Palliative and end of life care

for Black, Asian and Minority Ethnic groups in the UK

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

Natalia Calanzani, Dr Jonathan Koffman, Irene J Higginson
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June 2013

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THE NATIONAL COUNCIL FOR PALLIATIVE CARE

Race Equality Foundation

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Foreword

Every individual will have a view of what a 'good death' means to them. Recognising and meeting this aim for everyone should be the goal of all providers of palliative and end of life care. Much has been achieved in the past five years of increased political focus on End of Life Care, to identify and spread good practice, both in the organisation of whole services and in the delivery of care to each person who is dying. This report recommends that the focus of end of life care needs to shift from care for those with terminal cancer, to care for everyone, from all backgrounds and with all terminal illnesses.

Progress is already being made by ensuring that access to care is not influenced by a person's clinical diagnosis. Attention is now turning to recognising that ethnic and cultural differences impact on all aspects of health and the uptake of health care. There is good evidence that there is low use of end of life care services by people of Black, Asian and Minority Ethnic (BAME) groups. As more emphasis is given to the impact on health and social services of an ageing population, and the need to extend the capacity and cost effectiveness of care, it is clear that the numbers of people from BAME groups aged over 65 are increasing and that the challenge of how to ensure that end of life care is appropriate and accessible to them all is with us now.

This excellent report provides data on the wide diversity of BAME populations across the UK and emphasises that these groups will soon be representing a significant proportion of the over 65s, with almost a trebling of their numbers in 25 years. There is a great need to understand what factors have enabled some groups of the BAME population, particularly in areas of ethnic diversity, to feel able to access end of life care and to learn from these services.

It has become apparent however that for the large majority of this population, services are perceived to have been developed by health and social care professionals whose focus on issues of importance may not always coincide with those of users of those services. Misunderstandings, mistrust and a lack of cultural sensitivity on the part of providers of services are identified as reasons for low uptake but can begin to be addressed by the simple step of improved communication with the person and their family.

This report marks the start of a programme of work by many partners. A better understanding of the nation's changing demographics, of the needs of individual ethnic and cultural groups and of the types of services which will best meet their end of life care needs must be early outputs from the partnership. There are many areas which researchers will investigate further and many opportunities for service providers to work together with local communities to develop care which is sensitive and responsive to their needs as well as on a scale which will be needed for the large numbers of people who could benefit.

Better training is needed for health and social care professionals to enable them to provide appropriate care to people from the different ethnic, cultural and religious background within their locality. This may require them to make significant changes to the way in which they have traditionally worked with people and their families.

Policy makers and commissioners will also wish to understand the needs of their BAME populations and ensure that they deliver health and social care which is available on an equitable basis.

This report is important, thoughtful and timely. It should stimulate a process of better understanding of the needs of BAME groups and a subsequent improvement in the support available to those who are approaching the end of their lives. I am delighted that the momentum which has been established by the publication of the report will be sustained by a review in two years of the progress which has been made.

Dr Teresa Tate OBE, FRCP, FRCR

Executive summary

Background to this report

There is growing evidence that ethnic and cultural differences can influence patterns of advanced disease, illness experiences, healthcare seeking behaviour, and the use of healthcare 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 amongst 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. Firstly, we describe the characteristics of BAME groups in the UK (ethnic groups by age and geographical region, religion, language 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. Secondly, 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. Lastly, 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). 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 identify 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.

Age

The relationship between those from BAME groups and age is important; data for England show that in mid-2009 nine out of ten people over the age of 65 were White British (over 7.7 million people), but there have been substantial increases in the number of older people from BAME groups when comparing mid-2001 to mid-2009 (reaching over 700,000 people in 2009, with wide variation across groups). 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 (13.8%). In Wales there were around 18,500 people from BAME groups aged 65+ in 2009 (compared to over half a million White British residents in this age group). In Scotland and Northern Ireland, data on the foreign born residents show that they are usually younger than the UK born population.

Religion

The numbers and proportions of people who described themselves as Christian in England 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 over 13 million people in 2011). 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. In Wales it was noted a decrease in numbers for Jewish and Christian religions from 2001 to 2011, while there was an increase for all other religions and for those reporting to have no religion. In Northern Ireland there was an increase in numbers for religions other than Christian, but also for Catholic, Other Christian religions and a substantial increase for those either reporting to have no religion or not stating their religion.

Language

When it comes to language, in England over 90% of people had English as their first language in 2011, but one out of five people who did not have it as a principal language either could not speak it well or could not speak it at all (over 800,000 people). This could indicate a demand for translation services when in receipt of care. In Wales 97.1% had English as the first language in 2011 and 19,305 residents could not speak English well or could not speak it at all. Similar to Wales, in Northern Ireland 96.9% of residents had English as their principal language, while 14,469 people could not speak it well or at all.

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 estimated that by 2026 there will be over 1.3 million people from BAME groups aged 65+ (compared to over half a million in 2001); in 2026 almost half a million people from BAME groups will be aged 70+. Amongst BAME groups, the White Irish are expected to have the highest proportion of people aged 65+ (35.9% of its population is 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%).

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. Authors also recognised the importance of understanding social inequities (such as 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 their 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 so 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 of 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 population. 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 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 at home less often); 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 their population already over the age of 65) and the Gypsy and Irish Traveller communities. Almost 900,000 people in the UK 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 designed to improve care for BAME groups (or, in other words, assessing how beneficial they are to patients and families) 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 analyse data from the 2011 Census further and develop new population projections with the most recent data available.

1. Introduction

> We emerge deserving of little credit; we who are capable of ignoring the conditions that make muted people suffer. The dissatisfied dead cannot noise abroad the negligence they have experienced[1].

