

Cancer and black and minority ethnic communities briefing paper

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Cancer and black and minority ethnic communities

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Key Messages

- 1** | There is a higher incidence of certain cancers in black and minority ethnic communities and the general incidence of cancer in these communities is rising.
- 2** | Understanding the prevalence and experiences of cancer in black and minority ethnic groups is hindered by a lack of data relating to these communities.
- 3** | Patients who are members of black and minority ethnic groups report more negative experiences of cancer care than white ethnic groups.
- 4** | Health care providers have a poor understanding of the needs of black and minority ethnic communities. There is a lack of health education regarding cancer and awareness of the availability of support services is limited among black and minority ethnic communities. As well as this, there is a lack of cultural competence education for health providers, especially in cancer awareness.
- 5** | There is clear evidence of a lack of focus, priority and urgency of the cancer needs of black and minority ethnic populations in NHS policy documents and in NHS cancer data collection exercises.
- 6** | In spite of some of these shortcomings, there are several examples of best practice, often led by the charitable sector.

Introduction

Cancer is a serious public health issue in the UK. As the commonest cause of death in England and Wales (Department of Health 2015), there are an estimated 250,000 cancer diagnoses and 130,000 deaths from cancer annually, costing around £35 billion. It is estimated that 2.5 million people are currently living with cancer in the UK and this is predicted to rise to 4 million by 2030 (Maddams et al. 2012). Smoking, diet, alcohol and obesity are seen as being the cause of one third of all cancers. The most

common cancers registered in 2015 were breast, prostate, lung and colorectal cancers accounting for just over half of all the cancers registered (53%) (Office for National Statistics 2017). There is a greater risk of cancer with age, with fifty percent of all cancer cases in the UK occurring in those aged 70 and over for the period 2012-2014 (Cancer Research UK 2017).

In 2009, the first publication of a national analysis of the incidence and survival of cancer in black and minority ethnic communities was published by The National Cancer Intelligence Network and Cancer Research UK. Subsequently over the last 4 years The Cancer Patient Experience Survey, commissioned by Public Health England, has collated black and minority ethnic data (Quality Health 2014; 2015). Drawing from prevalence data, patient experience surveys, analysis of policy documents and appraisal of research studies, this briefing paper highlights evidence relating to cancer health inequalities experienced by black and minority ethnic populations living in the United Kingdom.

There is a general consensus that collecting data on ethnicity is difficult and a lack of consensus of who is part of an ethnic group. Ethnic categorisations have undergone many modifications over time due to the changing nature of ethnic identification with the exception of the category defined as “white” which is seen as the ethnic majority and assumed to be white, of British origin and English speaking (Office for National Statistics 2003). Due to this approach, other “white” groups who may be English speaking and who may or may not be from the British Isles, such as the Irish are not classified as a distinct group, leading to their invisibility in the data. Also missed out will be much smaller groups of people often new arrivals.

There is a higher incidence of certain cancers in black and minority ethnic communities and the general incidence of cancer in these communities is rising

Cancer incidence

It is often reported that people from black and minority ethnic groups overall are less likely to get cancer than white populations. However there is evidence that certain cancers can have a higher incidence in particular ethnic groups. For example, recent

data has shown that “People from the black ethnic group have higher rates of myeloma and stomach cancer, and males from the black ethnic group have higher rates of prostate cancer. Liver cancer is higher amongst people from Asian ethnic groups compared with the white ethnic group, as are mouth cancer in females and cervical cancer in the over 65s.” (National Cancer Intelligent Network [NCIN], 2015, p13). In the period 2006-2010, South Asian females and a group classed as “mixed” had higher number of new cases of breast cancer compared to other white and ethnic groups (NCIN 2015). Other earlier analyses of ethnic data from the period 2001 – 2007, where 83% of ethnic data was available, reported that Bangladeshi women and white men had the highest incidence rates of oesophageal cancer and Pakistani men and women had the lowest incidence rates. Black Caribbean men and women had the highest incidence of gastric cancer, whilst Indian men and women had higher rates compared with their white counterparts (NCIN, 2012).

