching them with differences in their body.

When treated in hospital, African-Caribbean female participants had positive experiences during treatment. Asian female participants felt underrepresented and spoke of cultural differences between themselves and health professionals, who made them feel uneasy.

Relationship between many people and their GPs are difficult leading to frustration and poor relationships which are lacking in trust which in turn is having the effect of some patients not attending appointments because of a fear of rejection or being dismissed out of hand. Once in hospital or clinics though the tension is reduced and experience with health professionals is better.

Many of the respondents rely on and rarely leave the local community and showed some misgivings about travelling to hospitals or clinics out of the area. News can and does travel through the community and the effect of someone's poor experience is likely to affect others when making the decision to attend appointments or screenings with consultants. Many people are scared and unsure of authority of professionals and may neglect to attend very important appointments which could effectively go towards preventing illness.

Cultural & Language Barriers

There is a cultural barrier which affects the likelihood of a good experience within healthcare settings. A lack of Black female doctors and a feeling of being in a minority on a ward has a dramatic effect on the experience of treatment and affects the likelihood of receiving treatment or presenting to a hospital. It is felt that many professionals do not understand or are not aware of someone cultural or religious needs. The issue of dress and gender was reoccurring and contributed to a negative view of how patients are seen and treated.

Language was also a subject raised by respondents. For many, English is not their first language. If they were unable to read the letter then they rely on someone to do it for them and to explain it to them. Literature available from GP surgeries and community centres is not considered to be aimed at BME communities. There are real issues with communication. If someone believes they will not be able to communicate easily with health professionals, it creates further barriers to good quality care and encourages non-engagement.

Support Service Awareness

There is a distinct lack in awareness of support service for BME carers. This was most evident during workshops where Macmillan Trafford was introduced to the participants. For many it was the first time that they had come into contact with the support service and for others the first time that they had become aware of the organisation.

Role as a "Carer"

Some did not see themselves as carers. The fulfilment of a duty to care for someone overrode being classified as a carer. This had an effect on someone who was likely to look for support and help. Participants who cared for spouses or parents were less likely to label themselves as carers and therefore did not feel seek further support.

Involved in Care

A third of participants noted that they felt they were not included when it came to the discussion of care for someone with cancer. Their interaction with GPs when attending appointments with those whom they care for was often poor, with half claiming they had little confidence when it came to primary care.

Information

There is a general feeling that information about cancer was not easy to come by and therefore not as accessible as it should be despite the amount of literature that is in their GP surgeries or health centres. Much of this information is seen as not relevant to them so they do not gather it. Carers currently access the most of their information from community groups. They also access local libraries, the television or a family member or friend.

BME representatives in services

There was a consensus that there is a lack of BME workers within health and support services; and having access to a BME worker can have a positive effect in understanding of needs, similarities in belief systems and reassurance of not being discriminated against. Carers felt more reassured and confident in talking to staff of the same cultural heritage.

“My mother was treated in an undignified manner whilst in hospital before she died... we were scared to leave her without a relative and used to take turns... it was a very stressful time but we did not receive any support or guidance. My mother was often left in an undignified manner with caused distress to the family... I remember getting some grace when one evening an African Caribbean Nurse came to me and said ‘it’s ok you can go home and get some rest... I’ll be looking after your mother this evening’... I felt so relieved as I knew that because she was Caribbean she would understand my mum’s needs... that was the first night that I slept soundly in weeks...” Story of a young carer

Recommendations

The following recommendations have emerged:

1. Cancer Awareness and Education

More education of cancer, its effects and support services available.
Much more marketing that emphasises the survival of the disease.

2. GP Interaction & Accountability

More equality in the service delivered by GPs and their accountability.
More BME professionals.

3. Services Awareness and Support

Targeted awareness-raising of cancer services and support available to BME users.
Local engagement with community and faith groups to improve service.

4. Cultural Awareness

Better use of community groups to deliver service and/or awareness.
Community champions specifically trained and be recognised and trusted in their community.

5. Information Delivery

Information in different languages placed in the community places and GP surgeries.
Use of the local media such as community radio station, audio and visuals.

6. Resources

NHS providers to engage more with their local BME communities regards service changes and developments.

1 Preface

Background

In the UK Cancer affects 1 in 3 people, although people from black and minority ethnic communities generally have lower levels of cancer (NCIN 2009).

Findings from the NCIN ethnicity report show higher incidence rates for:

- Prostate cancer for African and African Caribbean men is around twice as high as the rates for white men;
- Stomach cancer for both African and African Caribbean males and females is around 50% higher than the rates for white males and females;
- Liver cancer for both African and African Caribbean males and females is around twice as high as the rates for white males and females;
- Myeloma for both African and African Caribbean males and females is around twice as high as the rates for white males and females;
- Liver cancer for Asian males and females is around twice as high as the rates for white males and females;
- Mouth cancer for Asian females is around 50% higher than the rates for white females. For females aged over 65, rates are around twice as high; and
- Cervical cancer for Asian females aged over 65 is around twice.

BME patients with cancer also reported a poorer experience of cancer services than white patients. The 2010 survey identified statistically significant differences across the following 22 of 67 questions:

- Saw GP once or twice only before being told needed to go to hospital (Q1)
- Patient felt they were seen as soon as necessary (Q3)
- Health stayed about the same whilst waiting for appointment with hospital doctor (Q5)
- Staff explained completely what would be done during test procedure (Q8)
- Given easy to understand written information about tests (Q9)
- Results of tests explained in a way that the patient could understand (Q10)
- Completely understood the explanation of what was wrong with them (Q14)
- Definitely involved as much as they wanted to be in decisions about which treatment to have (Q14)
- Got understandable answers all/most of the time to questions posed to doctor (Q34)
- Doctors talked in front of the patients as if they were not there (Q37)

- Patient received answers from a ward nurse that were understandable all or most of the time (Q39)
- Had confidence and trust in all ward nurses (Q40)
- Ward nurses talked in front of the patient as if there were not there (Q41)
- Always/nearly always enough nurses on duty to care for patients (Q42)
- Patient often thought doctors/nurses were deliberately not telling them certain things (Q43)
- Give enough care and help from health and social services after discharge (Q52)
- Hospital staff definitely did everything they could to control side effects of Chemotherapy (Q56)
- Patient definitely given enough emotional support from hospital staff when an outpatient or day case patient (Q58)
- At last outpatient appointment with a cancer doctor, seen within 30 minutes (Q60)
- GPs and Nurses at the practice definitely did everything they could to support patient whilst they were having cancer treatment (Q64)
- GPs/other staff worked well together to give the best possible care (Q65)
- Patient did not feel that they were being treated as a set of cancer symptoms (Q67) rather than as a whole person

NCAT was interested in exploring further the experience of cancer in diverse groups and asked the Voice of BME - Trafford to carry out research specifically looking at the experience of Asian and African-Caribbean people affected by cancer residing in the Trafford area.