Nearly forty years ago the medical doctor, John Hinton, drew attention to the deficiencies that were evident in the care offered to many patients with advanced disease, and their families. While we have witnessed a growing understanding of the palliative care needs of patients and their families and an acceptance that death is universal, which makes it a universal public health concern, the actual provision of care at the end of life is still not always adequate. In recent years, both in the United Kingdom and elsewhere, questions are being asked about how much palliative care we need, from whom, where, and at what cost, given that accessible and good quality care towards the end of life must be recognised as a basic human right to all those who can benefit from it[2, 3]:

> Everyone has the right to (...) security in the event of sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his [or her] control
>
> (Article 25, United Nations Universal Declaration of Human Rights 2001)

Treating people equally and promoting dignity and respect are the key principles contained within this declaration. Since its introduction, all new legislation must comply with its principles. In recent years human rights in health and social care services have been given more attention[4] and extended to many groups in society. *A Joint Committee on Human Rights* (appointed by the Houses of Lords and Commons to consider matters relating to human rights in the UK) has reported on people with disabilities[5], people with learning disabilities[6], on children[7], and older people[8]. To date, however, this interest in ensuring that human rights extend to all sectors of society has not given enough attention to those at the end of life, specifically, the growing numbers of older members from Black, Asian and Minority Ethnic (BAME) groups living with and dying from cancer and other life limiting conditions including heart failure and dementia. This represents a critical time in their lives when there is no second opportunity to redress failings in care to them or their families.

The National End of Life Care Strategy recognises that high quality care should be provided for all people approaching the end of life, 'irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic status'[9]. It adopts a pathways approach (Figure A1 in the Appendix) focusing on addressing the needs of the individual, with an open communication and assessment of needs and preferences. The Strategy acknowledges, however, that although much has been achieved in the past few years, there is still much to be done in order to address inequities in the care provided at the end of life[10].

1.1 Differences that make a difference

Throughout human history, individuals, families, and groups have emigrated from their native homes to other places globally for many reasons: the prospect of education, economic, or social advantage; the need to escape war, political torture or other conflicts; or the desire to reunite with other family members. In 2005 alone, there were an estimated 191 million immigrants across the globe: approximately 64 million of these immigrants arrived in Europe and 44 million in North America, a tripling of the immigrant populations in these regions compared to twenty years earlier[11]. This trend is expected to continue to increase[12]. In Europe, the first decade of the 21st century has seen large waves of migration from both within and outside Europe. The number of European citizens migrating to a Member State other than their own country of citizenship increased on average by 12% per year during the period 2002–08[13]. Spain, Germany and the United Kingdom were the European countries with the highest immigration, receiving more than half of all immigrants in 2008[13]. Diversity is therefore a reality, with an increased proportion of people not living within their own native country or culture[14].

Ethnicity is a commonly used term when referring to social diversity; it is also a concept surrounded by enormous controversy and confusion (Box 1). Ethnicity is a 'multi-faceted and changing phenomenon' that may reflect a combination of a number of features including country of birth, nationality, language spoken at home, ancestral country of birth, skin colour, national or geographical origin, racial group and religion[15].

Ethnic minority health is increasingly recognised as a crucial 'tracer' for measuring the success in achieving health and patient preferred outcomes for the population in general[23], and for palliative/end of life care in particular[24–26], where there is growing evidence that we are not all equal in death. As cancer and chronic conditions affect more and more people from different ethnic and cultural backgrounds[27] it is important to understand how services best serve all people, and whether (and how), outcomes of care may vary. Robust and relevant intelligence is critical, particularly as growing evidence suggests that a significant number of people living with advanced disease miss out on palliative care and end of life care[28, 29]. For example, older patients[30–33], the poor[26, 34–36], and specifically those from BAME communities[37], are less likely than younger patients, White patients, and more affluent groups to use appropriate specialist services including inpatient hospices. This situation exists in the UK despite palliative care being free at the point of delivery from the NHS and the independent

Box 1 – Conceptual confusion and the language of diversity

Race, ethnicity and culture have the potential to be presented as explosive concepts[15]. All these terms have been used to explain patterns of disease, illness experiences, responses to treatment, and the use of services. However, confusion is still common. Firstly, researchers rarely define the terms they use[12]. Secondly, over the years, all terms have been used interchangeably, have been subject to misuse, or combined with other social metrics, for example social class or education[16]. Race can be understood as the classification of people on the basis of their physical appearance – with skin colour the most popular characteristic[17]. In the past it has also been used as a way of dividing humankind which has denoted inferiority and superiority, linked to subordination and domination[18]. Ethnicity, sometimes employed as a softer synonym for race, can be defined as: *Shared origins or social backgrounds; shared culture and traditions that are distinctive, maintained between generations, and lead to a sense of identity and group; and a common language or religious tradition*[19].

Ethnicity is fluid and depends greatly on context. For practical and theoretical reasons, the current preference is to permit the self-assessment of ethnicity[19]. Amongst other factors, culture underpins our ethnic identity. This too is a complex and problematic social concept with several definitions. Culture is a patterned behavioural response that develops over time as a result of imprints on the mind through social, religious, intellectual and artistic structures[20]. From this definition culture can be seen as a 'recipe' for living in the world[21]. However, this is a limited understanding of culture that, if used here, risks minimising discussions of cultural aspects of palliative and end of life care to lists of beliefs and practices from a range of so-called 'cultural' groups. This has also been referred to as the 'fact-file' or 'checklist'[22] approach that, while informative in interpreting behaviours, symbols, rituals, and other cultural practices of certain ethnic or religious groups that may be important and meaningful at the end of life, runs the risk of encouraging generalisations about individuals and groups based on cultural identity. This in turn may then lead to the development of stereotypes, prejudices, and misunderstandings.

charitable sector.

In this report we aim, firstly, to present key intelligence on the current demographic profile of BAME populations living in the UK according to the most up-to-date estimates from the 2011 Census. We also aim to examine and appraise demographic projections for BAME populations in the UK, the implications of which deserve attention. Secondly, we aim to identify and appraise evidence from literature reviews to describe the current state of palliative and end of life care provision for BAME populations living in the UK and in other English-speaking countries. We will report on unmet needs and inequalities in access to relevant service provision, and present recommended practices and measures to reduce inequalities and deliver high quality care.

2. Methods

This Section summarises the methodology applied to two distinct components of our work: the demographic data and population projections (shown in Section 3) and the review on the current state of palliative and end of life care provision for BAME populations (shown in Section 4). Table A2 in the Appendix defines some of the terms used throughout the report.

