



Report: Palliative and end of life care for Black, Asian and Minority Ethnic (BAME) groups in the UK

Demographic profile and evidence on the current state of palliative and end of life care provision

Executive Summary

Background to this report

There is growing evidence that ethnic and cultural differences can influence patterns of advanced disease, illness experiences, health care seeking behaviour, and the use of health care services. The End of Life Care Strategy highlights that although much has been done, inequalities still exist in the care that different groups of people receive at the end of life. In light of increasing national and international evidence of low use of end of life care services among Black, Asian and Minority Ethnic (BAME) groups it is critical to understand the influence of ethnicity and culture in the context of end of life care and to examine strategies and recommendations to address inequalities. This report therefore provides an evidence-base to understand the profile of BAME populations living in the UK, and identifies their unmet needs regarding palliative and end of life care. First, we describe the characteristics of BAME groups in the UK (ethnic groups by age and geographical region, religions, languages and characteristics of the foreign born population). We examine to what extent the BAME populations are expected to increase and grow older in the next few decades according to the most recent population projections. Second, we appraise the state of palliative and end of life care provision for BAME groups and present recommendations for policy, practice and research available from the literature. Last, based on these two sources of information we present further recommendations with the aim to improve care for BAME populations in the UK.

What can the Census tell us about BAME groups in the UK?

Ethnicity

According to the 1991, 2001 and 2011 UK Censuses, the UK has become more ethnically diverse in the past 20 years. This was especially true in England where both the numbers and proportions of people from BAME groups (all ethnic groups other than White British) have increased; in 2011 they represented a fifth of the population (10.7 million people) (Table 1). Wales, Northern Ireland and Scotland also experienced changes to the ethnic composition of their populations (especially due to a wave of migration since 2000). In England, Other White (4.6%), Indian (2.6%) and Pakistani (2.1%) were the largest BAME groups in 2011. However, Census data identifies that ethnic groups are not equally distributed across England. For example, while in London less than half of the population was White British, in the North East they represented over 90% of the population.

Religion

The numbers and proportions of people who described themselves as Christian in England have decreased from 2001 to 2011 (from 71.7% or over 35 million to 59.4% or over 31 million), while numbers and proportions of those having no religion almost doubled (reaching 13 million people in 2011) (Box 1). Numbers and proportions of people from religions other than Christian have also increased, with Muslims being the second largest religious group in 2011. Certain religious groups tend to concentrate in particular areas, such as Muslims in London, Bradford, Luton, Slough and Birmingham; Hindus in London and Leicester; Buddhists and Jewish people in London.

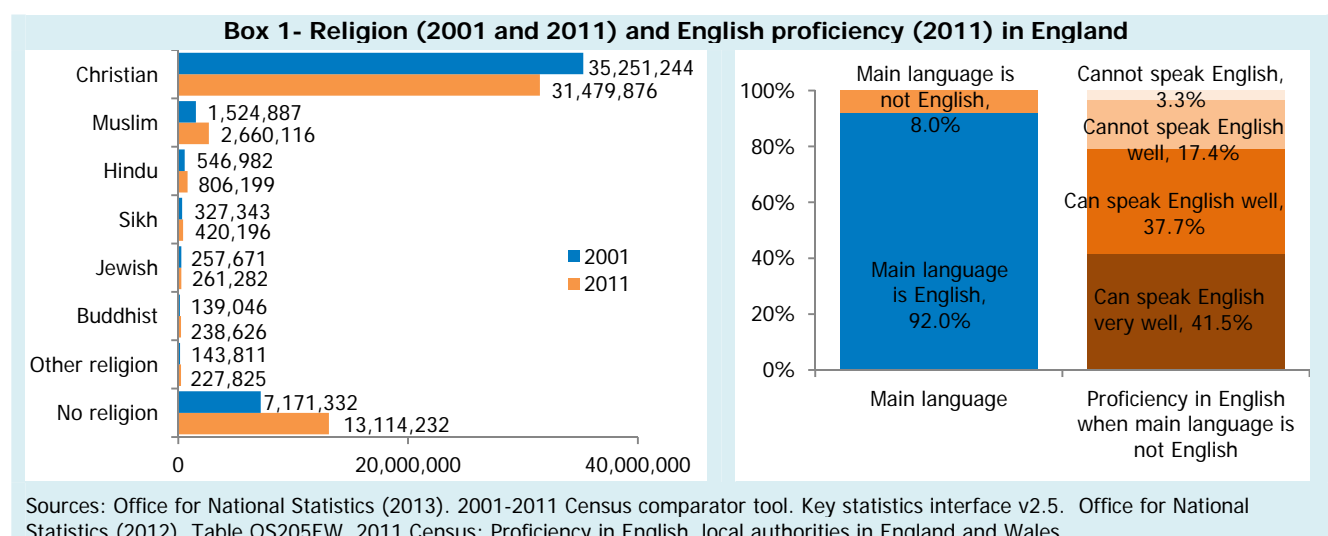
Table 1 - Population by ethnic group in England in 2001 and 2011