The report that follows provides further insight into the experiences and needs of Asian and African-Caribbean communities.

Paula Lloyd

*Associate Director Patient Experience
National Cancer Action Team*

2 Introduction

The Cancer Outreach Project (COP) is a research study working with Black and Minority Ethnic (BME) residents of Trafford who have experience of cancer either as a patient, a carer or as a professional. This project was undertaken during the calendar year 2011. Interim findings were reported to the local communities and professionals at a meeting in Old Trafford in March 2012, and further summary was presented in December 2012.

The aims of the Project were to:

- Build and secure a long lasting support network for BME cancer sufferers in Trafford by creating opportunities for them to represent their needs and interests where none exist.
- Increase cancer awareness amongst the local BME communities.
- Improve quality of care for patients, carers and families by building strong and productive relationships between patients, carers and professionals.
- Work closely with professionals to gain their views and assist in the development and uptake of the range of services available to patients and their families.
- Provide current information to government initiatives in order to amend and reform national policy with regards to treatment and care.

The objective was to improve quality of care for patients, carers and families by creating opportunities for them to represent their needs and interests where none exist.

The project endeavoured to aid existing organisations and services to expand and develop their expertise/service within cancer care where necessary. The project also worked with individuals who are cancer patients to achieve greater choice, control and empowerment over their own lives, in relation to health and social care, and advice and information regarding cancer care provision. We undertook this work by:

- Engaging with and gathering information from cancer patients from African Caribbean and Asian heritage, their carers, families and professionals.
- Presenting information gathered from patients, carers, families and professionals on their experiences of cancer & services, to the National Cancer Action Team.
- Feeding experiences into the National BME Cancer Voice.

Project Structure

The Cancer Outreach Project team consisted of two Outreach Officers (at any one time) and an Administrator Officer and was managed by a Board Member of The Voice of BME -Trafford. The following were part of the team:

- Neil Wall (Administration Officer)
- Angela Armstrong (Outreach Officer)
- Gulnar Khan (Outreach Officer)
- Carrol Nelson (Project Manager)

The outcomes were divided into four quarters and the team followed a detailed communication strategy in order to complete targets for each quarter.

The Delivery Team consisted of:

- Outreach Officers (Mariam Rahman, Gulnar Khan, Angela Armstrong)
- Administration Officer (Neil Wall)

Project Advisory Group

The PROJECT Advisory Group for the study consisted of a local health professional, a primary care trust commissioning officer, a service user, a specialist in black and minority ethnic cancer from the BME Cancer Communities based in Nottingham, as well as two Board members of the Voice of BME-Trafford. The members of the Advisory Group were:

Sherida Collins

Cancer Lead at NHS Trafford.

Dianne Nesbitt

Service User.

Rose Thompson

Director: BME Cancer Communities - Nottingham

James Nelson

Board Member: Voice of BME – Trafford

Carrol Nelson

Board Member: Voice of BME-Trafford

Professor Anil Jain

Consultant Radiologist at University Hospital of South Manchester

Paula Lloyd Knight

Associate Director for the National Cancer Action Team

3 Methodology

Qualitative methodology was used to discover, explore, describe and gather information from patients and carers from African Caribbean and Asian communities, who are particularly under-represented in research regarding their experiences of cancer services and cancer awareness.

This approach was used to generate data which would contribute to developing an understanding and improving services for these particular client groups. This would help the policy makers and provider agencies gain insight into how agencies can engage more effectively and deliver a quality services to Black and Minority Ethnic groups.

Data collection methods used were: interviews, transcripts from focus group feedback, one-to-one in-depth, open-ended questionnaires (which were piloted beforehand), and focus groups using NVivo9 Computer Aided Qualitative Analysis.

Due to the sensitivity and nature of the information needed for the project, patients and carers were given the opportunity to be interviewed individually. Therefore, we had meetings and discussions with the local community and cancer agencies.

The interview process provided good relationship between patient/carers and the interviewer. This offered an ideal opportunity for patient education and helped to build rapport necessary for effective professional relations, as it encouraged patients/carers to talk about experiences of services.

Some participants' reluctance to communicate with services drove the project staff to find different methods of consulting with service user to gather experience and information in the best way possible. It is recognised that this engagement can be difficult, the reason why this project has come to being, multiple sources of engagement were considered. Events and workshops were held for those who felt more comfortable in groups to discuss their experiences. For those participants who were very reluctant to discuss their thoughts in front of others, one-to-one interviews were held with them.

Marketing and advertising of the Carers Week event was done thorough local shops and business with posters and leaflets displayed giving the project and the planned event a visual presence. The use of local radio and newspapers helped to get the word out to the community. The importance of local radio shone through. Local community radio is important in Trafford. It has a strong listening base and caters for those where local commercial radio does not. To elderly members of the community it is an important resource and is a good way of gaining a community presence.

Alongside commercial interests such as shops and business the project's marketing was also displayed in GP practices and health centres throughout Trafford and further afield in The Christie Hospital, a specialist centre in Manchester for the treatment of cancer.

Outreach Officers held talks and information stands at group meetings and events advertising the project and its aims with a view to recruitment of participants.

The importance of “word of mouth” recruitment cannot be understated in the project. It was vital to properly explain the aims and objectives of the project and the significance that it may have in terms of affecting policy so that good quality cancer care can reach all members of the population. Several recommendations were made on behalf of the project which helped significantly with the recruitment of participants.

The Asian communities presented an issue where commonly spoken English was not a first language. This, coupled with the sensitivity of the work especially for elderly persons, posed an additional challenge for the project. After consultation with the leader of a local Asian Women’s community group, the decision was taken to pilot a varied questionnaire consisting of open, closed and multiple choice questions. It was suggested to us that many people were unlikely or unable to offer their full experiences due to issues of trust, and that posing questions to them would be easier instead of asking for an account of a difficult part of their lives.

Thus, using a mixed approach enabled the study to collect qualitative, quantitative statistical data. It gave the project valuable statistics such as the percentage of participants who did not have trust in local health professionals or those who have had a poor experience with the same professionals. This data highlighted some of the issues that were raised in the data gathering.

The interviews, transcripts of focus groups and experiences gathered at events were put through analysis using NVivo9. This software is developed for use specifically in social research such as health and psychology research and enables good analysis of qualitative data to identify common themes and trends. The software is commonly used by students during doctorates and fits well with the study that the Cancer Outreach Project conducted. The users of the software come from local government in the UK and educational institutions from both the UK and the USA.

Close attention was paid to every piece of information gathered to ensure that issues and particular experiences were noted carefully so as not to under-sell their importance to the study. For instance, the issues of cultural difference, language and support are vital and re-occurring in the study but are very different matters to people, especially when referring to printed literature and the language used in it which may not be a cultural difference at all. It was important that they were divided and listed separately. The use of analytical software allowed the project to delve deeper into the information and produce good analysis to accurately and properly represent the experiences of the participants.

