



# State of Health Black And Other Minority Groups

BHA Contribution to the Development of  
a Joint Strategic Needs Assessment (JSNA)

# Contents

<b>Introduction</b>	<b>Page 3</b>
<b>Mental Health</b>	<b>Page 5</b>
<b>Older People Affected by Dementia</b>	<b>Page 9</b>
<b>Cancer</b>	<b>Page 10</b>
<b>Heart Disease and Related Illnesses</b>	<b>Page 12</b>
<b>Human Immunodeficiency Virus (HIV)</b>	<b>Page 13</b>
<b>Diabetes</b>	<b>Page 16</b>
<b>Tuberculosis (TB)</b>	<b>Page 17</b>
<b>Palliative Care</b>	<b>Page 18</b>
<b>Disability and Health</b>	<b>Page 20</b>
<b>Race Equality and Human Rights</b>	<b>Page 22</b>
<b>Conclusion</b>	<b>Page 23</b>
<b>References</b>	<b>Page 24</b>

## **Acknowledgements:**

**BHA thanks all members of the Steering Group of Manchester Race & Health Forum and members of the external reference group for their assistance in contributing to the development of this document.**

**Produced by:  
Donna Miller**

# Introduction

With the implementation of the Health and Social Care Act 2012 there is greater emphasis on the process of undertaking Joint Strategic Needs Assessments (JSNA) across health and local government services which will identify priorities for inclusion in a Joint Health and Wellbeing Strategy (JHWS) for each local authority area. A JSNA enables local areas to:

- Identify health and social care needs
- Commission appropriate services
- Engage communities in improving health and wellbeing

Inequalities in health and wellbeing in each local authority area will be reported in the JSNA and effective implementation of a wellbeing strategy should result in equal access, treatment, outcome and equality of opportunity in health.

This report is intended to:

- i. Provide an overview of racial disparities in health currently being experienced by Black and other minority groups at a national level, though where available local information is provided. This is, however, limited as in most instances national evidence is replicated at a local level.
- ii. Provide practical examples of the way in which current trends in racial disparities can be tackled from a review of existing research recommendations and individual/group feedback on the quality of health services.
- iii. Contribute to the priorities to be included in a JSNA from a BME perspective.
- iv. Encourage commissioners to consider the impact of health inequalities on their legal obligations to protect human rights and meet their obligations within the provisions of the Equality Act 2010.

## The JSNA and Black and other Minority Groups

There has been a significant amount of national research conducted over the last 25 years that sets out the inequalities in health faced by Black and other minority groups. Health disparities are differences in health status that are driven by inequalities in society. Good health is shaped by many different factors such as lifestyle, income, educational attainment, job security, housing conditions, social networks, long term impact of migration, racism and discrimination and poor delivery and take-up of health care. A health inequality is, therefore, the cumulative negative effect of these factors. Patterns of inequality in health vary by ethnicity, from one health condition to the next.

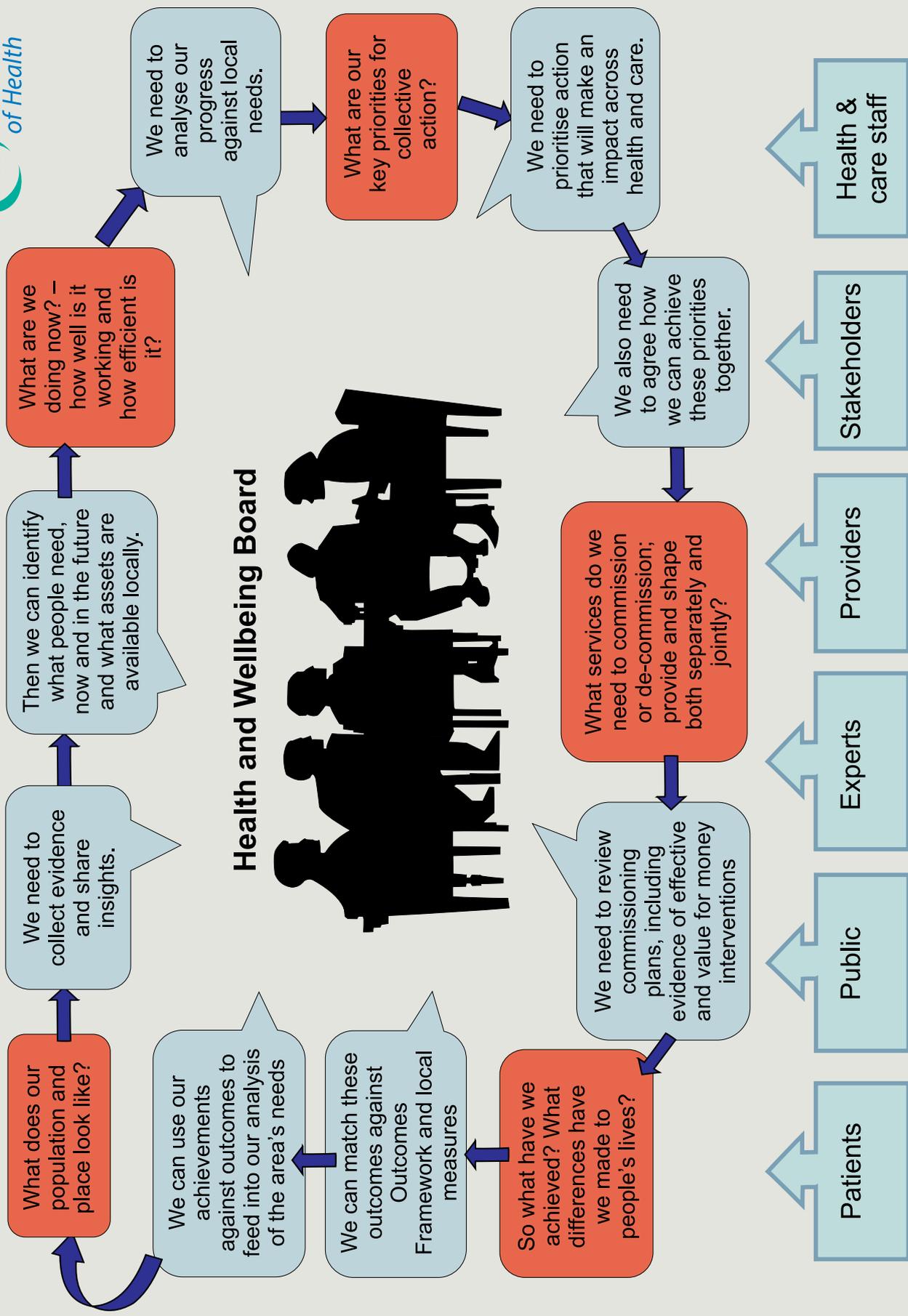
Differences in health of Black and other minority groups, compared to the rest of the population, are well documented nationally, whether from work delivered through national programmes such as Delivering Racial Equality or from the national health survey. Unfortunately some minority groups such as Irish, Irish Travellers, Gypsy and Roma communities and refugees and asylum seekers, who face significant health inequalities, are sometimes omitted from the JSNA. Such disparities are also evident across a number of risk factors for disease and disability such as smoking, obesity and lack of physical exercise.

While there is much research published on the needs of BME groups in general, there is a lack of published evidence on initiatives which positively improve the health and wellbeing of Black and other minority people and such initiatives tend to be short term.

Differences in the health of Black and other minority groups are most prominent in the following areas of health: mental health, cancer, heart disease and related illnesses such as stroke, Human Immunodeficiency Virus (HIV), Tuberculosis (TB) and diabetes. Additionally an increase in the number of older Black and other minority people in the UK is likely to lead to a greater need for provision of dementia services as well as the provision of culturally competent social care and palliative care.

The following attempts to set out both positive elements and issues of concern about the above areas as well as to identify ways in which the quality of services can be improved, addressing current racial disparities in the prevention, diagnosis, and treatment of chronic illnesses. Suggestions for improvements are drawn from a review of research published over the past 8 years and views of individuals, service users, voluntary and community organisations and health professionals.

# JSNA & JHWS: explicit link from evidence to service planning



Involving partners and the community ensures transparency and accountability

# Mental Health

## Key Trends

- In April 2010 the Care Quality Commission's (CQC) review of the final Count Me In<sup>1</sup> Census showed that little progress had been made in reducing the mental health admission rate for Black and other minority groups. 23% of inpatients in mental health services in 2010 belonged to these groups despite efforts over the previous 6 years to reduce admissions. The rates of admission, detention and seclusion were effectively unchanged and evidence from the Census outlined the following:
  - » Admission rates remain higher than average among some racial groups, especially those recorded as being Black or mixed race (White/Black) for whom rates were two or more times higher than average in 2010. In contrast, admission rates were consistently lower than average among the Indian and Chinese groups, and about average in the Pakistani and Bangladeshi groups.
  - » Detention rates had almost consistently been higher than average among those recorded as Black or mixed race (White/Black) as well as those classed as 'Other White'. The rates for being placed on a Community Treatment Order (CTO) were higher among the South Asian and Black groups.
  - » Seclusion rates were higher than average for the Black, Mixed (White/Black) groups and Other White groups, in at least three of the six censuses

The above were also identified as recurring themes in a subsequent report 'Monitoring the Mental Health Act in 2011/12'<sup>2</sup> which used data available quarterly from the Mental Health Minimum Data Set (MHMDS).