A study exploring cancer incidence from 1986 -2004 reported that cancer incidence is rising in South Asian communities in England (Maringe et al., 2013). The South Asian population was found to be 10 years younger than the non-South Asian population in their analysis in 2001. All cancer incidence for both South Asian and non-South Asian populations aged 15-84 was found to be rising, however the study reported a more rapid rise in South Asians compared to non-South Asians. The general incidence of many cancers is still lower in South Asians than non-South Asians but the incidence is rising at a quicker rate than non-South Asians, for example colorectal cancer incidence rose quickly but is still 40% lower than in non-South Asians. In lung cancer the incidence of cancer has reduced in non-South Asian men but has remained stable for South Asian men hence showing an increase in ethnicity over time. For breast cancer again the overall incidence is lower in South Asians than non-South Asians but in general the incidence rose faster in South Asians than non-South Asians. The study also found a weaker or no deprivation gradient for overall cancer incidence in South Asians. For urological cancers, incidence rates were found to vary considerably by ethnic group. A local study examining cancer incidence in South Asian and non-South Asian populations under the age of 30 living in Yorkshire, UK also reported an overall rise in annual cancer incidence rates in South Asians and predict if this increase continues then cancer incidence will be three times higher in South Asians than non-South Asians by 2020 (Van Laar et al., 2010).

Non-white groups had a low incidence of all urological cancers, except prostate cancer in black Caribbean and Black African, where prostate cancer incidence was more than double that of the white population. Prostate cancers were diagnosed less often in all other non-white groups and there were substantial differences in incidence between the Pakistani, Bangladeshi and Indian population (IRRs of 0.55, 0.64 and 0.33 respectively $P < 0.001$). Kidney cancer incidence was half the occurrence of that in Chinese and South Asians and within the South Asian group the Pakistanis had a higher rates than Bangladeshis and Indians (IRRs 0.67, 0.66, 0.46 respectively $P < 0.001$). Incidence rates for bladder cancer were two thirds lower in South Asian and Black populations, with no significant difference between Indians, Pakistani, Bangladeshi, Black Caribbean's and Black Africans. Chinese populations had the lowest incidence with a risk half that of the white population (Maruthappu et al., 2015). A study exploring the incidence of oesophageal and gastric cancer in England (Coupland et al., 2012) found that the incidence of oesophageal cancer in women was highest in Bangladeshi and lowest for Pakistani men and Chinese women compared to the white population. In men, Black Caribbean men had the highest rate of oesophageal cancer with IRR at 0.58 and Pakistani men had the lowest rates at IRRs at 0.17). For gastric cancers White men had the highest incidence of gastric cardia cancer than the other ethnic groups studied. Indian men and women and Pakistani men had a lower incidence of gastric non-cardia cancer and of gastric with an unspecified anatomical site (gastric NOS) cancer compared to White men and women. Black Caribbean men had a higher incidence of gastric non-cardia cancer compared to their White counterparts. Black Caribbean men and women and Black African men had a higher incidence of gastric NOS cancer.

The picture becomes more complex when the median age of certain cancer diagnosis amongst minority ethnic groups is considered, for breast cancer the media age for black women is 50 years compared with 62 years for the white population (NCIN, 2010). This lower age of diagnosis is likely to be significant due to the younger demographic profile of black and minority ethnic communities in the UK and also a different lifestyle will be playing a role since one third of all cancers are related to smoking, diet, alcohol and obesity (NCIN 2017). According to Shirley et al. (2014) currently only around 10 per cent of Bangladeshi, Pakistani and Black Africans are over 50 years old. The NCIN (2015) report concludes that as the black and minority ethnic population ages, the incidence of cancer will rise in England.

Reasons for higher rates of certain cancers.