4 Experience of the Carer

4.1 Summary

Information and data around BME cancer carers was gathered from an event for BME cancer carers held at Old Trafford Community Centre in June to coincide with National Carers Week to engage and gather information from carers regarding their experiences of cancer and services from their perspective. Workshops were held to gather the information, which included suggestions for solutions to the identified issues. In addition to the workshops a questionnaire was conducted via an electronic voting system to gather demographic as well as specific information and statistics relating to carer issues.

Within this event “Don’t be a Cancer Chancer” Training was delivered looking at signs and symptoms of cancers affecting the BME community and raising cancer awareness. The event was moderately attended by BME cancer carers.

An additional questionnaire was used during the project to capture data from carers unable to make the event.

4.2 Issues

“I lost my father to cancer 8 years ago. He did not acknowledge his symptoms and refused to talk about it. He was eventually persuaded to go and see a doctor. He did not want to realise he had cancer and was in denial. He was diagnosed in the February and died six weeks later.”

Participating Carer

GP interaction

GP’s don’t listen to you when you go with symptoms. Carers reported that when they have been to their GP they feel very rushed and don’t have enough time to talk to their doctor. Half of the group did not feel confident with their GP. When asked about the option of changing GP’s The majority stated that they would see another Doctor in the surgery but had not considered changing GP practice, despite having issues with the GP.

Health Services

Carers commented that they often felt not included when accompanying their cared-for to medical appointments and would like services to consider their active role as carers.

Information

Carers felt that information about cancer was not easy to come by and therefore not as accessible as it should be.

“ there isn’t a lot of information out there... and you’re not told what’s available unless you ask, but you don’t ask because you don’t know what’s available...”

Carers reported that they feel overwhelmed with the amount of literature that is in their GP surgeries or health centres but a lot of this information was not relevant to them so they don't necessarily gather any health information. Carers currently access the most of their information from community groups they access, local libraries, the television or a family member or friend. When cancer campaigns were discussed, they remember seeing advertisements on television but not billboard advertisements and national newspapers. However, they recalled cancer or health campaigns that were reported in local papers such as 'Old Trafford News' and BME specific publications such as 'The Voice', 'Asian Leader' and on local radio stations. It was felt that the general adverts did not specifically apply to them but applied mostly to Europeans and not those from BME communities.

Awareness of signs and symptoms

The feeling was that cancer awareness about signs and symptoms is not promoted enough or sometimes at all. At this stage of the project The Cancer Chancer Campaign had been launched. A billboard had been placed locally and attendees were asked their opinions on the advert. Only 2 attendees recall having noticed the advertisement. Most carers commented that they had become more aware since their cared for was diagnosed.

BME representatives in services

Overall commented that there was a lack of BME workers regarding Cancer/statutory support services, and that having access to a BME worker can have a positive effect with regards to understanding of needs, similarities in belief systems and reassurance of not being discriminated. Carers commented that they would feel more reassured and confident in talking to staff of the same cultural heritage. A young carer told a personal experience.

"My mother was treated in an undignified manner whilst in hospital before she died...we were scared to leave her without a relative and used to take turns...it was a very stressful time but we did not receive any support or guidance. My mother was often left in an undignified manner with caused distress to the family...I remember getting some grace when one evening an African Caribbean Nurse came to me and said 'it's ok you can go home and get some rest...I'll be looking after your mother this evening'...I felt so relieved as I knew that because she was Caribbean she would understand my mums needs... that was the first night that I slept soundly in weeks..."

Language

There are issues with the literature that is out there, especially for those who have language issues. The literature that is available in the community needs to be kept updated.

Cultural Awareness

The increased use of faith healers within the African and South Asian communities because of a lack of trust in the National Health Service. There is also a clear lack of understanding of cultural and religious awareness from services.

Myths and legends

There are many myths that currently exist especially in the older generation about cancer and the delivery of care.

Financial

Lack of financial support. Welfare rights for carers are not promoted enough.

4.3 Barriers

Language barriers

There is a common barrier in communication with the understanding of medical terminology, accessing interpreters, attending appointments on your own and not being informed that you can bring a representative with you. Language barriers also exist for those who do speak English as a first language i.e. older Caribbean people.

Cross Cultural Relationships

There is a lack of relationships with between services and BME communities. Front line staff are sometimes not aware of the needs of those from a different culture to their own. Cultural sensitive care needs to be developed.

Information

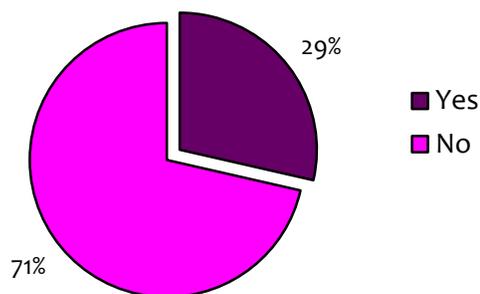
Not enough information is available in audio or visual format.

4.4 Solutions

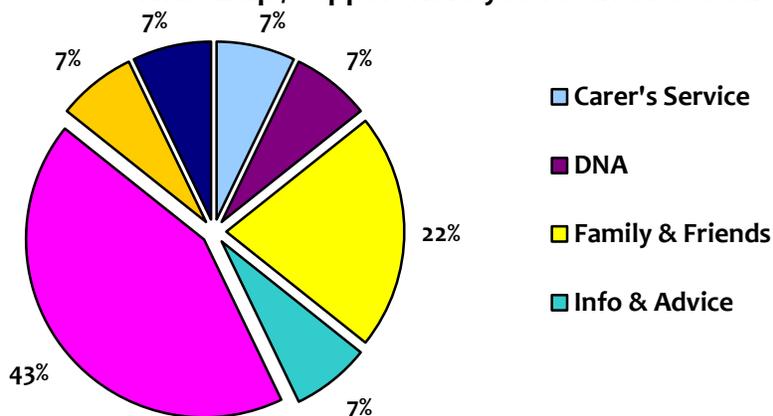
- Marketing campaigns and materials should reflect all ethnic groups by having BME images. More audio and visual material made available for BME communities. Use of plain English and less medical jargon on literature.
- Information to be made more readily available in appropriate places that will reach the target audience. i.e. BME support services, BME community Groups, Community Centres, Faith centres/churches and local libraries.
- Increase the use social mediums to access BME communities especially by using national and local radio stations.
- More BME tailored specific support for patients and carers – support groups, cultural appropriateness.
- Carers and family to be included more in discussions or appointments.
- The use of community champions from the BME community to work alongside services, possibly utilise BME volunteers to play an active role in service development and delivery.
- More awareness training is needed for the BME and disadvantaged non BME communities. Training needed on Signs & Symptoms and Examinations. The training is to reach the residents not just staff from services.
- Better access to and awareness of BME specific counselling.