2.1 Analysis of socio-demographic data and projections

In Section 3 we present socio-demographic data available free of charge from the Office for National Statistics (ONS), Northern Ireland Statistics and Research Agency (NISRA) and National Records of Scotland (NRS), formerly the General Register Office for Scotland (GROS). We focus on data from the National Censuses (1991, 2001 and 2011), but also present statistics from the Annual Population Surveys (APS) and the Labour Force Surveys (LFS) when Census data are not yet available (this is the case for Scotland)[38]. Census data are shown for usual residents and households, excluding visitors or short-term residents (those living in the UK for less than 12 months)[39].

Key characteristics including ethnic group, religion and language all help to provide a more detailed picture of social diversity in the UK[40]. We present demographics on ethnicity, religion and main spoken languages. We show the age composition for the English and Welsh population according to ethnicity (estimates are not available for Scotland and Northern Ireland). Importantly, these are experimental statistics developed by the ONS from mid-2001 up to mid-2009 and should be viewed with caution[41, 42]. Their estimates are shown by ethnic categories adopted by the 2001 Census; Census 2011 tables on ethnicity and age are not yet available.

This report also presents 2011 data on 'English proficiency' for England, Wales and Northern Ireland (a question of how well one speaks English when this is not their native language – shown in Table A3 in the Appendix). We show the most recent estimates on usual residents born outside the UK (for all the UK countries), their age and year of arrival to the UK (England and Wales) and the ten most common countries of birth in 2001 (for England, Wales and Northern Ireland) and 2011 (for all the UK countries).

The UK Census started requesting information about ethnicity in 1991 (in Northern Ireland the question was introduced in 2001[43]); ethnic categories and instructions on how to answer the question have been evolving since then (Table 1). We provide ethnicity data from 2001 and 2011 for the UK countries on a separate basis and also an additional analysis of all ethnic groups in England and Wales combined since 1991. Throughout the report we use the term BAME as any ethnic group other than White British; we also use the term 'minority ethnic group' when describing data from countries other than the UK (Sections 4 and 5).

Ethnicity data from 2001 and 2011 in England and Wales are broadly comparable, but there are some compatibility issues. Gypsy or Irish Traveller and Arab categories were only available in 2011. In 2001, it is possible that the former might have identified themselves with any of the other available White categories, while the latter seem to have chosen one of the Other categories[39]. The Chinese category was repositioned from the main category Other to the Asian/Asian British category in 2011. As a consequence there was a loss of comparability between 2001 and 2011 for the categories Chinese, Other Asian, the Asian main category and Any other ethnic group. The repositioning might also have had an impact on responses to the White and Asian category (part of Mixed/multiple ethnic groups)[39]. Ethnicity data from 2001 and 2011 in Northern Ireland are fully comparable[44], while ethnicity data from 2011 are not yet available for Scotland (Census questions for both countries are available in Table A4 in the Appendix).

The Census question on religion was introduced in 2001 (shown in Tables A5, A6 and A7 in the Appendix) and it is not mandatory. The question is about religious affiliation; the ONS highlights that there are other aspects of religion such as religious belief, religious practice or belonging which are not covered in their analysis[40]. We present data from 2001 and 2011 (except for Scotland as only 2001 data were available). There were changes from 2001 to 2011 in terms of instructions on how to answer the question. In England and Wales it is possible that some people may have ticked more than one answer in 2011 (but data remain comparable)[39, 44].

In addition to current and previous demographic profiles of BAME groups in the UK we also report on the most recent UK population projections. We searched the databases MEDLINE, PsycINFO, EMBASE and Social Policy and Practice for all original publications reporting on national population projections which included estimates for BAME populations in at least one of the UK countries. A time frame of five years (from 2008 onwards) was considered adequate

Table 1 – Census questions on ethnicity for England and Wales

Census 1991	Census 2001	Census 2011
Ethnic group Please tick the appropriate box: White ☐ Black-Caribbean ☐ Black-African ☐ Black-Other ☐ *please describe* Indian ☐ Pakistani ☐ Bangladeshi ☐ Chinese ☐ Any other group ☐ please describe If you are descended from more than one ethnic or racial group, please tick the group to which you consider you belong, or tick the 'Any other ethnic group' box and describe your ancestry in the space provided.	What is your ethnic group? Choose ONE Section from A to E, then **3** the appropriate box to indicate your cultural background. **A White** ☐ British ☐ Irish ☐ Any other White background, *please write in* **B Mixed** ☐ White and Black Caribbean ☐ White and Black African ☐ White and Asian ☐ Any other Mixed background, *please write in* **C Asian or Asian British** ☐ Indian ☐ Pakistani ☐ Bangladeshi ☐ Any other Asian background, *please write in* **D Black or Black British** ☐ Caribbean ☐ African ☐ Any other Black background, *please write in* **E Chinese or other ethnic group** ☐ Chinese ☐ Any other, *please write in*	What is your ethnic group? Choose **one** Section from A to E, then tick one box to best describe your ethnic group or background. **A White** ☐ English/Welsh/Scottish/Northern Irish/British[1] ☐ Irish ☐ Gypsy or Irish Traveller ☐ Any other White background, write in **B Mixed/multiple ethnic groups** ☐ White and Black Caribbean ☐ White and Black African ☐ White and Asian ☐ Any other Mixed/multiple ethnic background, write in **C Asian/Asian British** ☐ Indian ☐ Pakistani ☐ Bangladeshi ☐ Chinese ☐ Any other Asian background, write in **D Black/African/Caribbean/Black British** ☐ African ☐ Caribbean ☐ Any other Black / African / Caribbean background, write in **E Other ethnic group** ☐ Arab ☐ Any other ethnic group, write in

[1] In Wales, 'Welsh' is shown before 'English'. Sources: original Census questionnaires available from: www.ons.gov.uk/ons/guide-method/census/census-2001/about-census-2001/census-2001-forms/index.html and www.ons.gov.uk/ons/guide-method/census/2011/index.htm

since we were only interested in projections adopting more recent population estimates. We found three different publications which are described in Section 3. One refers to population projections for England and Wales published by Runnymede and the Centre for Policy on Ageing[45] (described by the author as both provisional and experimental), focusing on their projections up to the year 2026. The other two projections were published by Wohland et al[46] (also described by authors as provisional and experimental), and by Coleman[47]. We present the projections published by Runnymede and the Centre for Policy on Ageing into more detail because they focused on the ageing of BAME groups, which is most relevant for this report. However, it is important to note that these projections were based on experimental statistics on ethnic group and age published by the ONS[41], which might affect their accuracy.