There are some clear connections between behaviours and the prevalence of certain cancers. The chewing of areca nut and chewing tobacco is associated with increased risk of developing oesophageal squamous cell carcinoma (Akhtar et al.(2012) and has been reported to be a more common practice in Bangladeshi women than it is for individuals in other ethnic groups (Sproston and Mindel 2006). A study aimed at understanding ethnic differences in breast cancer concluded that the “differences are largely if not wholly” due to differences in existing known factors such as age at menarche, height, childbearing and breastfeeding history, alcohol consumption and use of menopausal therapy. The study concluded that when adjustments are made for these risk factors South Asian and Black women were shown to have similar breast cancer risks to white women (Gathani et al 2014). On a general population level, there are clear links between socioeconomic status and cancer incidence and mortality indicating an inverse correlation (Cancer Research UK, 2008). However this is not the case for all cancers, (Lundqvist et al. 2016) report data from a systematic literature review and meta-analysis of studies from Europe in which they summarise that women with higher socio-economic status show significantly higher breast cancer incidence.

Cancer Survival Rates

A cancer survival rate is the percentage of people who are still living after a certain period from the time of a diagnosis of cancer. Cancer statistics usually look at either 1 year or 5 year survival rates. Mortality rates are calculated based on figures of the number of people who died from cancer after diagnosis and this is also usually done using either a 1 year or a 5 year period. The survival rates from cancer for the period 1986-1995 for South Asians were higher than in non-South Asians for most cancers. However in recent analyses looking at survival rates from 1986-2004, the difference between the two groups has reduced over time. This was mainly due to the survival rate of non-South Asians increasing faster than for South Asians. South Asians were also found to experience high mortality in the first few months after diagnosis compared to non-South Asians, but were found to have lower rates of mortality than non-South Asians in the 5 years post cancer diagnosis. A picture is emerging of cancer survival rates that are similar to that of non-South Asians and it is proposed that the protective factor of ethnicity is disappearing (Maringe et al., 2015). Similarly a detailed analysis of breast cancer survival (Morris et al., 2015) reports no significant differences between the three ethnic groups classed as Asian, black and white. Assimilation and acculturation factors where South Asian populations over time and

through generations have taken on more western lifestyles are being put forward as reasons for this alignment in survival and mortality rates.

Cancer Screening

Jack et al (2014) found that the British White group were more likely to attend for breast cancer screening on a first and subsequent invitations and uptake varies by specific ethnic group with variations within the same ethnic group in different geographical locations. Big differences in attendance were found in South East and North London where Bangladeshi women had low levels of uptake compared to the White British and other groups. However in Central and East London where the majority of the Bangladeshi population resides, the uptake was similar to other groups. It is suggested that this may be due to several targeted projects in place at the time to improve screening. The study suggests further follow-up since there is continuing work to improve screening uptake in London. Culturally appropriate interventions to reduce differences in the uptake of screening were recommended by Szczepura et al., (2008) after they analysed data for breast and bowel screening uptake patterns over 15 years in the UK for South Asian populations. They found lower breast and bowel cancer screening uptake rates in the South Asian population with the ethnicity of the GP appearing to be associated with low uptake of bowel cancer screening but not breast cancer screening.

Cancer vaccination

In a recent study (Rockliffe et al., 2017) of 195 London schools, uptake was consistently high among South Asian ethnicities (Bangladeshi, Indian and other Asian) and consistently low among Black ethnicities (African and Caribbean).

Collecting and recording ethnicity data

One of the greatest barriers to acquiring knowledge related to black and minority ethnic health is the accurate collection and recording of ethnic monitoring data. In recent years, ethnicity identification in cancer diagnosis and treatment has improved, with a newly developed system of linking cancer registrations with other registration information and Hospital Episode Statistics data, such as admitted care, outpatient attendance and Accident and Emergency. However, there are still issues around the completeness of ethnicity in Hospital Episode Statistics (HES) data, Saunders et al 2013 discuss in their analysis of the accuracy of ethnic information in HES data for the major ethnic groups (Indian, Pakistani, Bangladeshi, Chinese, Black Caribbean and

Black African), there is a miscoding of about 20% to 35% of ethnicity data of all patients who self-report. For cancer registrations for some NHS trusts: six were identified as having less than 50 per cent completeness of ethnic data (NCIN, 2015, p27-29). The Listen Up report (The Basil Skyers Myeloma Foundation 2015) highlights the lack of ethnicity recording in the Joint Strategic Needs Assessment when they examined 5 local authority boroughs (Lambeth, Lewisham, Birmingham, Nottingham and Stockton on Tees) only one, Birmingham had identified gaps in knowledge and research in relation to cancers in Black and Minority ethnic groups.