Main groups	Subgroups	2001 n(%)	2011 n(%)
White¹	English/Welsh/Scottish/Northern Irish/British	42,747,136 (87.0)	42,279,236 (79.8)
	Irish	624,115 (1.3)	517,001 (1.0)
	Gypsy or Irish traveller	N/A	54,895 (0.1)
	Other White	1,308,110 (2.7)	2,430,010 (4.6)
Mixed/multiple ethnic groups	White and Black Caribbean	231,424 (0.5)	415,616 (0.8)
	White and Black African	76,498 (0.2)	161,550 (0.3)
	White and Asian	184,014 (0.4)	332,708 (0.6)
	Other Mixed	151,437 (0.3)	283,005 (0.5)
Asian/Asian British	Indian	1,028,546 (2.1)	1,395,702 (2.6)
	Pakistani	706,539 (1.4)	1,112,282 (2.1)
	Bangladeshi	275,394 (0.6)	436,514 (0.8)
	Chinese	220,681 (0.4)	379,503 (0.7)
	Other Asian	237,810 (0.5)	819,402 (1.5)
Black/African/Caribbean/Black British	African	475,938 (1.0)	977,741 (1.8)
	Caribbean	561,246 (1.1)	591,016 (1.1)
	Other Black	95,324 (0.2)	277,857 (0.5)
Other	Arab	N/A	220,985 (0.4)
	Any other ethnic group	214,619 (0.4)	327,433 (0.6)
Total	All ethnic groups	49,138,831 (100)	53,012,456 (100)

¹ Ethnic groups are the ones used by the 2011 Census. Comparison between Censuses is limited (see methods Section). Sources: Office for National Statistics (2003). Table KS06: Ethnic group .Office for National Statistics (2012). Table KS201EW. Ethnic group

Language

When it comes to language, over 90% of people had English as their first language in 2011 (Box 1), but one out of five people who did not have it as a principal language either could not speak English well or could not speak it at all (over 800,000 people in England), which could indicate a demand for translation services when in receipt of care.



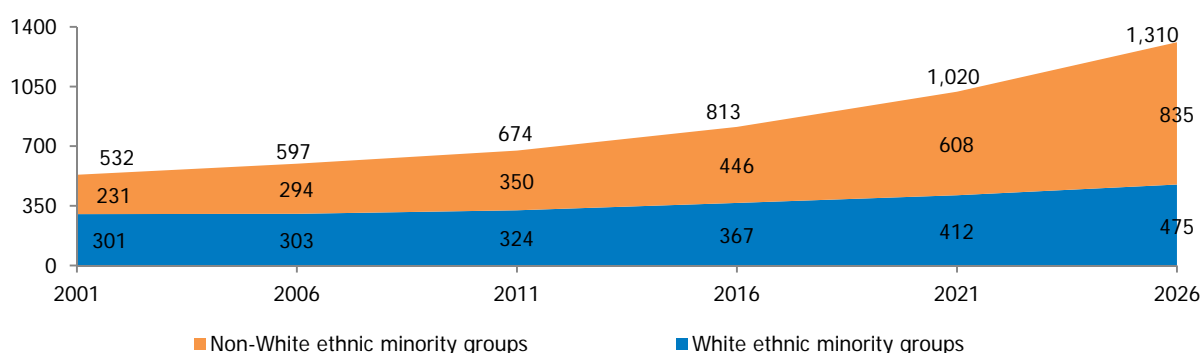
Age

The relationship between those from BAME groups and age is important; data for England and Wales show that in mid-2009 nine out of 10 people over the age of 65 were White British (over 7 million people), but there have been substantial increases in the number of older people from BAME groups (reaching over 700,000 people in 2009, with wide variation across groups) when comparing mid-2001 to mid-2009. About a third of the Irish population was aged 65+ in mid-2009 (the highest proportion across all BAME groups), followed by the White British (18.0%) and the Black Caribbean (14%). Data for Scotland and Northern Ireland show that the foreign born population is usually younger than the UK born population.