Population projections require robust data on migration, mortality and fertility. However, data sources are limited and usually based on the population's country of birth (case of both birth and death certificates – affecting estimates for fertility and mortality); estimates on ethnicity are derived from national surveys (which can suffer from sampling errors)[48] and Census data (which are only available every ten years). Migration data have been reported as incomplete and limited[47]. Projections represent an estimation of how the population is likely to be[45], they are not forecasts and do not attempt to predict the impact that future government policies, changing economic circumstances or other factors might have on demographic behaviour[49]. Therefore, projections should always be viewed cautiously; estimates also become considerably less reliable the longer projections go across time[49].

2.2 Identification and appraisal of evidence from reviews

In Section 4 we present a review of the current state of palliative and end of life care provision for BAME populations; this was informed by recommended methodology for undertaking systematic reviews published by the Centre for Reviews and Dissemination[50]. We aimed to identify reviews (systematic and non-systematic) describing the current state of palliative and end of life care provision for minority ethnic groups (living in the UK and other English-speaking countries), reporting on unmet needs and disparities in access or service provision, and/or presenting evidence based recommendations, successful practices and measures used to reduce disparities for these populations. We also aimed to use available evidence to recommend areas for further research and service delivery in order to better meet the needs for BAME populations. We report on the original minority ethnic categories as mentioned by authors in each review, therefore inconsistencies regarding terminology are possible.

Throughout the report we use the terms 'palliative' and 'end of life care' together since we did not wish to focus only on people at the end of life. We sometimes use the term 'hospice' when this was mentioned in the reviews. In the UK this might refer to palliative care provided in inpatient hospices, other institutional settings and at home. However, in the United States of America (USA) palliative care and hospice care have a different meaning. Palliative care may be provided to anyone who might benefit from it, regardless of prognosis. On the other hand, in order to receive hospice care the patient must have an expectancy of six months or less to live (certified by a medical doctor). Furthermore, in the USA hospice care is usually provided at home[51]. It is important to be aware of these differences when analysing the evidence.

Data sources/Search strategy

In order to avoid duplicate work and due to a restricted time frame to produce this review of evidence we have focused on published reviews (published in peer reviewed journals and grey literature) instead of primary studies. The following databases were searched from January 1992 to January 2013: Web of Science with conference proceedings, Inspec, Journal Citation Reports, MEDLINE, PsycINFO, EMBASE, ASSIA, CINAHL and Cochrane reviews. We defined a time frame of the past 20 years because older studies are highly likely to be out of date and therefore no longer relevant for the aims of this review. A search strategy with MESH and free text terms was adapted from relevant systematic reviews on the topic[25, 28, 52–54]. Further information on the searched databases and used keywords is available in Table A8 in the Appendix. We also checked the NHS

Ethnicity and Health Library using the term 'end of life care' (no year restriction). The reference lists of all included articles were checked for reviews eligible for inclusion. Consultation with an expert also resulted in possible reviews for inclusion (from peer reviewed journals and grey literature).

Selection of reviews/Inclusion and exclusion criteria

General inclusion and exclusion criteria were developed based on the project aims. We focused on the adult population due to their growing importance for palliative and end of life care provision in the current context of the ageing of the UK population. We included reviews reporting on UK studies and also reviews from other English-speaking countries (Canada, USA and Australia). When evidence only referred to a specific country we highlighted this in the results.

We included all reviews reporting on the provision of palliative and end of life care for adults belonging to one or more minority ethnic group when these reported on unmet needs; and/or disparities in palliative and end of life care. We only included evidence on needs and preferences when these were described in the included reviews that also reported on either unmet needs or disparities. BAME groups did not have to be the main focus of the reviews; we also included broader reviews as long as they analysed minority ethnic groups as a subgroup. We specifically excluded reviews focusing on epidemiological data only and unmet needs in general (including cancer treatment when this was not about palliative and end of life care). We also excluded overviews and purely descriptive papers which did not describe themselves as reviews. Full inclusion and exclusion criteria are available in Table A9 of the Appendix.

Screening references

After developing a comprehensive search strategy in order not to miss any relevant reviews, we expected to screen a large number of records. Therefore, the screening of reviews occurred in three stages: 1) screening titles against the inclusion and exclusion criteria to identify potentially relevant papers; 2) screening abstracts of papers identified as possibly relevant from stage 1; 3) screening full texts of papers identified as possibly relevant in stage 2. Stages 1 and 2 were done by a single researcher; the final selection of studies (stage 3) involved discussion with a second researcher; any disagreement was solved by consensus. The bibliographic software EndNote X6 was used to manage articles.

Data extraction and quality assessment of included reviews

Data from included reviews were extracted by one researcher into tables (in Excel 2010 and SPSS 19 for Windows) with categories defined according to the study aims. A second researcher independently checked the extracted data to verify any inconsistencies; disagreements were solved by consensus.

Considering individual aspects of methodological quality of studies instead of focusing on quality scores is recommended when doing quality assessment and synthesis of data[50]. There are several checklists available which can be used to assess quality of reviews. However, most were developed to assess systematic reviews (which is not the case in many reviews of palliative and end of life care for minority ethnic populations). We used a simple, validated index developed by Oxman and Guyatt[55] to assess the quality of review articles (full checklist available in Table A10 in the Appendix). We followed a similar methodology to the one applied in a recent appraisal of UK reviews on end of life care for minority ethnic groups[25], assessing only systematic reviews and critical reviews which followed a systematic approach. We focused on reporting individual aspects of quality for each review. Quality of studies was assessed by one reviewer; a second reviewer assessed a random selection of included reviews (10%) and disagreements were solved by consensus.

Data analysis and synthesis

We have used a narrative synthesis approach when reporting the findings from the included reviews. Narrative synthesis relies primarily on the use of words and text to summarise and explain findings; it uses a textual approach to 'tell a story' of the findings[56]. This is a commonly used approach when there is considerable heterogeneity in included studies in terms of methods, participants and interventions[50, 56]. The synthesis involved the juxtaposition of findings from the included reviews, with an analysis of their common themes and findings[56].