4.5 Statistics

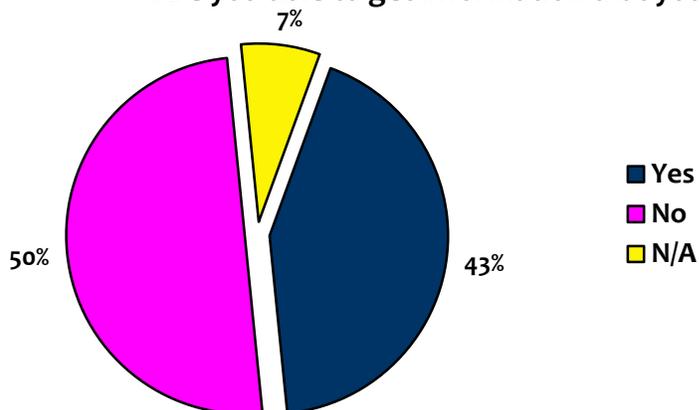
Do you feel you get enough support in your caring role?



What help / support have you received as a carer?



Are you able to get information that you need?



4.6 Conclusion

From the work that was done with carers in Trafford it was concluded that there are significant needs which need addressing.

Many carers, especially from the Asian focus, do not identify with the term carer. Caring for a loved one can be seen as a duty and not necessarily as fulfilling a role. The participants we spoke to who felt this way were not likely to look for any further help from services to aid them in their role as a carer.

There is a great unawareness of help that is available to carers. Many participants rely on family and friends for help or further information. Faith and the local community weighed in heavily as bases of help.

It is clear that with services such as Macmillan and the carers centres available to help carers that more awareness needs to be done within the black and minority ethnic community as many do not know of these services, which would invariably benefit them.

The reliance on community groups and other members of the community for help leads us to conclude that the way to raise awareness within the community is within the groups. As language issues persist to act as a barrier for carers, making a concerted effort to engage in familiar surroundings would be positive step to help out those who are simply unaware that there is help locally and sometimes unaware that they are indeed carers.

5 Experience of the Patient

5.1 Summary

The experience of the patient experience was captured through several methods. An event was held in September in Old Trafford inviting people who are experiencing or have experienced cancer directly from across the borough. The event involved group work between the delegates to provide a safer environment for people to discuss their experiences and to show that there are many people in the community with the same feelings as themselves. Alongside the event, a 35 point strong questionnaire was used to gather statistics and information the patients wanted to be able to submit confidentially.

5.2 Issues

GP interaction

Lack of cultural awareness. Many complaints of GP's who don't listen to patients. A common expression was not feeling capable of asking their GP to do more and feeling slightly intimidated.

Service & Pathway Awareness

There is a general misunderstanding of the pathway and service. Most contributors were unaware of right to a second opinion. It is felt that there was a lack of awareness of cancer support services. Popular believe amongst participants was that during their cancer journey they have been misinformed in relation to treatment, and contradictions made by cancer staff in relation to diagnosis and information. They felt strongly about the lack of support available or offered for family and children of patients. Often enough services are not culturally appropriate and some staff not culturally aware.

“Presumptions are made about patients intellect and can be very condescending... especially if you disagree or have an issue with how you are being treated or services”

Awareness of signs and symptoms before diagnosis

There is a very clear lack of cancer awareness with regards to signs and symptoms of most cancers with the BME community.

BME representatives in services

There is a clear need for more BME staff within services.

5.3 Barriers

GP Interaction

There is a strong sense of mistrust and misunderstanding when it comes to the relationships between patients and their GP's. Many participants complained that GP refused to listen to their concerns despite being told to attend your GP should you notice any difference in wellbeing. There are multiple experiences of GP's not taking seriously concerns of patients, which then lead to a late diagnosis of cancer.

There is a strong feeling that GP's do not like to be told by patients what is wrong with them considering they are the experts in their own bodies. This proved to be quite an emotive subject throughout the research.

Language barriers

It was felt that people need assistance with language i.e. being understood or understanding all the medical jargon being used.

Mistrust of Health Services

Experiences in healthcare not pertaining to cancer affected participants and the way they saw the Health Service and engaged with it. Older participants very often didn't leave their local areas and were intimidated by hospitals and doctors. Stories of mistreatment spread through the communities very quickly and have a lasting impact and influence on service provision. A common theme, which compounded the issue of mistrust, was misdiagnoses and the effect it has on communities. It was felt during work with participants that health professionals were not there for patients but themselves. This creates a division in the relationship between patients and doctors.

5.4 Possible Solutions

Cancer Awareness and Education

Education of cancer was a common recommended solution. Education about different cancers to dispel myths about treatments and how to avoid it. More prevention work with young members of the c communities.

GP Interaction & Accountability

More equality in the service delivered by GP's and accountability for when GP's get it wrong to help with issue of mistrust and no confidence.

Services Awareness

Better-targeted awareness raising of cancer services and support available to patients.

Cultural Awareness

Better understanding of different cultural values and beliefs. More work to dispel myths and legends of outdated practice. Better use of community groups to deliver service and/or awareness.

Information Delivery

Plain English literature with BME friendly design.

5.5 Focus Group

A focus group was held in Old Trafford in November. This group consisted of 5 women all with experience of cancer as patients. 2 members of the group were health professionals with a great deal of experience working within the NHS.

The group was prompted by questions and their discussions of experiences were recorded and scripted for further analysis.

Diagnosis

One of the participants was diagnosed after a routine mammogram at Withington Hospital and within a week an appointment was made at the Nightingale Unit at Wythenshawe Hospital. The participant described that she had no signs or symptoms and by attending a routine screening mammogram her life has probably been saved. A cone biopsy was taken and part of tissue removed from breast which was sent away for testing. Course of radiotherapy was started at the Christie.

The thought of attending Wythenshawe hospital for radiotherapy would be less scary because the Christie is associated with cancer and “you think it’s the end”. The Christie Hospital coupled with cancer was a very scary prospect. Diagnosis was explained by Consultant and the Breast Care Specialist Nurse.

Participant 2 discovered a tiny lump and thought nothing of it but made GP appointment nonetheless. GP referred to her Trafford and an appointment was received within a week. She was diagnosed at Trafford General Hospital after lump was found.

Participant 3 was extremely shocked when she found her diagnosis. Her GP put her at ease who was doctor from within her small religious community. He allayed her fears. She was not really sure of what cancer was. She had a lot of trust in the doctor who had operated in the community for a long time. Patient’s surgery was done privately and within a week of GP appointment. The same thing happened in left breast and the procedure was repeated. Patient never once considered that she had cancer as it was done very quickly.

Participant 4’s mother had a routine screening which lead to a diagnosis and further on a mastectomy. Doctor recommended participant 4 and sibling get tested which lead to being referred to Nightingale Centre in Wythenshawe. She was terrified. Test revealed pre-cancerous signs. She didn’t hear or recognise pre-cancerous cells but focused on cancer and only thought about the “big C word”. Staff at the Nightingale were very good. Staff explained she was lucky they detected and that they would do something about it and that they could take action very early. The participant just wanted it out of her body. She is very glad that she attended the appointment. The consultant explained her diagnosis to her. Spent time with her family and was very scared, frightened and shocked about the cancer. Thoughts about her children but tried to be positive. Initially just wanted to collect children from school and to be around them. The day got better as it went on because it was explained properly. The emphasis was on pre-cancerous cells which aren’t cancer but could develop into cancer but it was caught in time. Attending the appointment was very important.