Are the numbers of people from BAME groups expected to increase over time? Will people from BAME groups grow older?

Population projections suggest that both the numbers and proportions of people from BAME groups will increase in the UK, and they will represent a larger proportion of older people. In England and Wales it is predicted that by 2026 there will be over 1.3 million people from BAME groups aged 65+ (compared to over half a million in 2001) (Figure 1); in 2026 almost half a million people from BAME groups will be aged 70+. Amongst BAME groups, the White Irish is expected to have the highest proportion of people aged 65+ (35.9% of its population expected to be in this age group), followed by the Black Caribbean (13.4%), White Other (10.7%), Indian (10.6%) and Other Asian (9.6%).

Figure 1 – Projected increase in the numbers of people from BAME groups aged 65+ in England and Wales (in thousands)



Source: Lievesley (2010). The future ageing of the minority ethnic population of England and Wales. Older BME People and Financial Inclusion Report.

What do we know about the care being provided to BAME groups in the UK at the end of life?

We identified 45 literature reviews describing unmet needs and disparities in palliative and end of life care for BAME groups. These reviews principally focused on two issues: access to, and receipt of care (Figure 2). Authors also recognised the importance of understanding social inequities in society (such as social deprivation, differences in access to care in general, social exclusion and racism) when analysing unmet needs and disparities. They also identified several difficulties in relation to coding and monitoring ethnicity. Additionally, they warned against assumptions and the use of stereotypes when providing care for BAME populations (for example, assuming that everyone from the same group behaves the same way or not being aware of own values).

Access to palliative and end of life care

In terms of access to care, several authors reported that BAME groups had lower access to palliative and end of life care services when compared to White British people. This was associated with lack of referrals, lack of awareness of relevant services, previous bad experiences when accessing care, a lack of information in relevant languages or formats and family/religious values conflicting with the idea of hospice care. A number of authors stated that BAME groups are usually younger and consequently experience different types of cancer compared to the majority White population. However, they also stated that these trends are likely to change and this should not be seen as the only explanation to account for lower rates of service use.

Receipt of palliative and end of life care

Disparities and unmet needs when receiving care were also examined, especially issues regarding communication, end of life decision making and health outcomes (for example, pain). The most discussed issue was poor communication between the healthcare professional and the patient/family. This was associated with lack of sensitivity to cultural/religious differences, lack of availability or translators and low availability of training for healthcare professionals. Evidence on disparities on end of life decision making was more common in studies from the United States, with minority ethnic patients less likely to complete advance care planning documents and more likely to desire life-sustaining treatment (such as intubation and artificial feeding) than the majority White. The impact of mistrust (due to experiences of discrimination and poor

access to care) and the possible influence of religion on decisions were also emphasised. Many also stated that advance care planning is guided by Western values of autonomy and self-determination which are not applicable to several populations with a collective approach to decision making. Finally, some disparities regarding health outcomes were reported, such as worse pain outcomes for minority ethnic groups (mostly in the United States), differences in place of death (with minority ethnic groups dying less often at home); and less satisfaction with the care received.

Recommendations on how to improve care for BAME groups

The reviews presented several recommendations on how to improve care; these are summarised in this publication and include addressing social inequities in healthcare as a whole, involving BAME groups when developing new policies, providing palliative care for non-cancer patients, and improving ethnic monitoring nationwide. Authors emphasised the importance of cultural competency and communication skills training for healthcare professionals. Being sensitive and developing open, two-way conversations with patients and families was also encouraged. Authors warned against assumptions about how patients behave (or should behave). Authors suggested that strategies to reach BAME groups should involve the BAME communities and encouraged the recruitment of people from BAME groups. Authors advised researchers to assess if interventions which aim to improve care for BAME groups actually work/make a difference to patients and families and also to evaluate the care currently being provided to BAME groups. Authors recommended the use of different research methods (for example analysing patients over time instead of only analysing data records), and the use of standardised tools/measures. The need to better record/report ethnicity and develop more studies with underrepresented minority groups (such as White minorities) was also highlighted. A few authors also described "best practices" and initiatives to improve care, but it was not always reported how beneficial these were to patients and families. These practices were usually based in locations with a large number of people from BAME groups instead of being part of a wider, national initiative.