- A 2008 study by the Independent Police Complaints Commission on the use of Section 136<sup>3</sup> found that the rate of detention for BME people was almost twice as high as that for white people.
- Within mental health settings, higher rates of formal admissions under the Mental Health Act amongst the Black and minority ethnic population also significantly affect BME men.<sup>4</sup>
- There is a substantial body of evidence pointing to a negative relationship between mental health services and African and Caribbean men, who are under-represented as users of enabling services and over-represented in the population of patients who are admitted to, compulsorily detained in, and treated by mental health services. The consequences of this are poor engagement with

mainstream services, restricted choices and high levels of dissatisfaction with mainstream care.<sup>4,5</sup>

- Research relating to the Irish community shows the following:<sup>6,7</sup>
  - » The Irish population in Britain has a history of higher rates of mental ill-health than the general population.
  - » Irish people are substantially over-represented as users of psychiatric services, particularly for depression and alcohol related disorders.
  - » They are more than twice as likely to be hospitalized for mental health problems as native-born people in England and Wales.
  - » Irish rates of schizophrenia are second only to those of African-Caribbean people.
  - » Studies have shown that Irish-born people living in the UK have a higher rate of suicide than any other minority ethnic group living in the country.
  - » A study carried out in Birmingham<sup>8</sup> in 2008 looked specifically at the mental health needs of Irish women. One of the themes which came through strongly was the stigma which was attached to mental ill-health, especially among older women.
- For disadvantaged groups with transitory lifestyles - such as Gypsies and Irish Travellers - difficulty registering with a GP is a barrier to accessing primary care. There is also some evidence that health care providers and staff working within primary care settings may restrict access to such services for certain communities. This is also relevant to preventative programmes. Moving from a transitory lifestyle to housing can exacerbate mental ill-health.<sup>9,10</sup>
- Common mental disorders such as depression and anxiety are not considered as serious or disabling for the individual as psychotic disorders such as schizophrenia or bipolar disorder. However, as the disorders are far more common, they affect more people, and have a much greater impact on the community. One estimate suggested that they account for one third of days lost from work due to ill health. The Labour Force Survey suggests that common mental disorders such as depression and anxiety plus stress account for more than 40 per cent of days lost to ill health.<sup>11</sup>
- Disparities exist in both access to and quality of mental health care for Black and other minority groups. Examples of these disparities include the underutilization of psychiatric services by persons from minority groups, problems in getting people from these groups

to seek treatment, and the inappropriate prescribing of antipsychotic medications.

- The stigma attached to mental health problems within some groups and cultures may result in people avoiding acknowledging their mental health problems and seeking help, e.g. Jewish, Asian and Gypsy and Traveller communities. This can result in under-diagnosis, under-treatment and poorer prognosis for recovery.
- Research conducted by Mind has found that despite experiencing high levels of mental distress, refugees and asylum-seekers face many challenges accessing mental health services in England and Wales. Such challenges are further exacerbated by restrictive policies on such areas as healthcare.<sup>12</sup>
- Long term physical conditions are associated with increased risk of mental health problems. For instance, rates of depression are doubled in diabetes, hypertension, coronary artery disease and heart failure, tripled in end-stage renal failure, chronic obstructive pulmonary disease and cerebrovascular disease and seven times more common among those with two or more chronic physical conditions compared to healthy controls.<sup>13,14</sup>
- There is strong evidence of a higher prevalence of mental health problems among people living with HIV, compared with the general population. People who have been diagnosed with HIV are more likely to develop a mental health problem, for example anxiety or depression.<sup>14,15</sup>
- There is a link between sight loss and reduced wellbeing. For example, over one-third of older people with sight loss are also living with depression.<sup>16</sup>

## Measure to tackle disparities

### Access to Services

- For those individuals living with a psychotic illness such as schizophrenia there should be improved access to GP services and adequate hospital care in an environment that allows space and the opportunity to recover.
- GP surgeries should provide specialist mental health services to enable those service users who need additional support to receive that in their own community

rather than face being placed in a hospital setting with the prospect of isolation and potential regression in their state of health.

- It is necessary to raise the awareness of mental health issues in communities in order to reduce stigma and facilitate early access to appropriate support. Education about mental disorders and the treatment process is critical to reducing barriers to treatment among Black and other minority groups. The national 'Time for Change' programme is currently tackling these issues but there is a need to critically monitor the impact of this programme on Black and other minority groups. Suggestions for overcoming these barriers include a local public education campaign, educational presentations at community venues, and open information sessions at local mental health clinics. The recruitment of mental health champions within particular communities was proposed as a way of targeting the education programme and tackling the taboos about mental health that are held by some racial groups.
- Health promotion campaigns should be targeted at particular groups such as Gypsies and Travellers, refugees and asylum seekers, and Irish women, particularly as these groups were reluctant to approach, or did not know of, the health services available.
- Ensure that mental health services take account of the specific needs of refugees and asylum seekers. This requires an approach where dealing with practical needs through casework or good signposting occurs alongside any therapeutic interventions.

### Diagnosis, Treatment and Quality of Services

- Research from the Delivering Race Equality (DRE)<sup>17</sup> community engagement programme (2005-2008) identified the following factors that facilitate recovery: support from family and friends, 'keeping busy', a positive attitude, faith and religion, and medication. On the other hand the following were identified as obstacles to recovery: lack of support from family and friends, the stigma of mental illness, a return to an unchanged environment after treatment, a poor experience of treatment and disbelief that recovery is possible.
- The research also identified that service user and carer satisfaction with mental health services were key to recovery. As one of the community organisations commented: 'Where someone's illness was explained

and understood and a choice of treatment offered, in general people had a much better perception of the mental health services provided.'

The research also recognised that a more active role for BME communities and service users could help to provide effective support and help people to manage the discharge home. They could also provide an early intervention support network.

- Service users need to be confident that when they come into contact with the NHS (particularly through primary care) they are going to be given appropriate advice from an experienced practitioner as to the best treatment options available to them. The current trend that puts a heavy reliance on medication of individuals with a psychosis needs reviewing.
  - It should be recognised that medication may work well for some people but have a negative effect on others who may benefit more from group work or access to talking or other therapies. There is a tendency for over medication of Black African/Caribbean men who enter mental health services via the criminal justice system and lack of information about the long term effects of such medication. A greater access to psychological therapies is needed.
  - The criteria used to determine that an individual is suffering with a psychosis should be reviewed as this has resulted in the over-representation of Black men being stigmatised as having schizophrenia. The behaviour of some groups can be misinterpreted because of a lack of understanding of cultural norms and language by those conducting assessments.
  - The role of carers should be reviewed to ensure that a carer's assessment reflects the role of a carer as a partner in decision making about an individual's health and not as someone who is informed as an after-thought. Carers and the individual concerned should be given information about what is happening when a decision is made to section a person.
  - Recovery for some racial groups requires an understanding of the impact of negative social experiences caused by racial discrimination or harassment and identifying ways to overcome these and rebuild an individual's self-esteem and confidence. An improved understanding is needed of specific cultural issues and the impact racism and discrimination may have on some Black and other minority groups that may have led to their ill health.
- There needs to be meaningful communication between service providers and those groups that are over-represented in the mental health system (Black, mixed race and Irish individuals) so that services are more responsive and understand social and cultural issues thereby improving the service user experience. Equally the involvement of service users in the design and provision of services should be encouraged.
  - Control and choices should be improved by identifying alternatives to hospital admission, increasing access to psychological therapies and assisting individuals to make choices about accommodation and seeking employment. There should be a greater emphasis on providing information about mental health issues and services so that those groups that are over-represented in the system become knowledgeable users of mental health services and are more involved in decision making.
  - Good practice developed by community based BME mental health provision should be acknowledged and embedded into mainstream provision to develop a mainstream service that is responsive to different racial groups.
  - Increasing the number of under-represented groups in the health professions can help address health care disparities by both improving access and responding more effectively to the needs of minority populations. Greater health professions diversity will also provide increased opportunities for minority patients to see practitioners with whom they share a common race, ethnicity, or language. Race, ethnicity, and language concordance is associated with better patient-practitioner relationships and communication, and increases patients' likelihood of receiving and accepting appropriate medical care.
  - Culturally sensitive care can help providers understand what complementary and alternative treatments patients might be using, to recognize mental health problems that might otherwise be hidden, and to address concerns about sensitive issues such as sexuality and end-of-life care that are not easily discussed.
  - The provision of culturally and linguistically appropriate information materials and translation services are also

essential to ensuring that Black and other minority groups can navigate the health care system effectively and access all the benefits to which they are entitled.

### **Aftercare following treatment**

- Support should be provided to individuals to address social problems through identifying and securing accommodation, opening up routes into employment and providing access to welfare rights information.
- The services of BME mental health agencies should be made available to provide support to individuals, if requested.
- Evidence has consistently shown that employment is better for mental and physical health than unemployment. However, this only applies to good quality work which is characterised by a living wage, having control over work, being respected and rewarded, being provided with good quality in-work services such as occupational health services, and with adequate support to return to work after absence.<sup>18</sup>

### **Commissioning of services**

- Future commissioning for mental health services should acknowledge the contribution of Black and other minority groups in the voluntary sector and maintain their role in assisting service users, some of whom may have had negative experiences of mainstream psychiatric services
- A Health & Wellbeing Board and the CCGs should have specific strategies to address the mental health needs of Black and other minority groups and address any issues of over-representation and the provision of a health service that meets their needs.
- There has been further investment in Improving Access to Psychological Therapies (IAPT) in an effort to integrate talking therapies into individuals' treatment; however, in relation to Black and other minority groups, there needs to be a radical change in the way the NHS commissions talking therapies to allow more involvement of a wider range of therapies. In order to move to a new model of mental health treatment real choice in talking therapies needs to be available. For example, with the increase of older people living with HIV, provision should reflect the need for counselling services to improve emotional well-being in older people with HIV, particularly Black African women.

### **Data Collection**

- Significantly, the CQC noted that many service providers did not collect data which would have permitted it to monitor equality and anti-discriminatory compliance. This consequently limited the impact of strategies designed to reduce inequalities
- The Delivering Racial Equality review (DRE), published in December 2010, made clear that better monitoring and collection of information and better use of data to inform commissioning and provision intentions in health and social care is required. This should focus on what works for which communities; and how it can be captured in order to change and improve existing systems and processes.
- The report further stated that 'collecting and analysing valid and reliable data regarding these disparities provides the building blocks for identifying differences in care and developing targeted interventions to improve the quality of care delivered to specific population groups'. This is required regardless of whether those population groups are identified by geography, disability, socioeconomic status, race or ethnicity.
- There needs to be improvement in the monitoring of compliance with the Equality Act. The Equality Delivery System (EDS) is a framework that is supposed to include monitoring as one of its goals, within NHS trusts, but currently fails to identify corrective action that is required to change some of the trends outlined in this report.