Group remarked that as the surgery was done in a private/general there was less of a threat of cancer. Compared to visiting the Christie or the Nightingale Centre.

Group did not want to tell their extended families about their diagnosis.

Treatment

Participant 1 spoke that treatment was explained well. Radiotherapy was explained well. Patient went on a Tomoxifen medical trial. Did not like medication at all. Stopped the Tomoxifen trial after 2 months and has been well since.

Participant 2 had a Lumpectomy and removed some lymph nodes. She was placed on the Tomoxifen trial but suffered memory loss and from illness although continued on the trial for 1.5 years.

Participant 3 had two Lumps removed by surgery. Third lump has now appeared.

Participant 4 was very happy with the treatment received. Very quick turnaround time and happy with the professionals seen.

General feeling was that treatment was done quickly. There wasn't any waiting around

Quality of Care

Feeling that nurses may not have the time to be empathetic due to time and current working conditions in hospitals. Nurses on the ward were not very empathic considering the trauma that participants were experiencing although the Nightingale Unit and the Christie provide a very good service. Information was handed out and everything was explained well.

It was identified that those with specific cancer training were perhaps more likely to be able to help empathise more than a general nurse might be able to.

There was a negative aftercare experience which was rectified after liaison with PALS team. GPs should work as a team. It was sensed that GPs are difficult to get to.

Support

Participant 1 had information from specialist nurse and a telephone number to call at any time to talk about concerns.

Participant 2 received support from community GP.

Participant 3 went through the whole pathway without seeing her GP. Routine mammograms lead to surgery and then aftercare and saw her GP at the very end of the process. GP was unaware of the situation.

Services

All aware of the breast care nurse. One participant was offered counselling but declined because of strong family support although did not know about any support groups or services. Not made aware of Neil Cliff centre.

Information

A participant was given leaflets but did not want to continue reading about cancer and so did not look at them. Wanted cancer as far away from her thoughts as possible and to move forward.

Generally satisfied with the verbal information and knew where to go for further information although one participant did not know where to get information and just relies on community GP to learn about anything else.

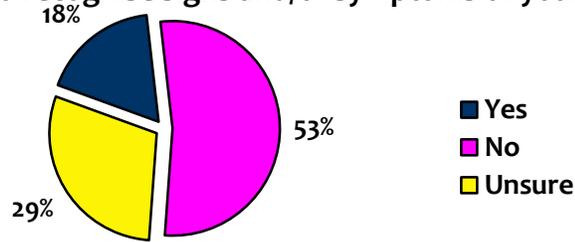
Information is available on TV and in leaflets in GP surgeries. Cancer is very common now. Language barrier gets in the way continues to be a hindrance for BME member of the community. More awareness is being done especially in the media for example TV soaps are running stories which are having a positive effect especially on awareness. It is a powerful medium.

Aware of Macmillan but did not need the service. Surprised to find out the services that Macmillan provide now.

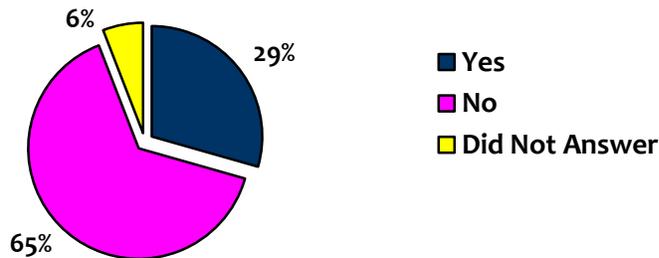
The group concluded that they were not sure how many people would know about services available to them. Because some were health professionals they knew where to go to look for help and services. People who are not aware rely on their GP's or Consultants to refer them to services as it is assumed that they would have the knowledge. All agreed that treatment has come a long way and advanced greatly in these last 4 decades. In their personal experience they now of people didn't know about cancer and did not get examined. Heart problems were better known and accepted. There was no health promotion getting people to go for screening although this is improving to help dispel cancer myths and this is still a taboo subject.

5.6 Statistics

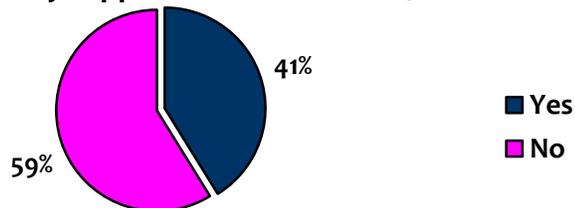
Were you able to recognise signs and/or symptoms of your cancer?



Were you provided with enough information about what is available to you to make a decision about your treatment/care?



Are you aware of any support services that are/were available to you?



5.7 Conclusions

The work with patients has showed that there is a severe lack of cancer awareness within the black and minority ethnic community. There is an urgent need to explain the facts about cancer and the treatments that are available. There are many myths that still exist in communities, which are affecting attitudes towards cancer. A focus group of five women was held, two of which were health professionals with several years' experience. Worryingly, they were the only participants who had good knowledge about cancer and services and the help that is available. Health promotion appears to be non-existent or ineffective in the black and minority ethnic community.

One of the strongest reoccurring themes was a lack of trust in primary care. Several participants were less likely to go to see their GP due to a bad experience or from friends or family who had similar poor experiences. This has impacted greatly in the minds of the participants and contributed to poor relationships and a lack of confidence in GP's by patients. Patients felt that was less accountability for GPs.

6 Experience of the Professional

6.1 Summary

Input into the research from health and community professionals is vital. Engagement with health professionals was not as forthcoming as would have hoped for. COP held a professionals event in October to gather information and feedback from local professionals. A questionnaire was sent out to all GP's in the Trafford borough.

6.2 Barriers & Issues

- Barriers and Issues to the Black and Minority Ethnic community accessing services.
- Language –Transactions and cost to access to services
- Cost -Health Promotion
- Information –formats, languages and locations
- Culturally aware staff –health care professionals not understanding differences
- Services been placed in the community.
- Services not flexible and G/P services poor.

6.3 Possible Solutions

- Better quality information for BME communities. Information in different languages placed in the communities not just at GP surgeries.
- Different ways of communication use of the local media such as radio, audio and visuals more TV documentaries, bill boards.
- Community champions specifically trained. Good leadership within communities.
- More black doctors would help the profession and more female doctors at breast screening.
- Must be recognised and trusted in their community
- More local engagement with community groups to improve service in local settings with faith groups.
- Targeted awareness where community gathers to raise awareness.
- Resources to deliver some local services in the community.
- More education about services to the community to build trust and confidence of service providers.
- More information been put out to everyone in lots of different places
- More Outreach work in the community with older people also.