There is also a need for up-to-date reporting on ethnic data: the National Cancer Intelligence Network July 2015 report was based on data collected in the period 2006-2010 and the last detailed report around the major ethnic groups and cancer, (Cancer Incident and Survival by Major Ethnic Group, (National Cancer Intelligence Network, 2009) refers to data from 2002-2006.

Whilst grouping larger visible ethnic groups into broad categories such as Asian and black can make analysis easier, it may be problematic as it can hide variations in the incidence of certain cancers in different ethnic groups. For example, reports by Coupland et al., (2012) highlight the problematic nature of classifying individuals into broader categories, their study found that Bangladeshi women had a higher incidence of this cancer and Pakistani and Indian women a lower incidence. Similarly Maruthappu et al (2015) highlights this issue in relation to prostate and urological cancers in the category "Black men". He reports that "large differences existed in these types of cancers between Black African and Caribbean populations, highlighting the need to differentiate between these groups" (pg 4). In the same way the "white" group becomes a catch all for all ethnic groups with a white skin colour. Therefore a significant number of white minority populations living in the UK such as those from an eastern European background, Turkish background or those who identify themselves as Irish become invisible, which in turn results in masking the real incidence of cancer and mortality in these groups.

Data collection based on observation of an individual's colour, such as skin colour, hair colour, dress code was found to still be a common method of data collection by health professionals who used this method to avoid discomfort, confrontation and fear of offending an individual (Iqbal et al., 2012). Though the study did find that the first most common method was self-reporting by the patients. Gulnaz et al (2012) found in their focus group research of a South Asian population sample to

understand the willingness and understanding around ethnic data provision, found that there was an overwhelming willingness to provide this data and an understanding amongst a number of individuals around the need for this data with suggestions that wider demographic information should also be collected such as language, religion and country of birth. There was also a consensus that data should only be collected once by G.P's and shared within the healthcare system.

Black minority ethnic patients report more negative experiences of cancer care than white ethnic groups

An analysis of the 2010 Cancer Patient Experience Survey found that patients from black and minority ethnic backgrounds were less likely to respond than those from a white background (Abel et al., 2016). Those that did respond were more likely to rate their cancer experience critically than those from a white background (Saunders et al., 2015; Pinder et al., 2016):

Table 1.

	White	Black	Asian
Care was excellent	57%	39%	36.8%
Always understood the Clinical Nurse Specialist	82%	77%	78.4%
Trusted and had confidence in hospital doctors	84%	78.4%	78.6%
Trusted and had confidence in ward nurse	70%	57%	60%

Cancer Patient Experience Survey (2010)

As a response to poor uptake in the Cancer Patient Experience Survey, BME Cancer Voice carried out a survey of BME cancer patients. They report findings from 661 respondents aimed at understanding how information is received by patients and the levels of satisfaction at differing points of the journey (BME Cancer Voice 2013). Online and telephone channels such as NHS direct were not places where the majority of patients received their information. They also reported that the Chinese ethnic group were the least informed. In terms of culturally appropriate service provision more than a quarter felt uninformed regarding advice or support that suited their cultural/religious/spiritual needs and more than half were not offered a prosthesis that was appropriate to their skin tone.

Trenchard et al., (2014; 2016) report variation by ethnicity of patients' ratings of communication and information. Asian and Chinese patients were less likely to receive understandable written information about side effects and were less likely to receive understandable answers to important questions directed at the doctor compared to white patients. In a breakdown of the "Asian" category, Bangladeshi patients were the least likely to receive answers to important questions.

Health care providers have a poor understanding of the needs of black and minority ethnic communities

There is a lack of health education regarding cancer and awareness of the availability of support services is limited among black and minority ethnic communities. As well as this, there is a lack of cultural competence education for health providers, especially in cancer awareness. Johnson (2013) argues that diversity needs to be embedded into the design and provision of cancer services. The key issues that must be addressed in order to achieve this goal are discussed below.