3. Current and projected profile of BAME groups in the UK

We start this Section by describing the current demographic profile of all ethnic groups in the UK (focusing on BAME groups – all ethnic groups other than White British), providing data separately for England, Wales, Scotland and Northern Ireland. This is followed by briefly highlighting the most recent UK population projections for BAME populations.

3.1 Current profile in England: ethnicity, language, religion, age and characteristics of the foreign born

Ethnicity in England

Data from the 2001 and 2011 Censuses show that England has become more ethnically diverse[57], with an increase in both numbers and proportions for all BAME groups from 2001 to 2011 (with the exception of White Irish). Although most residents reported their ethnic group as White British in 2011, there was a reduction in both numbers and proportions of people from this group (7.2% reduction in proportion or 467,900 fewer residents)[58, 59] (Table 2). Box A11 in the Appendix has ethnicity data from 1991 for England and Wales (shown together); it shows a substantial increase in ethnic diversity in the past 20 years.

In 2011 Other White was the second largest ethnic group in England (almost 2.5 million people or 4.6% of the population, an increase of more than one million people since 2001), followed by Indian (almost 1.4 million people or 2.6%) and Pakistani (1.1 million or 2.1%). In 2011, all BAME groups accounted for a fifth (20.3%) of the population in England (10.7 million residents) (Table 2).

The decrease in the proportion of White British happened in all regions in England, with the highest decrease in London (from 59.8% of the population in 2001 to 44.9% in 2011). The increase in both numbers and proportions of Other White also happened in all regions in England, with the highest increase in London (where more than one out of ten people was Other White in 2011). While London had the greatest change between the 2001 and the 2011 Censuses (in terms of an increase of people from BAME groups and decrease of the White British population), the North East had the smallest change (with White British decreasing by 2.8% in proportion and other ethnic groups increasing by less than 1%)[57]. Table A12 in the Appendix shows ethnic groups by English region in 2001 and 2011.

Distribution of ethnic groups across England is not homogeneous, and numbers and proportions for each group can differ widely across regions[57]. The region with the highest number of people from BAME groups is London, where in 2011 more than half (55.1%) of the population was from a BAME group and most ethnic groups represented above average proportions of the population (Figure 1). In 2011 the North East was the area with least ethnic diversity (93.6% of the population identified themselves as White British)[59].

Differences across local authorities are even more pronounced. The ONS reported that the local authorities with the highest percentage of White British were in the North East and North West; these were Redcar & Cleveland and Allerdale with 97.6% of their population being White British. In contrast, 16.7% of the population in Newham and 18.0% in Brent (both London boroughs) were White British[57]. This highlights the fact that in some areas BAME groups are the substantial majority of the population. The ONS website has developed a key statistics interface in which ethnicity (and other characteristics such as religion and country of birth) can be checked according

Table 2 – Population by ethnic group in England in 2001 and 2011

Main groups	Subgroups	2001		2011	
		Number	(%)	Number	(%)
White[1]	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

to local authorities in England and Wales (http://www.ons.gov.uk/ons/guide-method/census/2011/census-data/index.html).

Age distribution of the BAME groups in England

Census 2011 data on ethnic groups broken down by age had not been made available at the time of this publication. Estimates published by the ONS[41] using ethnic categories from the 2001 Census show that BAME groups are usually younger than the overall population, except for the White Irish. Over 8.4 million people were estimated to be aged 65+ in mid-2009, most of them (91.6% or 7.7 million people) were White British, the remaining 707,300 people aged 65+ belonged to a BAME group[60].

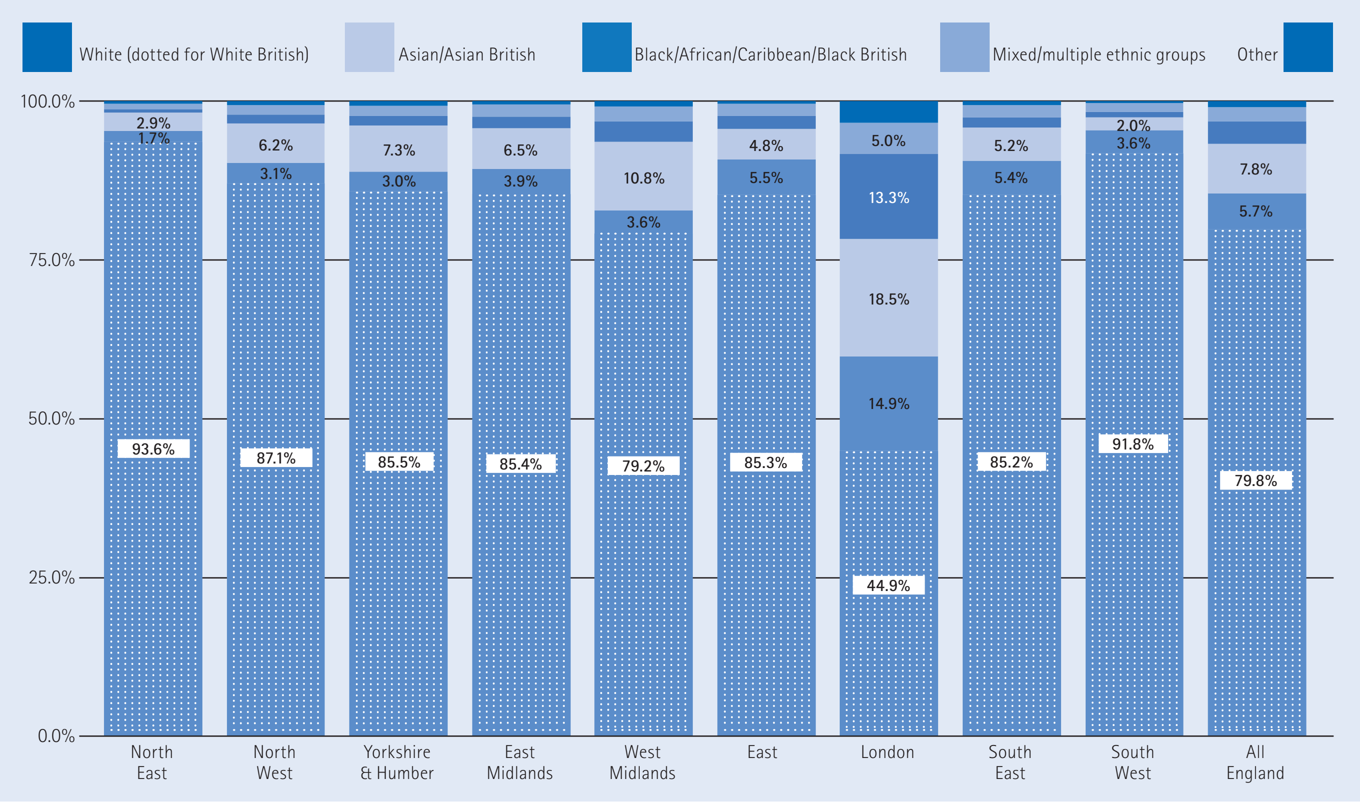
Estimates show an increase in the number of people aged 65+ in England across all BAME groups from mid-2001 to mid-2009 (Figure 2)[60, 61]. The highest increase in percentage occurred for the Other ethnic group (130% increase from 6.3 thousand to 14.5 thousand people), Black African (111% increase from 10.9 to 23.0 thousand people) and the Chinese (76.5% increase from 11.5 to 20.3 thousand people) categories.