# Older People Affected by Dementia

## Key Trends

- The current UK evidence base on supporting Black and other minority groups with dementia and their carers is limited with some evidence available from local surveys.<sup>1</sup>
- Overall, the proportion of BME people affected by dementia is broadly the same as that found among white people although, as yet, there have been no large-scale UK prevalence (frequency) studies in which there have been sufficient numbers of BME people in the sample to compare the frequency of different types of dementia across different ethnic groups.<sup>2</sup>
- There are over 11,500 people with dementia from Black and other minority groups in the UK.<sup>1</sup>
- Stigma may lead to a reluctance to use services as a person's dementia becomes public as well as a fear of the reaction to the diagnosis by members of a community. Carers may also find that they experience stigma because of their association with the person with dementia.<sup>2</sup>
- The Federation of Irish Societies carried out an exercise in 2010 mapping the services for elders within the Irish community and identified that in the absence of culturally sensitive mainstream or culture specific services, the Irish third sector had developed a range of innovative, person-centred services that are popular and well utilised by the community. Despite this there was still considerable unmet need in relation to older Irish people in general and for people with dementia and their carers specifically. The study noted that dementia is increasingly a key issue within the Irish community, yet there is evidence to suggest that Irish people were not accessing support from healthcare services. Within the community there are also disproportionately high levels of hypertension, coronary heart disease and strokes which can all contribute to the development of vascular dementia which is comparable to the African-Caribbean community.<sup>3</sup>
- Past studies report high levels of uncertainty among BME people about how to access dementia services and how these services could help. This picture is consistent with reports given by BME older people as a whole.<sup>2</sup>
- Early onset dementia (a rare type affecting people under 65) is more frequent among Black and other minority people with 6% of people having it compared to 2% of the white population.<sup>2</sup>
- There is evidence that Black and other minority groups with dementia present later to dementia services than their White counterparts, when their dementia becomes more severe.<sup>2</sup>
- Research suggests that Black and other minority groups are less likely to receive a diagnosis or receive it at a later stage thereby delaying access to memory assessment services.<sup>2,4,5</sup>
- Black and other minority groups and their families are more likely to see the symptom of dementia as 'normal ageing' which leads to the assumption that nothing can be done to assist them and results in families only seeking help when the dementia become more severe.<sup>2</sup>

## Measures to Tackle Disparities

- Lower levels of awareness about dementia, despite national television campaigns, and the existence of stigma within some communities may explain the lack of use of dementia services. Some Black and other minority groups do not recognise the term 'dementia' but use other everyday language to refer to the symptoms. Specific work at a local level needs to be undertaken with Black and other minority groups to raise awareness and understanding of the term and the services that are available to support individuals and their carers. Using neutral language in published information such as 'memory problems' for dementia and 'looking after' instead of being a 'carer' helps and this avoids making assumptions that people understand what is meant by these terms.<sup>2</sup>
- Although it is not currently possible to prevent dementia, there is potential for certain BME communities to reduce the risk of developing vascular disease and possible vascular dementia by adapting their diet and levels of exercise and by cessation of smoking. BME people seem to be at greater risk of developing vascular dementia, so resources providing relevant and useful advice to BME people on this topic are needed.<sup>2</sup>
- Any local campaign should stress the necessity for early diagnosis to ensure the dementia-like symptoms are not

# Cancer

being caused by conditions such as depression and to ensure treatment of that other condition where relevant. Equally campaigns need to be clear about the care and support to be provided dependant on the type of dementia that is diagnosed.

- Past research has identified various means of publicising information about dementia including: hosting activities at community centres and religious establishments; using DVD and videos – instead of publications - for those communities that have low levels of literacy; publicising information on local radio; appointing outreach workers to work with local communities; training community health champions and developing EPP (Expert Patients Programmes). Different approaches will be required for different communities. <sup>2</sup>
- Assumptions should not be made that Black and other minority groups do not want to use services because they do not enquire about them. If information on available services is not provided, people may not receive the information and support they require.
- People with dementia should be provided with good quality end of life care that acknowledges the impact that dementia will have on their ability to communicate their wishes and their memory, allows dignity and respect and acknowledges cultural and religious observance.
- Carers may feel reluctant to ask for help because it conflicts with cultural norms but information should be readily available and accessible to ensure support to carers, regardless of their racial group, on issues such as respite care, carer's assessments, care and support available etc.
- Domiciliary care is often necessary, as many minority ethnic communities regard residential care as inappropriate. However, this can work to increase the isolation both of older people as well as of their carers.
- The lack of provision of an environment in some day centres that recognises an individual's language, culture and religious requirements presents a barrier to the attendance of some racial groups.
- The vast majority of culturally competent care of elderly people, including those with dementia, is being provided by the BME voluntary sector as little other provision exists. There is, however, limited expertise in providing dementia services and there is a need for improved training.

## Key Trends

- Awareness of cancer is generally lower in Black and other minority groups than amongst white men and women and screening uptake is generally lower than the population as a whole. Uptake for breast, cervical and colorectal screening programmes is generally lower in minority communities. Although there may be some cultural factors involved in this, it is also likely to be related to deprivation. <sup>1</sup>
- Women from Black and other minority groups are more likely to present with more advanced breast cancers and have poorer survival rates than white women which may be explained by late presentation. This is particularly the case for Indian, Pakistani, Black Caribbean and Black African women who are more likely to seek medical assistance with advanced breast cancer. <sup>1</sup>
- Rowen et al found that women of African and Caribbean descent were being diagnosed with breast cancer on average 21 years earlier than their white counterparts. Further to this, the type of cancer that was being diagnosed within this group was more likely to be an aggressive form of the disease which was unresponsive to newer drugs and had poorer outcomes. <sup>2,3</sup>
- The Social Exclusion Unit found that those with low literacy were 6% less likely to attend cervical screening than women with higher basic skills. Low literacy could be a barrier to women failing to attend screening and following up appointments. <sup>2</sup>
- In comparison with White ethnic groups, Black groups have significantly higher rates of multiple myeloma and stomach cancer. <sup>1,2</sup>
- Black men have higher rates of prostate cancer. <sup>1,2</sup>
- Asian women have increased rates of cancers of the mouth, particularly those aged 65 and over. <sup>2,5</sup>
- Despite policies to reduce cancer inequality by enhancing awareness and improving access to services especially by minority groups, there is limited mention of the disproportionate mortality from most cancers among the Irish in Britain. <sup>3,4</sup>
- The relationship between deprivation and cancer is complex and multifaceted. Certain types of cancer –

such as lung, mouth and oesophagus – are more likely to be diagnosed in the most deprived groups. For other types of cancer – such as breast and prostate – death rates are higher among the most deprived despite the fact that incidence rates are lower.<sup>2</sup>

- There is evidence of inequalities at each stage of the patient pathway, from information provision through to palliative care.<sup>2</sup>
- It is estimated that some cases of cancer could be avoided if the population maintained a healthy body weight but obesity rates vary by BME group, particularly for women. Black African (38%), Black Caribbean (32%) and Pakistani (28%) women are more likely to be obese than women from the general population (21%).<sup>2,3</sup>

## Measures to Tackle Disparities

- Health information and support should be targeted at those groups with the worst cancer incidence and mortality rates, to ensure that their service needs are met. Such information should encourage and increase knowledge of developing a healthy lifestyle.
- The above should be supported by programmes to create sustained behavioural change as too often only short term programmes are developed. The impact of such programmes should be monitored and evaluated in a timely manner and influence future health strategy. Such programmes should include cancer awareness raising sessions and events to: engage, inform and empower communities to access relevant cancer services; inform BME groups about the low uptake of screening and the impact of late diagnosis; develop support networks that provide information and advice to patients, carers and their families and meet the cultural, linguistic and religious needs of BME groups.
- Community activities which are targeted to specific communities and led by voluntary and community organisations should receive greater support and be part of a partnership approach in local areas.
- Good practice in increasing cancer awareness should be developed using examples from successful campaigns in cancer and other disease areas and such good practice should be embedded into mainstream health practice or strategy development.
- There should be a greater level of community based

screening using mobile screening facilities. Mobile units should be located in areas that are accessible to BME groups and a partnership developed with local community organisations to disseminate details of the location of mobile units in advance.

- Some cancer charities provide information that is targeted at particular BME groups both written and in other formats. Such information requires some development beyond symptom recognition to include such things as healthy eating and advice on prosthesis fitting, hair loss and lymphoedema services.
- Current programmes designed to specifically train community health champions/trainers should target BME groups (both men and women).
- There should be greater support for development of BME Expert Patients Programmes (EPP) for cancer and other areas of chronic illness, e.g. TB, HIV, diabetes.
- Low literacy could be a barrier which causes women to fail to attend screening and following up appointments.
- Smoking is a major cause of inequalities in cancer incidence and mortality. Further work should therefore be undertaken to reduce tobacco consumption rates within particular racial groups where there is evidence of higher rates of smoking: men of Bangladeshi and Indian origin and women of Irish origin. Research should also be undertaken which aims to understand which interventions are effective in smoking cessation.
- There should be a greater level of partnership work with mainstream cancer organisations that may have developed information or have targeted programmes at BME groups which have proved successful and could be replicated in a local authority area.

# Heart Disease & Related Illnesses

## Key Trends

- In more than 90% of cases, the risk of a first heart attack is related to potentially modifiable risk factors, including smoking, poor diet, obesity/overweight, and insufficient physical activity.<sup>1</sup> 'It is not better treatment but prevention - ... including tackling the wider social factors that influence health – which is likely to deliver greater overall increases in healthy life expectancy'.<sup>2</sup>
- People of South Asian and African-Caribbean origin in the UK experience differences in risk of cardiovascular disease (CVD). South Asians are at increased risk of coronary heart disease (CHD) and stroke and are particularly prone to the metabolic syndrome. African-Caribbean people have less risk of CHD but greater risk of hypertension and stroke.<sup>3</sup>
- Bangladeshis have the highest rates of ischaemic heart disease (IHD) followed by Pakistanis, Indians and other South Asians.<sup>3</sup>
- Ethnic origin should be taken into account when assessing risk and when preventing or treating CVD.<sup>3</sup>
- South Asian men are more likely to develop CHD at a younger age, and have higher rates of a heart attack.<sup>3</sup>
- The rate of cardiovascular disorder diagnosed by a doctor is high among Irish men (14.5%), which suggests that it is important to ensure that they are targeted in health promotion work around CVD.<sup>3</sup>
- Stroke is the second most common cause of death in England after heart disease and closely followed by all cancers.<sup>4</sup>
- African-Caribbean people are twice as likely to have a stroke compared with white people.<sup>4</sup>
- Stroke is a leading cause of adult disability. More than half of all stroke survivors are left dependent on others for everyday activities.<sup>4</sup>
- Whilst stroke mortality rates are falling in all Black and minority ethnic (BME) groups, they are not falling as quickly as in the general population. This has resulted in an increased gap in stroke mortality rates between such groups and the general population.<sup>4</sup>
- Behavioural risks such as smoking and physical inactivity

are more common in some racial groups. The 2004 Health Survey for England identified that 40% of Bangladeshi men and 20% of Indian men smoked compared to the national average of 24%. In women the rates ranged from 2% for Bangladeshi women to 26% for Irish women compared with the national average of 23%.<sup>5</sup>