Where do we go from here?

Current evidence shows that overall, palliative and end of life care provision for BAME groups, is often inadequate. Demographic data tell us that the number of people from BAME groups will increase, and a substantial number of them will be older people who might need care. This raises questions on how care, which is currently reported as inadequate, will meet the needs of even larger numbers of people, including those usually not represented in research for example the White Irish (with one-third of its population already over the age of 65) and the Gipsy and Traveller communities. Over 800,000 people in England either cannot speak English well or cannot speak it at all. It is likely that there are older people amongst them and evidence shows that there is a lack of (or inadequate) translation services. Examples of best practice are understandably localised in areas with more ethnic diversity. However, this raises questions about whether minority ethnic groups living in less diverse areas would benefit from good practice shown to be working elsewhere. About two-thirds of the population in England reported having a religion, and it is likely that a number of them would have specific requirements at the end of life (which currently are not always met).

With all these issues and challenges in mind, we suggest studying the recommendations developed by authors and summarised in this publication to then plan care for BAME groups in the future. We also recommend the development of a national initiative to fund studies assessing the effectiveness of interventions (or in other words, assessing how beneficial they are to patients and families) designed to improve care for BAME groups and wide dissemination of results from these studies. It is important that those involved with care make the most of the demographic information available for free from national statistical bodies (especially data from the 2011 Census) to understand better the demographic profile of their local population. We also recommend the systematic, organised examination of practices which seem to be effective so these can be disseminated and adapted to other populations. Finally, research needs a stronger focus on assessing health outcomes for BAME patients and family caregivers. This should be done in collaboration with both policy and practice. Researchers should also analyse data from the 2011 Census further and develop new population projections with the most recent data available.

Figure 2 - Summary of the current state of palliative and end of life care provision for BAME groups

Unmet needs/disparities in access to palliative and end of life care and explanatory factors:

- **Lower uptake compared to White/majority groups**
- **Lack of referrals, knowledge and information**
- Lack of referrals
- Lack of knowledge of services (patients and professionals)
- Lack of knowledge about what hospice care involves
- Information not available in different languages/formats for those who do not speak English or cannot read
- Lack of cultural equivalents for words such as hospice
- **Religious and family issues**
- Hospice care conflicting with religion (giving up faith on God's power)
- Avoidance of open disclosure due to religious/family values
- Assumptions from patients (care is not available nor accessible) and care providers (family will provide care)
- **Structural/demographic/epidemiological issues**
- Previous negative care experiences: racism, insensitivity, lack of cultural awareness
- Geographical location of hospices; services not available in rural areas; postcode lottery
- Social segregation and social exclusion; disparities in the cancer continuum
- Socio-economic factors (income, deprivation, no health insurance)
- BAME groups younger than the majority White populations
- Lower prevalence of certain types of cancer and higher of chronic conditions

Unmet needs/disparities in receipt of palliative and end of life care and explanatory factors:

- **Communication**
- Poor communication
 - Lack of sensitivity to cultural and religious issues
 - Lack of translation resources and advocates
 - Problems with using family/friends as translators
 - Low number of minority doctors
 - Scarce availability of training to help professionals
 - Consequences: mistreatment; unmet religious needs; uncertainty and stress for professionals
- **End of life decisions**
- Less likely to complete advance care planning documents and more likely to desire life-sustaining/aggressive treatments (mostly USA data)
 - Mistrust from patients
 - Influence of religion (God is the one to decide)
 - Western values of autonomy/right to self-determination not applicable to everyone and contrast with family/community decision-making
- **Outcomes, home death and satisfaction with care**
- Pain control
 - Worse pain outcomes (mostly USA data)
 - Insufficient availability of opioid medication
 - Pain severity underestimated (e.g. due to language)
 - Lack of awareness from professionals that people have different attitudes and responses to pain
- Less likely to die at home than the majority White
- Less satisfied with care, lower care ratings, more problematic caregiving role

Source: Included studies