7 Recommendations

7.1 Cancer Awareness and Education

The education of cancer was a commonly recommended solution by the participants. That addresses different cancers to dispel myths about treatments and how to avoid it.

More preventative work with younger members of the communities to change behaviour; for example, messages which show how looking after yourself relating to healthy eating and exercise can you help reduce getting cancer. Much more marketing that emphasises the survival of the disease.

7.2 GP Interaction & Accountability

The study found that participants would like more equality in the service delivered by GPs and accountability for when GPs get it wrong to help with issue of mistrust and no confidence.

More black doctors would help the profession and more female doctors at breast screening.

7.3 Services Awareness and Support

The study also highlighted the need for better-targeted awareness-raising of cancer services and support available to BME service users through more local engagement with community groups to improve service in local settings with faith groups alongside BME based support services within the community to include support for men.

7.4 Cultural Awareness

Similarly, participants felt there that there needs to better understanding of different cultural values and beliefs by professionals. Participants would like more work to dispel myths and legends of outdated practice. Better use of community groups to deliver service and/or awareness.

Community champions specifically trained and be recognised and trusted in their community. Good leadership within communities.

7.5 Information Delivery

The study also found that participants would like to have Information in different languages placed in the communities not just at GP surgeries in places of worship.

The use of the local media such as community radio station, audio and visuals, more TV documentaries, bill boards with BME friendly design.

7.6 Resources

Resources to deliver local cancer services in the BME community would be highly beneficial and cost effective to providers. As this would enable the BME communities to access information regards prevention and early detection.

NHS providers to engage more with their local BME communities regards service changes and developments.

8 Acknowledgements

Our work would not be possible without the active help and advice of many people. We are indebted to the following for their support, advice and guidance, and, above all, persevering with us:

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Judith Thompson: Macmillan -Cancer Manager Trafford

Gaynor Burton : Equality and Diversity Manager Trafford MBC

Adele Coyne : Principal Community Cohesion and Equalities Officer Trafford MBC

Rose Thompson : Director Nottingham Voluntary Action Centre for BME Cancer Communities

Dr Chris Gillespie : Consultant Psychologist Royal Derby NHS

Mr Lester Barr : Consultant Surgeon in Breast Care Nightingale Centre Wythenshawe

Jenny Cowell : Communication Officer Manchester Public Health Development Service

Dianne Nesbitt : Clinical Nurse Case Load Manager Manchester NHS and service user

Voice of BME - Trafford Board Members

N Khan Moghal	Chair
Juanita Yau	Vice Chair & Project Staff Supervisor
Anita Kaur-Potiwaal	Honorary Secretary
Irvine Williams	Treasurer
Adele Coyne	
Denise Douglas- Armstrong	
Jimmi Nelson	Project Staff Supervisor
Carrol May Nelson	Project Manager
Leslie Bell	
Dianne Nesbitt	

9 Conclusion

The study identified from its participants there are many Barriers and Issues to the Black and Minority Ethnic community accessing services. This includes the following: Language Interpretation services and cost to access to services, Health Promotion Information in different formats, languages and locations and lack of culturally aware health care professionals.

Carers in Trafford concluded that there are significant needs which require addressing. Many carers, especially from the Asian communities, do not identify with the term carer. Caring for a loved one can be seen as a duty and not necessarily as fulfilling a role. The participants who took part in the study highlighted as a result of this duty they were not likely to look for any further help from services to aid them in their role as a carer.

Thus, there is a great unawareness of help that is available to carers. Many participants rely on family and friends for help or further information. Faith and the local community weighed in heavily as bases of support.

Service users are looking for culturally appropriate support services within their community.

The reliance on community groups and other members of the community for help led us to conclude that the way to raise awareness within the community is within the groups. As language issues persist to act as a barrier for carers, making a concerted effort to engage in familiar surroundings would be positive step to help out those who are not accessing main-stream support services.

Similarly, the patients who participated in the study showed that there is a severe lack of cancer awareness within the black and minority ethnic community. There is an urgent need to explain the facts about cancer and the treatments that are available. There are many myths that still exist in communities, which are affecting attitudes towards cancer. A focus group of five women was held, two of which were health professionals with several years experience. Worryingly, they were the only participants who had

Another strong reoccurring theme was a lack of trust in primary care. Several participants were less likely to go to see their GP due to a bad experience or from friends or family who had similar poor experiences. This has impacted greatly in the minds of the participants and contributed to poor relationships and a lack of confidence in GP's by patients. Patients felt that was less accountability for GP's.

Finally, a study conducted by Dr Chris Gillespie highlighted the need for more "Cross Cultural Communication" to be developed to help professionals work more effectively with diverse community service users. (Dr Chris Gillespie, NHS Consultant Psychologist 2011)

10 References

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Appendices

A.1 Case Studies

Case Study 1

Ms D who has experience of Breast Cancer

Ms D, now 41, was diagnosed with breast cancer at the age of 39, single parent living with a 16 year old child. Ms D speaks very little English.

Ms D got up one morning and realized one of her breast look, felt and the colour had changed. She called her GP receptionist and explained in depth her signs and symptoms; she tried to get an appointment with her GP for the same day but had to wait 4 days before she was seen.

She had to wait a further 5 days for a referral letter to come for her appointment at the hospital. After many test she was diagnosed on the day of her appointment that she had breast cancer. All day she was at the hospital with various nurses and specialist and didn't have access to an interpreter.

On her way home catching 2 buses it was about 7pm and dark outside, Ms D didn't know where to go home; home or to a friends or to ring someone to speak too. Out of no where her best friend appeared, she went to her home and told her. Then they went to Ms D home so that her friend could tell her child about her mum's diagnosis. As Ms D didn't know how she would be able to tell her child.

Ms D mentioned "When I got home I ran upstairs and sat on a prayer mat and prayed to Allah and cried for hours on end and my child and friend just sat downstairs, it was so traumatic, I felt isolated and afraid". I never cried after that time again though. For many months her child was extremely stressed and left her studies, started not care for herself, stayed out till late, couldn't eat, start bad habits and became isolated from home matters and more into anti-social behaviour.

As Ms D chemotherapy started, the more Ms D drifted away from her child and extended family due to arguments. Ms D was approached by a local voluntary organisation that supported the family on a regular basis to give guidance, emotional support and advice. Following regular input after many months Ms D had a better understanding with her child. As their relationship was better now Ms D was informed that the treatment was not working and she would have a major operation and would need one of her breast removed. This was a traumatic time for the family but her child was at the side of her other all the time. She cared for her mother full time after the operation too.

Now, Ms D has fully recovered. Her child is now at college, and has a part time job and is a carer.

Quote:

“I believe my faith Islam played a major part in my recovery and gave me the support I needed including my friends and family. I have become confident and tell women about my experience and encourage them to regularly check themselves and empower people to take their health seriously”.