- As with the general population, smoking prevalence in Black and other minority groups tends to decrease with age with the highest rates in those aged 16-34. Exceptions are Black Caribbean and South Asian men in whom prevalence is highest in those aged 35-54.<sup>6</sup>
- Obesity is a major risk factor for cardiovascular disease, as well as Type 2 diabetes, hypertension, metabolic syndrome, osteoarthritis and cancer. The Government's Foresight programme showed that over half of the UK adult population could be obese by 2050, resulting in total annual direct and indirect costs of obesity of approximately £50 billion in 2050.<sup>7</sup>
- Obesity rates vary by BME group, particularly for women. Black African (38%), Black Caribbean (32%) and Pakistani (28%) women are more likely to be obese than women from the general population (21%).<sup>7</sup>

## Measures to Tackle Disparities

- A coronary heart disease prevention and control service for South Asians held programmes in workplaces, mosques, temples. There was a reduction in salt intake and use of oil in cooking, and a reduction in weight and blood pressure. Such targeted programmes should be part of a continuous programme of health awareness.
- A review of the impact of the stroke (F.A.S.T)<sup>8</sup> campaign in the North West concluded that the campaign appeared to be successful in getting information to BME groups but further work was needed so that they appreciate the extent of risks in particular communities.
- Various examples of good practice are cited in literature relating to tackling coronary heart disease within BME communities. This ranges from the production of fact sheets, healthy eating guides and cookery books targeted at particular communities to DVDs that convey health messages to minority groups as well as the provision of information on greater rehabilitation following a heart attack for people of South Asian origin. One of the key problems is that there is limited evaluation of these examples of good practice and the impact they have and a lack of continuity in good practice identified.

# Human Immunodeficiency Virus (HIV)

## Key Trends

- The link between social deprivation and poor sexual health is well documented, as well as the unequal distribution of sexual ill health across the population. It is recognized that the greatest burden is borne by women, gay men, teenagers, young adults and black and other minority groups.
- HIV is an infection that disproportionately affects two key populations: Black Africans and men that have sex with men (MSM). In 2011 HIV prevalence was approximately 30 times higher for these groups than the general population in England. Factors such as acquiring infection abroad, HIV related stigma and discrimination contribute to this disparity.<sup>1</sup>
- The most deprived areas in England also have the highest HIV prevalence. 8% of Africans living with HIV in England reside in the North West.<sup>1</sup>
- Whilst about two-thirds of people living with a diagnosed HIV infection in 2011 in the UK were male, about two-thirds of Black Africans living with a diagnosed HIV infection were female.<sup>2</sup>
- An estimated 51,500 heterosexual men and women were living with HIV, of whom 10,500 were African-born men and 20,300 were African-born women.<sup>1</sup>
- Infections acquired through heterosexual contact accounted for 2,990 (48%) of new diagnoses in 2011. Furthermore, 57% of heterosexuals diagnosed in 2011 were Black African and 4% were Black Caribbean.<sup>1</sup>
- Half of the 36,360 people accessing HIV care in 2011 had acquired HIV heterosexually of whom 64% (23,210) were Black African, 4% (1,490) were Black Caribbean and 22% (8,080) were White. MSM made up 44% (31,830) of people accessing HIV care, of whom 87% (27,700) were White.<sup>1</sup>
- The number of Black Africans living with a diagnosed HIV infection has increased from 9,339 in 2002 to 25,331 in 2011. This is nearly a four-fold increase.<sup>2</sup>
- A higher proportion of older adults (aged 50 years and over) were diagnosed late (61%; 530/870) compared with younger adults (45%; 2,430/5,410).<sup>2</sup>
- Diagnosis of migrants with HIV most often occurs at a late stage of infection, when antiretroviral treatment is less likely to be effective. Late diagnosis contributes to poorer health outcomes and makes treatment less effective. A number of factors contribute to late diagnosis including lack of access to health services; negative experiences of HIV in country of origin; and lack of knowledge about HIV treatment and access to HIV services. All migrants can face barriers to accessing appropriate primary care, stemming from communication problems, social isolation and economic hardship.
- The incidence of tuberculosis (TB) among people diagnosed with HIV has declined over the past decade. Nevertheless TB incidence among heterosexuals living with diagnosed HIV was substantially greater than that in the general population in 2010. Incidence rates were highest among those diagnosed late and those not on Anti-retroviral Therapy (ART).
- Stigma, discrimination and fear of others knowing about their status dissuade some BME groups from accessing HIV services or taking the test. Stigma can lead to discrimination and other violations of human rights which affect the well-being of people living with HIV in fundamental ways. In countries all over the world, there are well-documented cases of people living with HIV being denied the right to health-care, work, education, and freedom of movement, among others.<sup>3</sup>
- Recent research (Lancet July 2012) found despite being less at risk, Black MSM were more likely to be HIV positive (15 times more than the general population). This is partly explained by the finding that HIV positive Black MSM were less likely to start HIV treatment, adhere to medication or be virally suppressed than other MSM or other ethnicities, driving new infections. The research recommends interventions that neutralise structural factors e.g. anti-gay, violence, discrimination.
- Within African communities, there is significant intolerance, discrimination and prejudice for MSM particularly within faith communities. Within MSM communities, African men can experience racism and coupled with homophobia, this can prevent African MSM from engaging in any HIV prevention programmes.
- Considerable lack of awareness and fear of HIV still exists amongst the public as well as amongst health professionals. A patient experience survey conducted by Manchester Race & Health Forum outlined experiences of patients receiving treatment. Differences in the quality of treatment and care were evident in interviews conducted

with some individuals who were diagnosed with HIV and there appears to be a lack of professionalism and ignorance about HIV transmission from some health staff who provide a service for such patients. One individual living with HIV referred to a comment made by a nurse at a local hospital: *“Put 6 gloves on for treating this one”*, which is wholly unacceptable for any health professional to make.<sup>4</sup>

- From 1 October 2012, an amendment to the Charging Regulations means that HIV treatment is no longer chargeable to any overseas visitors and is provided in the same way as treatment for other sexually transmitted infections for which NHS treatment is free to all. This amendment responds to the significant evidence on the benefits to public health of providing HIV treatment to all in clinical need.<sup>5</sup>
- With advances in treatment people are living with HIV into old age and will increasingly need greater social care support. In a study undertaken into HIV and ageing by the Joseph Rowntree Foundation three quarters of the respondents were concerned about future access to social care such as home help owing to their mobility problems. Many expressed anxiety about needing to use home care or residential care because of perceived, and sometimes experienced, prejudice and ignorance about HIV within these services.<sup>6</sup>
- People with pre-existing mental health problems are at a higher risk of HIV infection than general population, related to vulnerability, stigmatisation and health inequalities.<sup>7</sup>
- There is now a wealth of evidence that people with HIV have higher rates of depression, suicidal thoughts and anxiety and most other psychological disorders than the general population.<sup>8</sup> This is attributed to understandable psychological reactions and adjustment to diagnosis, but exacerbated by vulnerability factors in people disproportionately affected by HIV who often face many additional challenges such as homophobia and racism.
- There is now a substantial amount of literature that recognises relationship of mental health problems and poor adherence. This not only affects adherence to Highly Active Antiretroviral Therapy (HAART), but also hospital attendance and follow up. In studies about adherence, depression is cited as the strongest single predictor of poor adherence to drugs.<sup>9</sup>
- Psychological intervention can help to reduce symptoms of mental distress, as well as improving functioning and

treatment adherence and therefore can have a direct benefit on physical health. This is also substantiated by evidence of improvements in immune system functioning.<sup>10</sup>

## Measures to Tackle Disparities

- From current practice it is recognised that stigma and discrimination about HIV can be tackled through community based or community focussed initiatives that provide accurate information on HIV transmission and information on access to health care. Little however appears to have been undertaken in work places or health services to tackle stigma or discrimination in an institutional setting. This needs to be rectified, particularly in health services where some individuals living with HIV face inferior services from their GPs, dentists and hospital care. Within healthcare services codes of practice and professional conduct need to be in place and enforced to ensure there is no breach of the Equality Act or the Human Rights Act.
- There are particular challenges that individuals with HIV have to face on a daily basis and negative attitudes from health professionals could present a barrier to current policy to encourage a greater increase in testing and uptake of specialist services by particular racial groups, thereby improving health outcomes.
- Living with HIV can be associated with an individual's ability to work, financial difficulties and social problems such as residential status. The wider social determinants of health should be addressed in order to reduce these inequalities and further-more to reduce transmission among these populations. For example some people with HIV aged 50 and over (particularly Black African women) need support to stay in or re-enter the workplace where possible, including access to good, clear advice on benefit entitlements and to debt counselling and financial planning as part of long-term condition management.<sup>6</sup>
- Counselling and peer support mechanisms should be incorporated within long-term condition management strategies for older people with HIV by both funders and service providers.<sup>6</sup>
- Social care services for older people should have in place best practice policies for dealing with blood-borne conditions and should provide basic training in HIV awareness and sensitivity to all frontline and managerial staff likely to encounter service users with HIV. Those who commission and fund such services should require this as a basic quality measure.<sup>7</sup>

- Standardised guidelines on infection control should be available and applied to reduce any stigma-enabling anxieties that health care workers may have about the transmission of HIV and other illnesses. The consistent use of such guidelines will also help to protect the identities and rights of patients.
- Raising awareness through the media has always proven to be a successful way of promoting positive attitudes towards people living with HIV, but it is unclear whether current programmes are sufficient in targeting Black African and Caribbean communities at a local level.
- HIV home sampling kits should be made more available and a system in place to enable individuals to get their results with a support mechanism in place for those who have a positive diagnosis.
- A universal offer of an HIV test should be available to all patients diagnosed with TB and all people living with HIV should be routinely offered screening for TB.
- Safer sex programmes promoting condom use and HIV testing should remain a priority for men that have sex with men (MSM) and Black African and Caribbean communities to reduce on-going transmission and undiagnosed infection.
- HIV testing is a standard part of a pregnant woman's antenatal care and it is argued that increased and regular testing should be introduced. At the beginning of March 2013, the A&E department of the Royal London Hospital commenced the pilot of a routine HIV testing project – offering patients who need a blood test the choice to accept or decline a HIV test. The hospital's Tower Hamlets patient population has HIV prevalence five times higher than the national average, and in this context better detection is vital. Depending on the findings of this pilot the idea should be considered by other hospitals.