The highest increase in numbers occurred amongst the White British (over 415,000 additional people aged 65+ from 2001 to 2009). However, the proportion of older White British has decreased since 2002 (from 93.3% of the population aged 65+ in 2001 to 91.6% in 2009).[60, 61]

About a third (32.5%) of the White Irish population was aged 65+ in 2009 (the highest proportion across all ethnic groups); this is followed by the White British (18.0%) and the Black Caribbean (13.8%).[60] Table A13 in the Appendix shows the complete age distribution for White British and BAME groups in mid-2009.

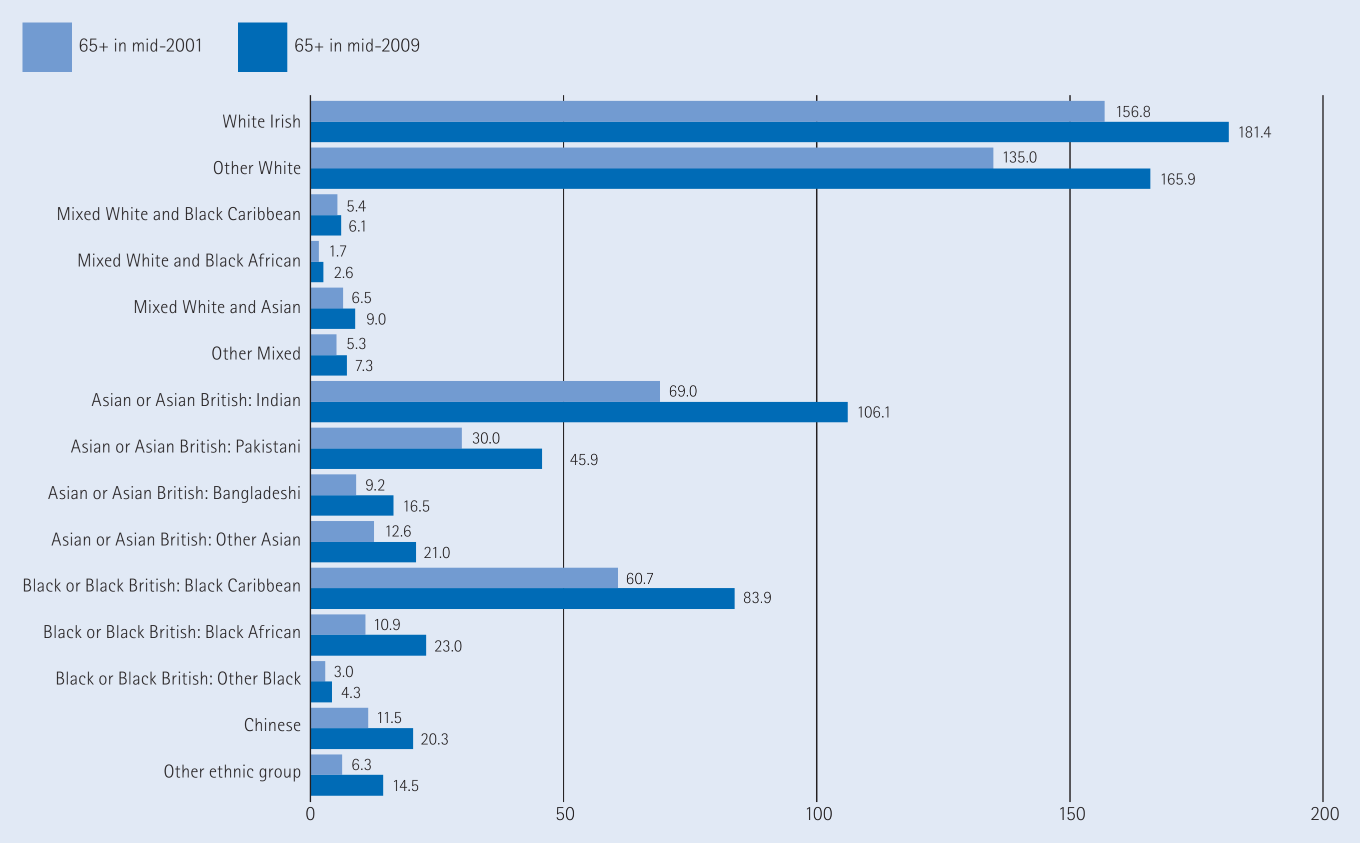
Table A14 in the Appendix shows the estimated population aged 65+ (men) and 60+ (women) by ethnic group and English regions in mid-2009. It shows that London had the highest number of older people across all BAME groups. For example, over half of older Black African and Black Caribbean, almost half of older Bangladeshi, Other Asian and Other Black and four out of ten older Indian lived in London[62]. Amongst non-White BAME groups, East Midlands, West Midlands and the South East together accounted for almost four

Figure 1 – Proportion of main ethnic groups across English regions in 2011



Source: Office for National Statistics (2012). Table KS201EW. Ethnic group, local authorities in England and Wales.