Access to cancer care

Delays in entering the cancer care system results in both a delayed diagnosis and delayed treatment. A number of factors are contributors to delay. The commonest reason given for a delay in seeking help is being unable to recognise symptoms as possible cancer (Smith et al., 2005). People who do not recognise symptoms are more likely to wait longer than two weeks before visiting a doctor. Older people, men, the less educated and those from black and minority ethnic groups were found to be less likely to recognise cancer warning signs, such as a persistent cough, breast changes and rectal bleeding (Quaife et al., 2013). A lack of knowledge of cancer symptoms has an impact on help seeking behaviour (Ismail et al 2015). Marlow et al., (2015) report that Pakistani women in their study reported that there was a general lack of awareness of what cervical cancer was or what indeed a cervix was amongst older Pakistani women.

A further factor is a delay in referral. The majority of cancer referrals to secondary care are made by GPs. Yet there is evidence from the Cancer Patient Experience Surveys that black and minority ethnic patients are more likely than white patients to

have a delayed referral to secondary care: patients from ethnic groups were more likely to have visited their GP three or more times before a hospital referral was made for suspected cancer compared to white patients (Lyrtzopoulos et al., 2012). Patients from ethnic minority background reported a poor experience of involvement in decisions about treatment (El Turabi et al., 2013).

Communication provision

There is evidence of poor practice in terms of assessing and providing appropriate communication provision for people with cancer (Fazil et al., 2015): “Clinicians were particularly careless in their willingness to proceed with consultations in the absence of appropriate interpreting services despite clear evidence that patients have a very poor and often virtually non-existent grasp of English” (p.101). Good communication is particularly hindered due to the scarcity of culturally trained interpreters and is a significant issue for staff (Richardson et al., 2006). Richardson et al. (2006) reported that they were often aware of their shortcomings with a “sense of distress amongst health care professionals about their frequent inability to provide good care to patients from black and minority ethnic groups” (p.98). Kai et al., (2007) found that the uncertainty experienced by health professionals when caring for diverse populations can contribute to health inequalities through hesitancy and inertia.

Palliative care

Poor communication, and a lack of sensitivity to cultural religious differences, of available translators, and of awareness of services/information were identified as barriers to accessing and receiving palliative and end of life care for black and minority ethnic populations (Clanzani et al., 2013). Clanzani et al., (2013) concluded that “overall palliative and end of life care for black and minority ethnic groups is often inadequate” (p.9) and made several recommendations such as developing new policies focused on black and minority ethnic groups, improving ethnic monitoring and providing cultural competence training to improve care. Johnson (2009) found that the main barrier to palliative care was the fear among health professionals of doing the wrong things and causing offence or appearing discriminatory or racist. He recommends that health care professionals should change their approach and be open to making mistakes and learning from patients and carers.

Research

Being a participant in clinical cancer trials has shown to have better outcomes than those who are having normal population based treatment (Djulgovic et al., 2008). Recruitment in cancer clinical trials has been found to be significantly lower for black and minority ethnic populations compared with white cancer patients (Godden et al., 2010).

Lack of focus, priority and urgency of the cancer needs of black and minority ethnic populations

A crucial starting point to ensure that cancer care for black and minority ethnic populations is given special attention within the NHS is in developing policies that address issues affecting this population. Black and minority ethnic cancer health inequalities do not appear as a focused priority in health policy documents. The current NHS Outcomes Framework 2015-16 (Department of Health, 2014) and the new NHS Outcomes Framework 2016-2017 (Department of Health 2016) include cancer priority improvement area but the focus is on “reducing health inequalities” (p4) with no mention of black and minority ethnic health. Further policy drivers for reducing inequality in cancer such as Improving Outcomes: A Strategy for Cancer (Department of Health 2011) and the five year forward view plan for cancer Achieving World Class Cancer Outcomes: Taking the Strategy Forward all lack a clear lens for addressing the needs of black and minority ethnic populations. In Achieving World Class Cancer Outcomes: Taking the Strategy Forward (NHS England 2016), the only outcome specific to black and minority ethnic populations is to increase black and minority ethnic representation in the Cancer Patient Experience Survey (Quality Health 2014: 2015). In the Improving Outcomes: Strategy for Cancer Fourth Annual Report (NHS England 2014), it is clear that there is no clear strategy to tackle cancer in black and minority ethnic populations with ethnicity only mentioned to advise that results are available for all tumours diagnosed between 2006 and 2010 with breakdowns by age, sex, deprivation and ethnicity (p19).