Part of the evaluation of NAHIP, which was the national HIV prevention programme for African people in England, focussed on black African people living in England who were in relationships where one person had diagnosed HIV and the other did not (i.e. HIV serodiscordant).<sup>11</sup> The evaluation identified the following ways in which services could be improved:

- Provide and continually reinforce culturally appropriate HIV prognosis information for black African people and

their partners and ensure that clinical information is clear and accessible.

- Deliver targeted one-to-one and couple-based therapeutic support for those in emotional and psychological need.
- Interventions to support and empower people with diagnosed HIV to disclose to their sexual partners need to be bolstered and significantly extended, with sharing of best practice between community and clinical providers.
- The partners of people with diagnosed HIV require tailor-made written information about HIV prognosis and transmission as well as safer conception options.
- Evidence of the effects of gender inequality among African women was substantial. Interventions to address this need to be wide-ranging, from policy advocacy and structural change, to micro-financing initiatives and provision of training to enable women to better negotiate the sexual relationships they desire.
- Instigate community development initiatives and extend interventions to boost the confidence of people with diagnosed HIV to better negotiate happy and healthy relationships.
- Promote and provide an array of male and female condoms for both risk reduction and sexual pleasure.
- Raise the profile of people's difficulties with condom use in community and clinical settings as well as increasing availability of interpersonal counselling and support to address these issues.
- Provide information, advice and support about harm reduction tactics beyond condom use, including: reducing facilitative factors during sex, having non-penetrative sex, considering viral load and infectiousness, and knowing how and when to access Post Exposure Prophylaxis (PEP).
- Provide safer conception advice to all people with diagnosed HIV and their partners while also working to ensure that safer conception options are accessible.
- Identify people whose sexual negotiation and self-efficacy needs are high and provide sustained therapeutic support.
- HIV-related stigma is widespread and its impact is considerable. Wide-ranging interventions to address HIV stigma must be strengthened and consolidated.

# Diabetes

## Key Trends

- According to Diabetes UK more than 2 million people in the UK have diabetes and people from Black and other minority groups are up to 6 times more likely to develop diabetes than white people.<sup>1</sup>
- Type 2 diabetes is up to six times more common in people of South Asian descent and up to three times more common among people of African and African-Caribbean origin. Type 2 diabetes has the highest association with obesity.<sup>1</sup>
- In 2000, the first cases of Type 2 diabetes in children were diagnosed in overweight girls aged nine to 16 of Pakistani, Indian and Arabic origin. It was first reported in white adolescents in 2002. In 2004, children of South Asian origin were more than 13 times more likely to have Type 2 diabetes than white children.<sup>2</sup>
- According to the Health Survey for England 2004, doctor diagnosed diabetes is almost four times as prevalent in Bangladeshi men, and almost three times as prevalent in Pakistani and Indian men compared with men in the general population.<sup>2</sup>
- Among women, diabetes is more than five times as likely among Pakistani women, at least three times as likely in Bangladeshi and Black Caribbean women, and two-and-a-half times as likely in Indian women, compared with women in the general population.<sup>2</sup>
- In the same survey, diabetes was generally rare among those aged 16–34, but was highest among Indian men (2%), Black African men (2%) and Irish women (1.7%).<sup>2</sup>
- Diabetes is a major risk factor for heart and kidney diseases, amputations, stroke, blindness and other conditions causing severe disability. Black women have a higher prevalence than white women for four related conditions - heart failure, coronary heart disease, hypertension, and stroke. Black men have a higher prevalence than white men for three of the four conditions - heart failure, hypertension, and stroke.<sup>1,3</sup>
- Those communities that are least well educated are more likely to have retinopathy, heart disease and poor diabetes control.<sup>4</sup>
- One in five people with a severe mental illness has diabetes.<sup>4</sup>

- Research (Saunders et al, 2007) reported a high prevalence of diabetes and a lack of knowledge of risk factors or of the implications of having the condition among Gypsies and Travellers. It also found that the risk of premature death from cardiac disease was particularly high for Gypsy and Traveller men.<sup>5</sup>
- Certain conditions are known to be more prevalent in the Irish community generally and impact on diabetes. Haemochromatosis is a particular example of a genetic condition which is much more common in people of Irish heritage. It is a disorder which is characterised by iron overload and may be undiagnosed because it is less frequently seen in the general population. Early treatment is important in preventing long-term damage and complications of the condition can also include diabetes.<sup>6</sup>

## Measures to Tackle Disparities

- Increased levels of awareness of the signs and symptoms of diabetes and its serious consequences.
- Education programmes for people with diabetes so they have a good understanding of the increased risks of heart disease, strokes and kidney disease and the importance of foot-care and retinal screening.
- Routinely disseminate information about prevention screening and support services to all BME communities using diverse and targeted media and community locations.
- Local support networks are successful in encouraging a healthy lifestyle and self-management of diabetes, and encourage regular monitoring of blood glucose, blood pressure, cholesterol levels, retinal screening, foot checks, kidney function and weight levels.
- Continuation of care to control an individual's diabetes whilst in hospital, particularly those who are elderly, disabled or suffer with a mental health problem.

# Tuberculosis (TB)

## Key Trends

- In 2011 in the UK, a total of 8,963 cases of tuberculosis (TB) were reported. TB notifications and rates have remained relatively stable since 2005.<sup>1</sup>
- The majority of non-UK born cases originated from South Asia (59%, 3694) and sub-Saharan Africa (24%, 1484).<sup>1</sup>
- Information on ethnic group was available for 96% of cases reported in 2011. The largest proportions of cases were Indian (26%, 2261), White (20%, 1762) and Black African (18%, 1557).<sup>1</sup>
- The majority of cases were notified from urban centres, amongst young adults, those from countries with high TB burdens, and those with social risk factors for TB.<sup>1</sup>
- Over half of reported TB cases had pulmonary TB.<sup>1</sup>
- The proportion of eligible patients reported to have received Directly Observed Therapy (DOT) remains low.<sup>1</sup>
- As in previous years, London accounted for the highest proportion of cases in the UK (39%, 3511), followed by the West Midlands region (11%, 1,011). The main burden of disease remains concentrated in large urban areas.<sup>1</sup>
- HPA (2011) states that common perceptions among Black and other minority groups which contribute to stigma include: belief that TB infection also means co-infection with HIV; fear that one's relatives will be 'marginalised'; belief that TB reflects poor living conditions; belief that TB results from poor hygiene.<sup>1</sup>
- There is a strong stigma attached to TB in many minority communities (HPA 2011). While communities may understand the risk of developing TB, a failure to undertake treatment or to complete courses of drugs can lead to further spread of the disease and the development of multi-drug resistant strains.
- The incidence of tuberculosis among people diagnosed with HIV has declined over the past decade. Nevertheless TB incidence among heterosexuals living with diagnosed HIV was substantially greater than in the general population in 2010. Incidence rates were highest among those diagnosed late and those not on Antiretroviral Therapy (ART).<sup>2</sup>

- Overcrowding and poor housing conditions are proven risk factors for TB transmission. Poor housing can increase the risk of getting TB, making it spread faster and making it harder for the individual and family members to recover. Overcrowding and poor ventilation make it more likely that you will catch TB.<sup>3</sup>
- There is qualitative and anecdotal data showing lower treatment completion rates among Roma TB patients. Roma women (as women and as members of an excluded minority group) face particular health system discrimination. The role of health care workers in perpetuating TB stigma could be particularly pertinent when looking at the Roma community, who may lack trust in health care systems that have sometimes excluded or mistreated them. Low TB knowledge and health literacy may also result in failure to access TB testing or treatment. Individuals may not know that they are experiencing symptoms of a potentially fatal disease or that the disease is treatable.<sup>4</sup>

## Measures to Tackle Disparities

- Creating local awareness within Black and other minority groups is vital in reducing the spread of TB, by building competency, initiating social accountability and giving confidence to TB patients to dispel the myths related to the disease.
- Approaches that emphasise work with refugee community groups are felt to be particularly important. The ability to link new arrivals with the appropriate existing social networks and communities is beneficial to health. Services catering for refugees need to work across sectors and in particular to link to housing, social services, education and the voluntary sector.
- Engagement activities with minority communities can reach out to populations who often have infrequent contact with health care authorities and help overcome widely perceived barriers in TB control. During the course of TB treatment, a patient spends little time with health care professionals and a significant portion of time with family and community members. Their surroundings need to be well informed about the illness and the importance of treatment completion to overcome patient fear, anxiety and stress. This community-centred approach has the potential to increase the referral of TB patients to health care providers, stopping the vicious cycle of infection and improving the outcome of treatment.