Figure 2 – Estimated number of people aged 65+ from BAME groups in England (in thousands)



Sources: Office for National Statistics (2011). Table EE4: Estimated resident population by ethnic group, age and sex, mid-2001. Rel. 8.0 Table EE4: Estimated resident population by ethnic group, age and sex, mid-2009. Rel. 8.0.

out of ten older Indian, while the West Midlands, Yorkshire & the Humber and the North West together accounted for half of all older Pakistani[62].

Religion in England

Census data show that in 2011 the majority of the population in England (59.4% or over 31 million people) reported being Christian, but numbers and proportions have fallen since the question was introduced in the 2001 Census (when proportion was 71.7% of the population, or over 35 million people)[58, 63] (Figure 3). Muslims were the second largest religious group in 2011 (with almost 2.7 million people or 5.0% of the population – an increase from 2001 when they represented 3.1%)[40, 64]. There was an increase in numbers for all other main religions in England from 2001 to 2011, but there was also a substantial increase in the numbers and proportion of people who reported having no religion (from 14.6% in 2001 to a quarter of the population in 2011 – over 13 million people). Both in 2001 and 2011 almost four million residents did not answer the voluntary question on religion (numbers not shown in Figure 3)[40, 64].

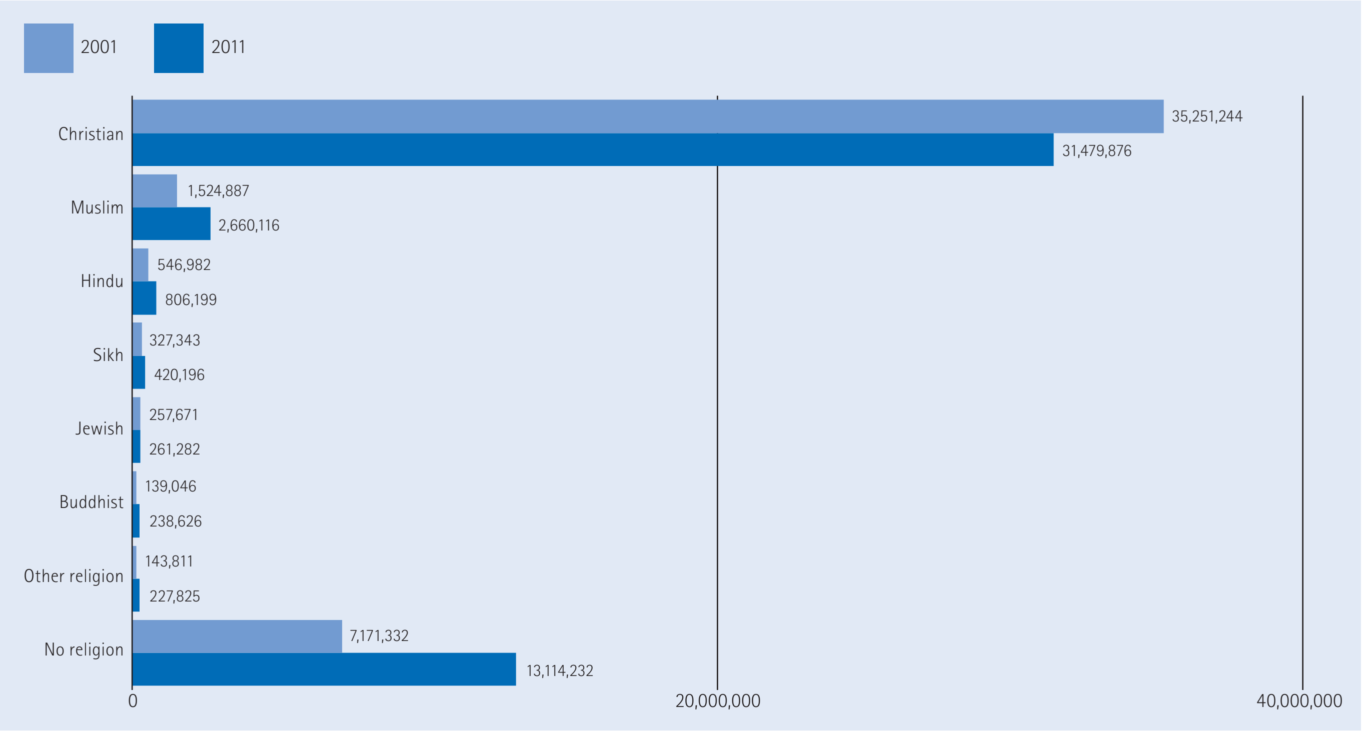
Similar to trends in ethnicity, London was the most diverse area regarding religion in 2011, having the lowest proportion of Christians (under half of the population) and highest proportion of all other main religions (except Sikh which showed the highest proportion in the West Midlands)[40]. Table A15 in the Appendix shows data on religion by English regions. The South West had the highest proportion of people reporting no religion (29.3% of the population), while the North East and the North West reported the highest proportion of Christians (about two thirds of the population in both regions)[40]. Also similar to trends in ethnicity, certain religious groups tend to concentrate in particular areas. Examples are the concentration of Muslims in London, Bradford, Luton, Slough and Birmingham; Hindus in London and Leicester; Buddhists and Jewish people in London[40].

Language in England

Over 90% of the population in England had English as their main language in 2011. The second most spoken language was Polish (1% of residents or over half a million people) (Box 2). Panjabi was the third most spoken language, followed by other South Asian languages: Urdu (fourth), Bengali (fifth) and Gujarati (sixth)[65].