Besides a lack of attention to ethnicity in policy, the analysis of ethnic data, which is crucial in understanding the prevalence, treatment and survival of cancer, is not routinely available in the National Cancer Intelligence Reports. In addition, ethnicity

data analysis that does become available is usually at least 5 to 6 years behind in time and most likely out of date.

Routinely recording ethnic data has slowly improved over the years but without clear penalties for non-compliance, this practice does not have the priority that it deserves and needs. Ensuring that ethnic data is recorded at all times should become part of basic care in the NHS and there should be serious key targets for NHS trusts and penalties for non-compliance.

These clear failings of policy directives have resulted in a lack of urgency to prioritise the cancer care for black and minority ethnic populations.

Best practice examples and way forward

Interventions

Interventions to address barriers to accessing services have emerged over the last 15 years. A review of colorectal cancer interventions to improve screening found that simple interventions, such as a person face-to-face or on the end of a phone explaining the basic steps of the colon cancer screening process, can lead to modest improvements in screening uptake in minority patients. This process was found to be time intensive and costly and therefore would only be possible through a large centralized service which could bring down costs. Other strategies, such as training physicians to effectively communicate with patients who have low health literacy, have also been shown to be effective (Naylor et al., 2012).

Patient navigators/advocates can also improve patients' experience of cancer related care. Studies have found that the quality of navigators and advocates matters, and that those with good interpersonal skills, well matched with the patients, can improve knowledge and understanding of the illness (Fazil et al., 2015; Pascal et al, 2013).

Resources

Health promotion

- The Prostate Cancer Charity commissioned Benjamin Zephaniah to write a promotional theatre piece to explore the issues and create a debate around

prostate cancer in black men. The piece called De Botty Business was a huge success and illustrates how the use of culturally appropriate terminology combined with theatre can be so powerful in getting the message across.

Campaigning for improvement

- Champions for Change Cancer Services is a service commissioned by the National Cancer Action Team as part of its Cancer Does Not Discriminate campaign. This is a campaign for improvement where local people volunteer their time to provide their views and opinions to make recommendations about cancer services and related health and well-being services.

Reports

- Marie Curie Cancer Care published two reports on end of life care for minority ethnic communities: Palliative and End of Life Care for Black, Asian and Minority Ethnic Communities in the UK and Next Steps: Improving end of life care for Black, Asian and Minority Ethnic people in the UK.
- Macmillan (2014) have produced an overview report in a simple and easy to read format entitled: The rich picture on people with cancers from BME groups.
- Hear Me Now: The uncomfortable reality of prostate cancer in black African-Caribbean men and Hear Me Now: One year on.
http://www.tings.org.uk/index.php?option=com_phocadownload&view=category&id=2&Itemid=277.
- Black Health Initiative Cancer Patient Survey:
<http://www.blackhealthinitiative.org/BME%20Cancer%20Voice%20Patient%20Survey%20Report.pdf>

Training resource for health professionals

- Professionals responding to cancer and ethnic diversity (PROCEED) is a multimedia training tool for educators within the health and allied professions (Kai J (ed.) 2005).

Conclusion

Key strategies relating to cancer are failing to include cancer in relation to black and minority ethnic populations. Instead there is a blanket approach to “inequalities” which is not specific to particular populations and their needs. Analysis of ethnic data does not have an urgency or serious differentiation, with the majority of available

data being over 5 years old and analysed using broad ethnic definitions. Cancer charitable organisations such as Macmillan and Marie Curie have led the way in providing an overview of black minority cancer and the National BME Cancer Alliance have produced guidance to improve NHS policy drivers. Smaller black and minority ethnic-led organisations such as the African Caribbean Leukaemia Trust, Irish in Britain, the Chinese National Health Living Centre, and the Black Health Initiative continue to work at local and national level to influence policy and practice, as well as directly providing services and delivering projects to improve outcomes for their communities.

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