# Palliative Care

- Brent Council established a Health Trainers Programme (Happy Healthy Households), targeted specifically at the migrant and refugee local community. The workshops, led by community health trainers, disseminate culturally appropriate information on actions that households can take to reduce the risk of TB infection. A photography initiative was set up alongside this as a creative method of engaging the community. Community members took pictures of poor housing conditions around their houses and the resulting photographs were formatted into posters and exhibited during World TB Day 2012 at Brent Town Hall.<sup>5</sup>

## Key Trends

- Lower levels of awareness of hospice and palliative care and language differences amongst minority groups may limit their use of services.<sup>1,2</sup>
- There is evidence to suggest that people from deprived areas are less likely to use palliative services and those who do are less likely to do so in their own home. Causes of inequality in access to palliative care include: shortages of specialist staff, increased demand for services and lack of knowledge about the needs of patients from deprived areas or BME communities. BME groups are less likely to be referred to and use hospice cancer services.<sup>1,2</sup>
- A number of studies have found that BME cancer patients and their carers were not using available palliative services because they were less likely to meet their needs. They also found that there was a need for palliative services to be provided in more culturally sensitive ways in order to meet the needs of BME patients.<sup>3</sup>
- The needs of terminally ill Gypsies and Travellers are being overlooked by hospitals and GPs, according to research carried out by Jesper et al (2008). None of the people interviewed in the study (regardless of accommodation status) were able to use palliative care services for their family members. The reasons included pride in caring for a person at home, clashes with medical staff over large numbers of visitors, and limited knowledge of the services available. Enforced mobility reduced access to GPs and made it difficult to organise programmes of palliative care to support Gypsies and Travellers who wished to die at home.<sup>4</sup>
- A study which looked at fear of dying concluded that 'enabling older people to express fears about dying is likely to be important when planning supportive end-of-life care. Practitioners should not assume that fears about dying are the same in different social groups, or that extensive family support is protective against such anxiety. Older people from minority groups had more anxieties about dying than others, and were more likely to express fear the more extensive their family support'. These findings have implications for commissioners and practitioners of primary and secondary care.<sup>5</sup>
- The Marie Curie Cancer Care launched a pilot project

in 2006 (Delivering Choice Programme) which aimed to improve palliative care access to BME groups through the appointment of a link worker. The programme identified that interpreters felt they did not know enough about end of life care and needed support, particularly after delivering bad news and in discussing preferences for where people wanted to be cared for and die.<sup>6</sup>

- There has been little work to date addressing spiritual care for BME populations, despite indications that some racial groups have a strong reliance on spiritual belief and practice. In particular, there is little guidance for palliative care services on how to meet the spiritual and cultural needs of people from BME groups. Specific challenges include a lack of evidence to inform service provision (e.g. evaluated service models and spiritual care services), and barriers to BME groups accessing palliative care (e.g. mistrust of medical institutions, fears of racism and misperceptions of palliative care).<sup>7</sup>
- Allowing a family member to die at home may be deemed unacceptable to some racial groups and may differ between generations.

## Measures to Tackle Disparities

- A simple means of screening for spiritual needs should be integrated into routine patient assessment on admission. This ensures that religious affiliation and appropriate faith leader (if applicable) are recorded in patient records, along with other cultural/ faith needs. This should recognise that patients with no formal religion may nevertheless have spiritual needs.
- Patients should be offered a range of spiritual resources, including access to a range of appropriate faith leaders, a 'quiet space', support groups, one-on-one counselling and other therapies.
- Assessment of spiritual wellbeing/ spiritual needs should be undertaken with consent and in a way which respects patients' personal boundaries and needs for information and ensures assessment results in culturally appropriate responses to spiritual need.<sup>7</sup>
- Encourage BME spiritual leaders/ faith groups to educate members of local palliative care teams regarding the spiritual needs of local BME populations and the resources/ support available. This should be facilitated by inviting spiritual leaders to visit the unit and

attend training events and offering mutual education, training and support by palliative care and local community and faith groups on an ongoing basis.<sup>7</sup>

- Referral systems should be in place and used by palliative care teams to refer to local BME faith groups/ spiritual leaders who have been trained in palliative care. Equally faith groups/spiritual leaders should be encouraged to refer individuals to palliative care services.
- The availability of spiritual care services should be promoted in a range of formats (e.g. through leaflets in multiple languages, large print and Braille), and be available throughout a person's course of treatment. Additionally information should be provided of support groups established for patients from a minority group.
- There should be an organisational commitment to cultural sensitivity among staff members which recognises the complexity and diversity of culturally specific beliefs and practices.
- Training should be provided to interpreters to ensure they have sufficient knowledge about end of life care, delivering bad news and discussing preferences for where people wanted to be cared for and die.<sup>6</sup>
- The availability of spiritual care services should be promoted in a range of formats (e.g. through leaflets in multiple languages, large print and Braille), and be available throughout a person's course of treatment. Additionally information should be provided of support groups established for patients from a minority group.
- There should be an organisational commitment to cultural sensitivity among staff members which recognises the complexity and diversity of culturally specific beliefs and practices.
- Training should be provided to interpreters to ensure they have sufficient knowledge about end of life care, delivering bad news and discussing preferences for where people wanted to be cared for and die.<sup>6</sup>

# Disability and Health

## Key Trends

- There are at least one million disabled people who are Black or from a minority ethnic background in the UK – and this number is growing.<sup>1</sup>
- There tends to be a lower prevalence of impairments amongst BME disabled people of working age, but over the age of 40 prevalence increases dramatically.<sup>1</sup>
- Pakistani and Bangladeshi groups have the highest rates of disability in old age of any ethnic group.<sup>1</sup>
- 44% of BME disabled people live in household poverty, compared with 32% of all disabled people and 17% of the population as a whole.<sup>1</sup>
- Individual incomes for BME disabled people are 30% lower than for the general population.<sup>1</sup>
- Less than 4 in 10 BME disabled people of working age are in employment.<sup>1</sup>
- Many disabled people face stigma in their daily lives, meaning that they are negatively marked out by their impairments. Research relating to minority groups also reports their experiencing stigma that remains particularly acute within some minority communities. Additionally social isolation was especially evident for women, migrants and carers. In contrast with other research there was little to suggest that BME disabled people can rely on their extended family to provide care.<sup>1</sup>
- Services are not yet fully inclusive for disabled people from ethnic minority backgrounds, and many report poor experiences of accessing statutory and voluntary services.<sup>1</sup>
- Given the size and expected growth of the BME disabled population, it is also a demographic imperative that their needs are more fully addressed by policy. Person-centred, local, and flexible services would be more valuable and accessible for BME disabled people.
- Individuals from BME communities are often under-represented in the uptake of learning disability services. The prevalence of a learning disability, when compared to the rest of the population, is three times higher than average for South Asian people and significantly higher

in the African Caribbean community (Amzi et al, 2006). Yet in a local study conducted by INLOGOV in 2012 only 0.2% of clients were recorded as being from South Asian backgrounds, and 0.05% as Black Caribbean.<sup>2</sup>

- BME people with learning disabilities and their families continue to experience inequalities in health and social care despite various efforts to improve engagement.<sup>3</sup>
- Understanding and responding to a 'learning disability' continues to be an issue within some communities, affecting whether and how people come forward for support.<sup>4</sup>
- In 2008, Deaf Education Advocacy Fellowship (DEAF) conducted a piece of research to canvas the views and experiences of deaf BME individuals about mainstream services. Sixty percent of respondents identified problems in accessing healthcare services. With the transformation of the health system, there is an opportunity to improve access for people.<sup>5</sup>

DEAF identified a lack of exposure to other British Sign Language (BSL) users in their community as many deaf BME people have a disadvantage in their ability to use BSL functionally. This has an impact when accessing information via a Sign Language Interpreter as their understanding of standard BSL is often poorer than their non-BME peers. Much of the signed communication used in the home environment will be specific to their family members, who through time have developed many 'home signs' to aid their domestic communication needs (e.g. drink, dinner, bedtime).<sup>5</sup>

- Many deaf people from minority backgrounds feel isolated and do not have peer networks of support available, especially in rural areas. This means that they are often isolated from access to specialist services that are available to deaf people.<sup>5</sup>
- There is a national shortage of Sign Language Interpreters from a BME background. This means that there is a lack of awareness amongst such professionals of culturally specific signs used and a lack of knowledge of cultural issues that is needed to ensure a positive experience within mainstream services. This means that challenges exist even when provision has apparently been made. Additional measures will need to be put in place within new health structures such as Healthwatch if they are to engage with all communities.<sup>5</sup>

- People from Black and other minority communities are at greater risk of some of the leading causes of sight loss such as glaucoma.<sup>6</sup>
- Asian people have a greater risk of developing cataracts compared to the Black population and white population.<sup>6</sup>
- Black and Asian populations have a greater risk of developing diabetic eye disease compared to the white population.<sup>6</sup>
- 59% of service users of Henshaws Society for Blind People are over the age of 65 and 15% of their service users are from BME backgrounds – higher than the 8% UK average.<sup>6</sup>

## Measures to Tackle Disparities

- Joint Strategic Needs Assessments should be used as the basis to collect information on the needs of different local BME communities and people with disabilities from these communities.<sup>7</sup>
- BME disabled people's needs and views have often fallen between the two areas of disability and race equality policy. These two policy areas need to be integrated to develop effective support for BME disabled people.<sup>1</sup>
- Work on the needs and issues of people with learning (and other) disabilities from BME communities should be given the prominence that it merits. In many places such communities should not be regarded as minority at all but central to the responsibilities of the local statutory agencies.<sup>3</sup>
- It is important to be clear about what monitoring is in place to check how well people with learning disabilities from BME communities are accessing support services. It is vital that statutory agencies fulfil their responsibility to undertake Equality Impact Assessments on services and developments. These assessments need to be rigorous and knowledgeable in reflecting the issues experienced by people with learning disabilities from BME communities, and their families.<sup>3</sup>
- There was concern that agencies should make additional efforts to identify and then work appropriately with those who were really vulnerable – such as older

carers - who could be from any community. Older family carers have greater need for structured translation and interpretation support, suggesting that targeting of resources could help. The importance of local support to overcome language barriers needs to be properly addressed on a continuing basis as local BME communities develop and change.<sup>3</sup>

- There is a greater need for statutory agencies to be more aware of the range of needs of disabled people. For example there needs to be critical health awareness in BSL in order for deaf BME people to gain access to health information in their first language. This is essential in enabling deaf BME communities to understand their rights and ensure equitable access to health services.<sup>5</sup>
- It is essential to source appropriately trained and experienced interpreters who have worked with the deaf BME community in order to ensure effective access to mainstream services. For example, it may be necessary to utilise the service of a deaf BME Relay Interpreter, who would be able to culturally mediate this information from differing BME backgrounds. This would mean that any standard BSL/English interpreter could be used alongside such a specialist provision, which in turn would not unnecessarily delay the waiting time for the deaf person's health appointment.<sup>5</sup>
- The emerging new health structures, such as Healthwatch, should engage with specialist advocacy services to ensure that appropriate support is being given to disabled people.<sup>5</sup>

# Race Equality & Human Rights

From April 2013, new legal duties set out in the Health and Social Care Act will come into force. In exercising their functions, NHS England and CCGs must have regard to the need to reduce inequalities, both in terms of access and around health outcomes of patients. They must also secure integrated provision of services, within the health system and beyond it, where this would reduce inequalities in access or outcomes. In addition, there are duties on the Secretary of State, Monitor and NHS Foundation Trusts to integrate these duties into their plans and report progress on them annually.