Main concerns Ms D raised:

Would have liked interpreter at all appointments

1. How to break the news to loved ones
2. Cost for travel as this was so expensive
3. Support for family specially for children aged 16-18
4. Advice on where to go for support on how to balance life
5. Information on benefit and contact details of local benefit services.
6. Information on local cancer services like Macmillan.
7. Service providers to e.g. given basic understanding of language issues, culture, food/diet, prayers and hijab.

Case Study 2

Mr X a Black Caribbean man who came from the Caribbean in 1958. Lived in Stretford in the Borough of Trafford in a semi-detached house with his wife, worked as a train driver and bus driver.

Father of nine children who he raised with his wife. He was a very loving devoted husband and good father and very respected in the community by his fellow country but lost his wife to breast cancer at the age of 55 years.

Mr X had been complaining of stomach bloating and gas when he eats, this continued for over a year. He was prescribed Favicon by the GP.

At the age of 64 this became progressively worse and he began to complain of not feeling very well in his stomach and decided to go visit his G/P again. The symptoms became worse and he ate very little due to feeling full very quickly. After many visits the G/P sent Mr X to the hospital for an X-ray and scan however, the participant had a car accident and missed the appointment.

After he recovered from the accident Mr X went to his GP in April 1988 to ask for another appointment for his investigation. The doctor did not listen to Mr X. In early December 1998 Mr X's daughter took her father to the GP and insisted on him investigating her father now.

The appointment arrived on 9th December.

This was a gap of 'eight months' by this time the participant continues to feel worse and to lose a lot of weight.

December 1998 Mr X was seen at Seymour Grove Hospital and was quickly referred to Trafford General Hospital for further investigation. He attended with his daughter and the investigation showed a tumour in his stomach, a biopsy was taken and they were advised to go to G/P in around nine days for the results.

Mr X made an appointment for the G/P with his daughter to see the G/P. At the arrival of the appointment with his daughter the G/P asked Mr X to lie on the couch and began to squeeze his stomach telling the participant it was just wind.

His daughter proceeded to inform the G/P it was not wind as her father had been diagnosed with a tumour and we have come for the results. The G/P did not read Mr X file and was unaware of the participants diagnosis of a tumour after seeking the notes we were then told it was malignant 'cancer'.

Mr X was sent to see a Consultant at Salford Hope Hospital by then the tumour was advanced.

Mr X had the stomach cancer removed in the January, the operation was unsuccessful and the cancer had begun to spread. He was sent home with pain killers and given four months to live. At first he was very low in spirit and felt let down by the NHS eventually he accepted this was the end. He died at home peacefully with his family on 20th May 1999.

Medical issues

- Hypertension
- Gas
- Severe weight loss

Other issues

Mrs X was discharged from hospital without any plan of care, or home support. The painkillers were not very effective and made him constipated. He also had no appetite as he felt low in mood.

The G/P was called out on numerous occasions for a change in medication to make the participant comfortable. Mr X was nursed at home by his loving sons and daughter.

Conclusion

This Case Study highlighted the poor level of service from the participants G/P who failed to listen to the participant and act upon his complaint earlier and takes his complaint seriously rather than treating him in appropriately. GP Neglect.

Daughter stated participant said he has been fit and healthy all his life and as worked all his life and contributed to the NHS and the only time he was in need of the NHS it failed him.

A.2 Data

Carers Data

Focus					
African Caribbean	Asian	Total			
5	9	14			
36%	64%	100%			
Age					
45					
Average Age					
Gender:					
Male	Female	Total			
1	13	14			
7%	93%	100%			
What is your first language?					
English	Urdu	Gujarati	Total		
9	3	2	14		
64%	21%	14%	100%		
What is your faith/religion?					
Christian	Islam	Total			
5	9	14			
36%	64%	100%			
Area of residence (Ward):					
Old Trafford	Stretford	Urmston	Total		
12	1	1	14		
86%	7%	7%	100%		
What is your ethnicity:					
Asian/Asian British	Black/Black British	Indian	Pakistani	Total	
4	5	1	4	14	
29%	36%	7%	29%	100%	
Where you born in the UK?					
No	Yes	Total			
6	8	14			
43%	57%	100%			
Have you had or require any interpreting or translating services?					
Yes	No	Did Not Answer	Total		
2	11	1	14		
14%	79%	7%	100%		
Do you live with the person you care for / support?					
Yes	No	Total			
7	7	14			
50%	50%	100%			
Are you currently employed?					
Yes	No	Total			
7	7	14			
50%	50%	100%			
If Yes (please tick which statement applies to you)					
DNA	I do not feel supported by my employer	I feel supported by my employer	N/A	Self Employed	Total
1	1	4	7	1	14
7%	7%	29%	50%	7%	100%

How long have you been in your role as a carer/supporter?						
1-3 years	3-5 years	5 years +	6 months - 1 year	Less than 6 months	Total	
6	2	1	3	2	14	
43%	14%	7%	21%	14%	100%	

Who is the person you look after?			
Other Relative	Parent/Parent-in-law	Partner/Spouse	Total
2	8	4	14
14%	57%	29%	100%

How old is the person you look after?						
35-44	45-54	55-64	65-74	74 and over	DNA	Total
1	2	1	4	5	1	14
7%	14%	7%	29%	36%	7%	100%

What type of cancer does the person you care for have or had?							
Bowel	Brain Tumour	Breast	Lung	Myeloma	Prostate & Bowel	Stomach	Total
3	1	3	2	1	1	3	14
21%	7%	21%	14%	7%	7%	21%	100%

When were they first diagnosed?				
Between six months and one year ago	In the last six months	Over five years ago	Two - Three years ago	Total
2	4	3	5	14
14%	29%	21%	36%	100%

Do you feel you get enough support in your caring role?		
Yes	No	Total
4	10	14
29%	71%	100%

What services or support have you used to help you with your caring role in the past?										
None	Faith	GP	Carers Centre	Family	Macmillan	Marie Curie	Crossroads	Social Services	Community Group	Total
4	2	5	1	1	4	1	1	1	1	17
24%	12%	29%	6%	6%	24%	6%	6%	6%	6%	100%

What help / support have you received as a carer?							
Carer's Service	DNA	Family & Friends	Info & Advice	None	Social Services	Support from Cancer Services	Total
1	1	3	1	6	1	1	14
7%	7%	21%	7%	43%	7%	7%	100%

Where do you currently get information about caring?									
Health Services	Hospitals	N/A	Relatives / Friends	Health Services	Support from Cancer Services	TV	Internet	Total	
1	1	7	2	2	2	1	1	17	
6%	6%	41%	12%	12%	12%	6%	6%	100%	

Are you able to get information that you need? i.e. Written, Verbal or media information.			
Yes	No	N/A	Total
6	7	1	14
43%	50%	7%	100%

Where would you look for further information about cancer/ health issues?							
DNA	Cancer Service	Family Friends	Health Services	GP	Internet	Community Group	Total
3	3	6	6	6	3	1	28
11%	11%	21%	21%	21%	11%	4%	100%