The Equality Act 2010 imposed a general equality duty on public authorities and other bodies, when exercising public functions, to consider the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity and to foster good relations. There is therefore a responsibility on agencies established as a result of the Health & Social Care Act 2012 to have regard to the need to tackle race inequality in access, treatment and outcomes of Black and other minority patients when carrying out their functions. This relates to national bodies such as NHS England, the Care Quality Commission (CQC), MONITOR and Healthwatch England. At a local level this is relevant to, local authorities, Clinical Commissioning Groups (CCGs), individual trusts and the local Healthwatch.

Additionally such bodies have a legal duty to comply with the provisions of the Human Rights Act (HRA) in everything they do, and failure to comply is both a violation of international human rights commitments and unlawful under the HRA. The Act also imposes some 'positive obligations' on public bodies to take proactive steps to secure people's human rights. This includes ensuring that individuals are not neglected in hospital and that patients have food, water and necessary medical treatment and managing the care of individuals with a mental health illness.

The Equality & Human Rights Commission undertook a Human Rights Review in 2012 to assess how well Britain was meeting its human rights obligations under the European Convention of Human Rights and the Human Rights Act 1998 (HRA).

The review stated that health and social care commissioners and service providers do not always understand their human rights obligations and the approach of regulatory bodies was not always effective in identifying and preventing human rights abuses.

Additionally it showed that some groups that are socially marginalised or particularly vulnerable do not enjoy full protection of their rights.

When looking at the issue of human rights of Black and other minority groups in the provision of health services the over-representation and treatment of such groups in acute mental health settings is of significant concern. The CQC has highlighted a number of human rights issues relating to the use of Community Treatment Orders (CTOs), including concern about appropriate usage, over-representation of Black and other minority groups among those issued with CTOs and a lack of consistent practice when involving patients in care decisions, such as the details of their CTO. The CQC also highlighted a number of other factors which have an adverse impact on patients' human rights. For example, in some facilities inadequate staffing ratios affected people's rights to fair and dignified treatment. The rights of vulnerable adults, and children and young people to dignified treatment, and to be safe and protected from harm, were adversely affected by the lack of Child and Adolescent Mental Health Services (CAMHS) units, or of single-sex provision in some facilities.

Compulsion in treatment, and the implications for people's human rights, is a particular issue for mental health services. Men, especially Black men, appear to face a higher degree of compulsion in seeking or receiving care for their mental health problems. The consequence of this is that Black men are more likely to be sectioned under the Mental Health Act or to be referred for treatment via the criminal justice system. In its annual report on the use of the Mental Health Act in 2010, the CQC stressed the importance of proportionality where human rights might be an issue. Black and other minority communities were also at greater risk of compulsory admission to mental health services and were over-represented in high security units. In its 2011/12 review of the Mental Health Act the CQC acknowledged a recurring theme in relation to Black and other minority groups and stated:

*'The human rights of patients are often affected by controlling practices that only seem to serve the hospital's needs. Hospitals have a difficult task in balancing the realities of detention and compulsory treatment with the requirement that they provide services according to a principle of least restriction on patients. But it has proved all too easy for cultures to develop in which blanket rules deny people their basic rights – especially the right to dignity.'*

# Conclusion

In its review a number of examples of breaches of the HRA were identified including the imposition of a blanket ban on mobile phone usage by detained patients that take no account of the patient's right to respect for private life and correspondence under Article 8 of the HRA. An individual's right to health is reflected in the following articles of the HRA:

- Article 2: the right to life
- Article 3: prohibition on torture, inhuman and degrading treatment
- Article 5: right to liberty
- Article 6: right to a fair trial
- Article 8: right to respect for family and private life, home and correspondence
- Article 14: non-discrimination

## Measures to Tackle Disparities

- The CQC recommended that NHS England, local authorities, clinical commissioning groups and specialist commissioners must commission services that guarantee a person's dignity, recovery and participation. Clinical commissioning groups and local authorities must ensure that local needs assessments for community services and commissioned models of care are informed by an understanding of their statutory duties under the Act and by the experiences of people who use services.
- Each CCG should develop an equality and human rights strategy with a related action plan which sets out how it will take steps to eradicate race inequalities. The policy should emphasise the necessity of collecting equality data to monitor the impact of the equality policy as well as to make full use of equality impact assessment in determining the best approach to introducing a new service or changing existing provision.
- All CCG board members and staff should receive training on equality and human rights and their application in the NHS.
- In the commissioning of services CCGs, local authorities and NHS England should put a greater emphasis on setting out contractual requirements around equality, diversity and inclusion which lead to improved health outcomes as well as improved equality monitoring. This is equally applicable to joint commissioning with the Health and Wellbeing Boards.

It is extremely worrying that disparities in health of Black and other minority groups are still evident, and with some health conditions that difference is explicit and has been the case for some time. A challenge remains for newly established bodies, responsible for commissioning health services, such as CCGs and NHS England to ensure that the needs of Black and other minority communities are reflected in their commissioning plans and outcomes are monitored to ensure parity in access, treatment and outcomes. Equally there is an expectation that local public health teams will engage and involve Black and other minority groups in their local area in the development and delivery of prevention strategies that relate to those conditions that are prevalent in their communities.

It was clear from the literature review undertaken into particular health conditions that there is a significant amount of good practice that exists in tackling health disparities. Equally there were examples of models of engagement with black and other minority groups that resulted in positive outcomes. These models, however, continue to be ignored or are only supported on a short term basis and are not properly integrated into services and prevention programmes being delivered. Additionally, good practice exists in the work conducted by national charities but there is limited evidence of partnership working with the statutory health sector. This situation needs to change if health disparities of Black and other minority groups are to be seriously tackled. There is a need for improved outreach to Black and other minority communities using a range of methods and in partnership with national charities, where applicable. This programme of work should not be short term but a continuous programme of activity that is embedded into the delivery plan of a health and wellbeing strategy.

It should be recognised that voluntary and community organisations have had a significant role, over the years, in identifying particular health needs in Black and other minority communities as well as providing local health and wellbeing services. This expertise needs to be acknowledged and used in developing local strategies to enable an improvement in race inequalities that exist. Additionally, local Healthwatch bodies need to take the opportunity to develop their relationships with Black and other minority groups as well as have a greater focus on tackling inequalities. The evidence on racial disparities that exist at a national and local level needs to be used to challenge how health and social care services are delivered and Healthwatch should have a significant role in using such evidence to influence commissioning and the delivery of appropriate services.

# References

## Mental Health

1. Care Quality Commission, (2009) Count me in, Results of the 2009 national census of inpatients on supervised community treatment in mental health and learning disability services in England and Wales.
2. Care Quality Commission (2011), Monitoring the Use of the Mental Health Act in 2011/12
3. IPCC (2010) Police Custody as a 'Place of Safety'. Examining the use of Section 136 of the Mental Health Act 1983 [http://www.ipcc.gov.uk/Documents/section\\_136.pdf](http://www.ipcc.gov.uk/Documents/section_136.pdf)
4. Wilkins D, Kemple M (2010), Delivering Male: Effective practice in male mental health, Men's Health Forum
5. Mtetezi,(2007) Developing Mental Health advocacy with African and Caribbean men
6. Fitzpatrick, M., 2005, Profiling mental health needs: what about your Irish patients? British Journal of General Practice, October 2005. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1562353/>
7. Bracken P, Greenslade L, Griffin B & Smyth M (1998) Mental health and ethnicity: an Irish dimension British Journal of Psychiatry 172 pp.103-105
8. UCLAN (2008) Report Of The Community Led Research Project Focusing On The Mental Health Needs Of Irish Women In Birmingham <http://www.better-health.org.uk/resources/research/report-community-led-research-project-focusing-mental-health-needs-irish-women-bi>
9. J Attenbury, (August 2010) Fair Access for All? Gypsies and Travellers in Sussex, GP Surgeries and Barriers to Primary Healthcare
10. Shelter, (February 2008) Good Practice Guide: Working with Housed Gypsies and Travellers
11. Health & Safety Executive (2009) Health and Safety Statistics 2008/09, Health and Safety Executive
12. Mind (2009) A Civilised Society, Mental Health Provision for Refugees and Asylum-seekers in England and Wales
13. NICE (2010) Depression in adults with a chronic physical health [www.rcpsych.ac.uk/files/samplechapter/NICEdepressionCPHP-SC.pdf](http://www.rcpsych.ac.uk/files/samplechapter/NICEdepressionCPHP-SC.pdf)
14. Kings Fund, Long-term Conditions and Mental health, The cost of co-morbidities, [www.kingsfund.org.uk/.../long-term-conditions-mental-health-cost-](http://www.kingsfund.org.uk/.../long-term-conditions-mental-health-cost-)
15. NAT (2010) Psychological Support for People living with HIV, National Aids Trust [www.nat.org.uk/.../Psychological%20support%20for%20plwh.pdf](http://www.nat.org.uk/.../Psychological%20support%20for%20plwh.pdf)
16. RNIB, Sight Loss Facts and Figures (Online) [http://www.rnib.org.uk/professionals/socialcare/services/olderpeople/research/Pages/olderpeople\\_and\\_sight\\_loss\\_facts\\_and\\_figures.aspx](http://www.rnib.org.uk/professionals/socialcare/services/olderpeople/research/Pages/olderpeople_and_sight_loss_facts_and_figures.aspx)
17. Fountain J, Hicks J (2010) Delivering Race Equality in Mental Health Care: report on the findings and outcomes of the community engagement programme 2005-2008, University of Central Lancashire <http://www.better-health.org.uk/resources/research/delivering-race-equality-mental-health-care-report-findings-and-outcomes-community>
18. Marmot M. Fair society, health lives: the Marmot review; strategic review of health inequalities in England post-2010. The Marmot Review 2010

## General References:

The Schizophrenia Commission (2012) The Abandoned Illness: A report from the Schizophrenia Commission. London: Rethink Mental Illness.