Have you been involved in discussions regarding the care of the person you		
Yes	No	Total
10	4	14
71%	29%	100%

Patient Data

African-Caribbean	Asian	Total							
8	9	17							
47%	53%	100%							
Age									
56									
Average Age									
Female	Male	Total							
13	4	17							
76%	24%	100%							
What is your first language?									
English	Guajarati	Punjabi	Urdu	Total					
10	4	1	2	17					
59%	24%	6%	12%	100%					
What is your faith/religion?									
Christian	DNA	Islam	None	Total					
5	2	9	1	17					
29%	12%	53%	6%	100%					
Area of residence (Ward):									
Sale	Gorse Hill	Hale	Old Trafford	Sale West	Stretford	Total			
2	1	1	11	1	1	17			
12%	6%	6%	65%	6%	6%	100%			
What is your ethnicity:									
Asian/Asian British	Black Caribbean	Black/Black British	Indian	Pakistani	Total				
1	2	6	3	5	17				
6%	12%	35%	18%	29%	100%				
Where you born in the UK?									
Yes	No	Did Not Answer		Total					
8	8	1		17					
47%	47%	6%		100%					
What type of cancer have you been diagnosed with?									
Unknown	Bowel	Breast	Breast and ovarian	Lung	Non Hodgkin's Lymphoma	Papillary Thyroid Carcinoma	Secondary Breast Cancer	Throat	Total
1	2	8	1	1	1	1	1	1	17
6%	12%	47%	6%	6%	6%	6%	6%	6%	100%
How long have you been living with/had cancer?									
Up to six months	Between six months and one year		Two - Five years	More than five years	Total				
1	1		9	6	17				
6%	6%		53%	35%	100%				
Were you able to recognise signs and/or symptoms of your cancer?									
Yes	No	Unsure			Total				
3	9	5			17				
18%	53%	29%			100%				
Would you have benefited from attending sessions that focused on teaching signs, symptoms, early detection and risk reduction?									
Yes	No	Unsure			Did Not Answer		Total		
9	2	5			1		17		
53%	12%	29%			6%		100%		
Are you registered with a GP?									
Yes	No	Total							
17	0	17							
100%	0%	100%							
How many times did you see your GP before you were told you had to go to hospital?									
1	2	3	4	5+	None	Not Applicable			Total
6	3	1	2	2	1	2			17
35%	18%	6%	12%	12%	6%	12%			100%
Were you offered any emotional support at any point during diagnosis and treatment?									
Yes	No			Total					
4	13			17					
24%	76%			100%					
Did you feel that your GP was someone who understood how you felt?									
Yes	No	Unsure			Total				
6	8	3			17				
35%	47%	18%			100%				
Did you feel comfortable talking to your GP about your symptoms?									
Yes	No	Not Applicable			Total				
8	8	1			17				
47%	47%	6%			100%				

<i>How was your diagnosis made?</i>					
Routine Medical Check	Routine Cancer Screening	GP Referral	Second Opinion	Other	Total
1	2	10	1	3	17
6%	12%	59%	6%	18%	100%

<i>Did you ask for a second opinion?</i>			
Yes	No	Not Applicable	Total
2	14	1	17
12%	82%	6%	100%

<i>Are you aware that you can request to see an alternative GP or Consultant</i>		
Yes	No	Total
8	9	17
47%	53%	100%

<i>Was your diagnosis explained so that you understood your illness?</i>			
Yes	No	Unsure	Total
11	5	1	17
65%	29%	6%	100%

<i>Did you receive help or support in telling family and friends about your diagnosis?</i>			
Yes	No	Total	
4	13	17	
24%	76%	100%	

<i>Who explained your diagnosis to you?</i>						
GP	Other Health Professional e.g. Consultant, Clinician	Family Member	Friend	Self-Diagnosis	Other (state)	Total
0	15	2	0	0	0	17
0%	88%	12%	0%	0%	0%	100%

<i>Did you have to rely on an interpreter?</i>			
Yes	No	Not Applicable	Total
4	10	3	17
24%	59%	18%	100%

<i>Were you provided with enough information about what is available to you to make a decision about your treatment/care?</i>			
Yes	No	Did Not Answer	Total
5	11	1	17
29%	65%	6%	100%

<i>Did you have a choice as to which hospital you go to for treatment?</i>			
Yes	No	Total	
1	16	17	
6%	94%	100%	

<i>Did hospital staff explain the purpose of your tests, what your drugs were for and the potential side effects are etc.?</i>					
Yes	No	Unsure	Not Applicable	Did Not Answer	Total
9	5	1	1	1	17
53%	29%	6%	6%	6%	100%

<i>Did you seek alternative treatments?</i>			
Yes	No	Total	
3	14	17	
18%	82%	100%	

<i>Are you aware of any support services that are/were available to you?</i>			
Yes	No	Total	
7	10	17	
41%	59%	100%	

<i>If yes, do/did you access these services?</i>				
Yes	No	Not Applicable	Did Not Answer	Total
3	4	9	1	17
18%	24%	53%	6%	100%

<i>How confident are you in discussing your issues with professionals?</i>						
Confident	At ease	Comfortable	Uncomfortable	Not Confident	Total	
5	2	3	5	2	17	
29%	12%	18%	29%	12%	100%	
<i>How confident are you in discussing your issues with your family/friends?</i>						
Confident.	At ease	Comfortable	Uncomfortable	Not Confident	Total	
5	4	4	4	0	17	
29%	24%	24%	24%	0%	100%	
<i>Where do you receive support from at the moment?</i>						
Just Family	Family & Friends	Hospital Staff	Macmillan	No Support being received	DNA	Total
3	2	3	1	2	1	12
25%	17%	25%	8%	17%	8%	100%
<i>Are you aware of your employment/welfare rights as someone with cancer?</i>						
Yes	No	Did Not Answer			Total	
2	12	3			17	
12%	71%	18%			100%	
<i>Are you aware of any cancer patient grants?</i>						
Yes	No	Did Not Answer			Total	
1	15	1			17	
6%	88%	6%			100%	

A.3 VBME-T Aims and Objects

The aim of **VBME-T** is:

To give a voice to the BME (Black and Minority Ethnic) communities and improve their participation and representation at all decision-making levels in Trafford, in order to address the inequalities experienced by BME people and improve their life opportunities in every sphere i.e. education, housing, health, business, community, politics, leisure.

The Objects of **VBME-T** are:

- To provide an effective voice for the BME voluntary and community sector to influence policy makers via accountable representation and co-ordinated responses to consultation.
- To build relationships, trust and co-operation in the BME communities in Trafford.
- To promote communication, the sharing of good practice, peer support and partnership working through meetings, events, seminars, conferences, and publications.
- To provide leadership for the BME voluntary and community sector organisations.
- To deliver capacity building support to improve the efficiency, effectiveness and quality of voluntary and community sector organisations.
- Undertake activities to address issues affecting the BME communities in Trafford.

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