## Older People affected by Dementia

1. Statistics – Alzheimers Society, <http://www.alzheimers.org.uk/statistics>
2. SCIE Research Briefing: 35, Black and minority ethnic people with dementia and their access to support and services, March 2011, [www.scie.org.uk/publications/briefings/briefing35/](http://www.scie.org.uk/publications/briefings/briefing35/)
3. Meeting the needs of Irish elders: Findings from the mapping of activities of Irish organisations in England & Wales. London: Federation of Irish Societies, 2010. Older Irish people with dementia in England - Federation of Irish [http://www.irishbritain.org/demo/files/files/Older\\_Irish\\_people\\_in\\_England\\_with\\_dementia%5b1%5d.pdf](http://www.irishbritain.org/demo/files/files/Older_Irish_people_in_England_with_dementia%5b1%5d.pdf)
4. Royal College of psychiatrists (2009) Psychiatric Services for Black and minority ethnic older people, Royal College of psychiatrists
5. Mukadam, N., Cooper, C. and Livingston, G.(2010) 'A systematic review of ethnicity and pathways to care in dementia', International Journal of Geriatric Psychiatry, <http://dx.doi.org/10.1002/gps.2484>

### General references:

Tilki M, Mulligan E, Pratt E, Halley E, Taylor E, (2011) 'Older Irish people with dementia in England. Advances in Mental Health'. 9,(3) : 221-232

Adelman, S (2010) 'Prevalence and recognition of dementia in primary care: comparison of older African-Caribbean and white British residents of Haringey', PhD thesis, University College London.  
<http://eprints.ucl.ac.uk/19622/1/19622.pdf>

Lawrence, V, Murray, J, Samsi, K and Banerjee, S (2008), 'Attitudes and support needs of Black Caribbean, South Asian and White British Carers of people with dementia in the UK', British journal of Psychiatry, vol 192, no 9, 240-246  
<http://bjp.rcpsych.org/content/193/3/240.full>

---

## Cancer

1. Evidence to March 2010 on cancer inequalities in England, [www.ncin.org.uk/equalities](http://www.ncin.org.uk/equalities)
2. Cancer and Health Inequalities: An introduction to current evidence, Cancer Research UK (Online)
3. Federation of Irish Societies (2011) Cancer Awareness within the Irish community
4. Middlesex University,( 2009) The Forgotten Irish, [eprints.mdx.ac.uk/6350/1/Tilki-Forgotten\\_Irish.pdf](http://eprints.mdx.ac.uk/6350/1/Tilki-Forgotten_Irish.pdf)
5. National Cancer Intelligence Network and Cancer Research UK (2009). Cancer incidence and Survival by Major Ethnic Group, England 2002-2006

---

## Heart Disease and Related Illnesses

1. NICE (2010). Prevention of cardiovascular disease at population level
2. DH (2010) Healthy Lives, Healthy People – Our strategy for Public Health in England
3. The British Heart Foundation (2007) Ethnic differences in cardiovascular risk Fact file No.5 (2007)
4. British Heart Foundation and the Stroke Association (2009) Stroke Statistics 2009
5. Health Survey for England 2004: Health of Ethnic Minorities Full Report, [www.hscic.gov.uk/pubs/hse04ethnic](http://www.hscic.gov.uk/pubs/hse04ethnic)
6. Cancer Research UK:Smokers by Ethnic Group  
<http://www.cancerresearchuk.org/cancer-info/cancerstats/types/lung/smoking/lung-cancer-and-smoking-statistics>
7. McPherson K et al (2007), Tackling Obesities :Future Choices – Project Report – Modelling Future Trends in Obesity & Their Impact on Health, Government Office for Science
8. NHS NW, (March 2010) Stroke Insight Research on Act F.A.S.T Campaign and BME Communities

## Human Immunodeficiency Virus (HIV)

1. HIV in the United Kingdom: 2012 Report, Health Protection Agency  
<http://www.nat.org.uk/HIV-Facts/Statistics/Latest-UK-statistics/Black-Africans.aspx#sthash.wkHoZMZB.dpuf>
2. National Aids Trust (NAT), HIV Facts, <http://www.nat.org.uk/HIV-Facts/Statistics/Latest-UK-Statistics.aspx>
3. UNAIDS (2005) HIV Related Stigma, Discrimination and Human Rights Violation,
4. Miller D, (2012) Patient Experience Survey: Black and Other Minority Groups in Manchester, BHA for Health Equality
5. DH (2012), HIV Treatment for Overseas Visitors – Guidance for the NHS
6. Joseph Rowntree Foundation (2010), A National Study of Ageing and HIV (50 plus), [www.jrf.org.uk/publications](http://www.jrf.org.uk/publications)
7. Petrak, J & Miller, D. 2002 Psychological management in HIV infection in The Psychology of Sexual Health (eds D. Miller & J. Green) Oxford, Blackwell Science.
8. Zinkernagel, C, Taffe, P, Rickenbach, M, Amiet, R, Ledergerber, B, Volkart, A.C, Rauchfleisch, U, Kiss, A, Werder, V, Vernazza, P and Battegay, M. (2001) Importance of mental health assessment in HIV infected outpatients. Journal of Acquired Immune Deficiency Syndromes, 28, 240-249.~
9. Gonzalez, J, Batchelder, A, Psaros, C & Safren, S. 2011 Depression and HIV treatment nonadherence. Journal of Acquired Immune Deficiency Syndromes, 58, 2, p181-187.
10. Carrico, A & Antoni, M 2008 Effects of psychological interventions on neuroendocrine hormone regulation and immune status in HIV positive persons: a review of randomised control trials. Psychosomatic Medicine 70, p575-584.
11. PLUS ONE – HIV sero-discordant relationships among black African people in England, Sigma Research, 2011.

### General Reference:

A Framework for Sexual Health Improvement in England, DH, March 2013

---

## Diabetes

1. Diabetes UK (2012) Key statistics on Diabetes, April 2012
  2. Health Survey for England 2004: Health of Ethnic Minorities Full Report [www.hscic.gov.uk/pubs/hse04ethnic](http://www.hscic.gov.uk/pubs/hse04ethnic)
  3. Diabetes UK, State of the Nation 2012
  4. Diabetes UK (2006), Diabetes and the Disadvantaged: Reducing Health Inequalities in the UK
  5. Roberts A, Adkins J, Lewis H et al (2007), Conference presentation: Coronary Heart Disease and Mental Health in Gypsies and Travellers in Wrexham: Redressing the Balance, CPHVA Annual Conference
  6. Irish Haemochromatosis Association
- 

## Tuberculosis (TB)

1. Health Protection Agency (HPA) – Tuberculosis in the UK: 2012 Report, July 2012
2. HIV in the United Kingdom: 2012 Report, Health Protection Agency  
<http://www.nat.org.uk/HIV-Facts/Statistics/Latest-UK-statistics/Black-Africans.aspx#sthash.wkHoZMZB.dpuf>
3. Better Housing Briefing 20: Tackling the prevalence of Tuberculosis amongst poorly housed minority ethnic communities in London – [www.better-housing.org.uk](http://www.better-housing.org.uk)
4. Open Society (2007) Confronting a hidden disease: TB in Roma communities,
5. Archive UK (online case study), [www.archiveuk.org](http://www.archiveuk.org)

## Palliative Care

1. Firth S, (2001), Wider horizons: Care of dying in multicultural society. London: National Council for Hospice and Specialist Palliative Care Services.
  2. Gunaratnam, Y,(2007) 'Improving the Quality of Palliative Care', Race Equality Foundation
  3. Evidence to March 2010 on cancer inequalities in England, [www.ncin.org.uk/equalities](http://www.ncin.org.uk/equalities)
  4. Jesper E et al,(2008) 'A qualitative study of the health experience of Gypsy and Travellers in the UK with a focus on terminal illness, <http://wrap.warwick.ac.uk/267/>
  5. Bowling A, Iliffe S, Kessel A, Higginson IJ, (2010), Fear of dying in an ethnically diverse society: cross-sectional studies of people aged 65+ in Britain, Department of Primary care and Population Health, University College London
  6. Website case studies:  
<http://www.endoflifecare.nhs.uk/search-resources/resources-search/case-studies/imported-case-studies/improving-palliative-care-access-for-bme-communities.aspx>
  7. Kings College London (2009), Spiritual care recommendations for people from Black and minority ethnic (BME) groups receiving palliative care in the UK – with special reference to the sub-Saharan African population  
<http://www.csi.kcl.ac.uk/files/Spiritualcarerecommendations-Executivesummary.pdf>
- 

## Disability and Health

1. Equalities National Council/SCOPE,(March 2012), Overlooked Communities, Overdue change: how services can better support BME disabled people. <http://www.scope.org.uk/drupal-fm/213/download>
  2. Tonks K, Staite C,(2012), Learning disabilities & BME Communities: Principles for Best Practice. INLOGOV Briefing, June 2012.
  3. Poxton R, Taylor J, Brenner D, Cole A, Burke C, (July 2012), 'Reaching Out to people with learning disabilities and their families from Black and Minority Ethnic Communities'. Foundation for People with Learning Disabilities
  4. Race Equality Foundation Briefing Paper,(2010), 'Towards race equality in advocacy services: people with learning disabilities from black and minority ethnic communities'
  5. Silver D, Patel E, (2011), The Impact of Health Reform on Deaf BME Communities, 2011. One NW and Deaf Education Advocacy Fellowship  
<http://www.onenorthwest.org.uk/doc.asp?ID=115&Doc=/documents/One%20North%20West%20and%20DEAF%20Briefing%20vfinal.doc>
  6. RNIB, Department of Health, Henshaws, McLaughlan, Eyecare Trust, UK Vision Strategy (2013)
  7. Calton R, (2012), Life Support: The provision of social care for people with Hearing Loss
- 

## Health and Human Rights

1. Health & Human Rights Review 2101, Equality & Human Rights Commission  
<http://www.equalityhumanrights.com/human-rights/our-human-rights-work/human-rights-review/the-review/>
2. Monitoring the Mental Health Act in 2011/12, Care Quality Commission
3. UNAIDS (2005) HIV Related Stigma, Discrimination and Human Rights Violation

**BHA** *for equality  
in health  
and social care*

BHA  
Democracy House  
609 Stretford Road  
Old Trafford  
Manchester  
M16 0QA

Telephone: 0845 450 4247  
Fax: 0845 450 3247  
Email: [info@theBHA.org.uk](mailto:info@theBHA.org.uk)  
Website: [www.theBHA.org.uk](http://www.theBHA.org.uk)

BHA is a limited company registered in Cardiff  
Company No. 3818058  
Registered Charity No. 1079727

Issued: May 2013  
Designed by: Ben Easterbrook, BHA