The majority of residents who did not possess English as their principle language in 2011 could either speak it well or very well (79.2% of them

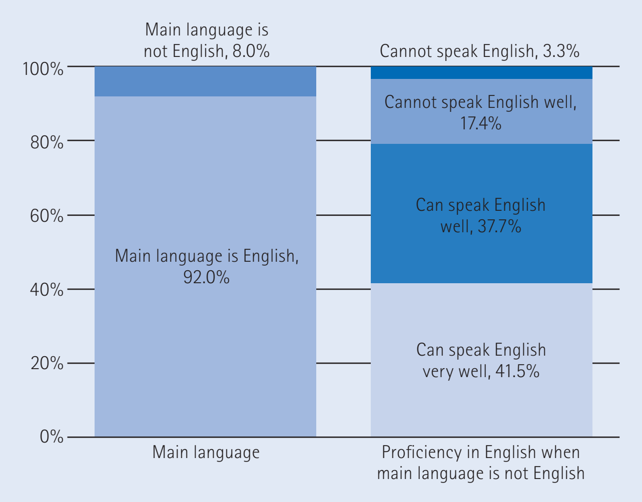
Figure 3 – Religion in England in 2001 and 2011



Source: Office for National Statistics (2013). 2001–2011 Census comparator tool. Key statistics interface v2.5

Box 2 – Residents' top ten main languages and English proficiency in 2011 (England)

Top ten main languages	Number	(%)
English	46,936,780	(92.0)
Polish	529,173	(1.0)
Panjabi	271,580	(0.5)
Urdu	266,330	(0.5)
Bengali (with Sylheti and Chatgaya)	216,196	(0.4)
Gujarati	212,217	(0.4)
Arabic	152,490	(0.3)
French	145,026	(0.3)
Portuguese	131,002	(0.3)
Spanish	118,554	(0.2)
All other languages	2,026,262	(4.0)
All residents aged 3 and over	51,005,610	(100)



Sources: Office for National Statistics (2012). Table QS204EW. 2011 Census: Main language (detailed), local authorities in England and Wales. Office for National Statistics (2012). Table QS205EW. 2011 Census: Proficiency in English, local authorities in England and Wales

or over three million people). The remaining residents (a fifth of those whose main language was not English – over 800,000 people) either could not speak English well or could not speak it at all[66]. Table A16 in the Appendix shows English proficiency according to regions in England. It shows that London and the West Midlands were the regions with the highest proportion of people who could not speak English well or could not speak it at all (4.1% and 2.0% respectively); these were also the regions with the highest proportion of people who did not have English as their main language. The North East and the South West had the highest proportion of people with English as their main language and the lowest proportion of people who could not speak English well or could not speak it at all (0.6% in each region). It is important to better understand this group that does not speak English (e.g. their age, their ethnic group and their socio-economic circumstances); this will be possible when the ONS releases aggregated tables later in 2013[66].

Foreign born populations living in England

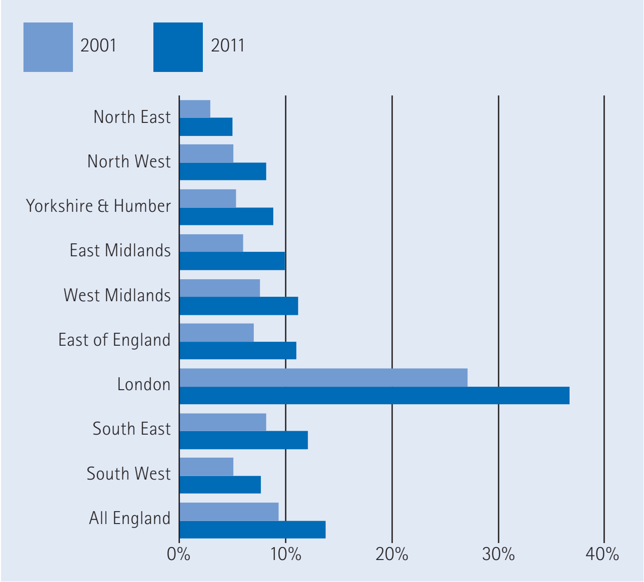
Migration to England in the 20th Century was strongly characterised by those coming from the British Commonwealth countries. This included immigration from the Caribbean and India throughout the 50s and 60s (peaking in the early 60s), from Pakistan largely in the 70s, from Bangladesh mainly in the late 70s and early 80s and from Hong Kong in the 80s and 90s[67]. There was also a flow of Indian immigrants who were expelled from East Africa in the late 60s and early 70s. After the 80s, migration included large numbers from the rest of the European Union and numbers from non-European and non-Commonwealth countries (related to worldwide growth of the number of refugees, but also to economic growth in the UK). There has also been a long history of migration to England from Ireland[67].

It is important to highlight that people born outside the United Kingdom do not necessarily consider themselves as belonging to a BAME group[68]. Furthermore, being born abroad and being a UK citizen are not mutually exclusive – many foreign born residents might have received citizenship since arriving to the UK; children of UK citizens may also have been born abroad because their parents worked overseas[69].

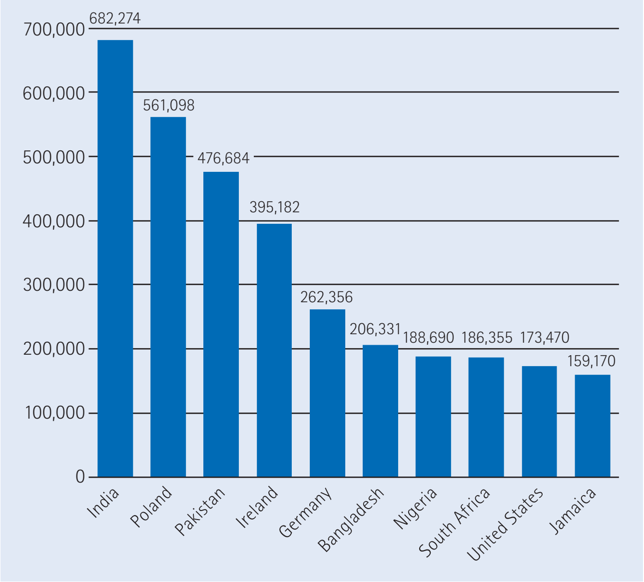
In 2011, 86.2% of all residents in England (over 45 million people) reported that they were born in the UK. Although the number of residents who were UK born has increased by almost 1.1 million since 2001, there has been a decrease in terms of the proportion of the population (in 2001 the UK-born represented 90.7% of all residents). On the other hand, both numbers and proportions of the foreign born population have increased since 2001, reaching over 7.3 million people (13.8% of the resident population) in 2011 compared to almost 4.6 million in 2001 (or 9.3%)[64, 69]. Across England, London had the highest proportion of foreign born residents in 2011 (36.7% or almost 3.0 million) while the North East had the lowest (5.0% or 128,573 people)[69] (Box 3). There was an increase in the number of usual residents born outside the UK after 2001 in all regions of England, with the largest increase in numbers in London and the South East[69]. Figure A17 in the Appendix illustrates the uneven distribution of the foreign born population across England.

Box 3 – Usual residents in England born outside the UK

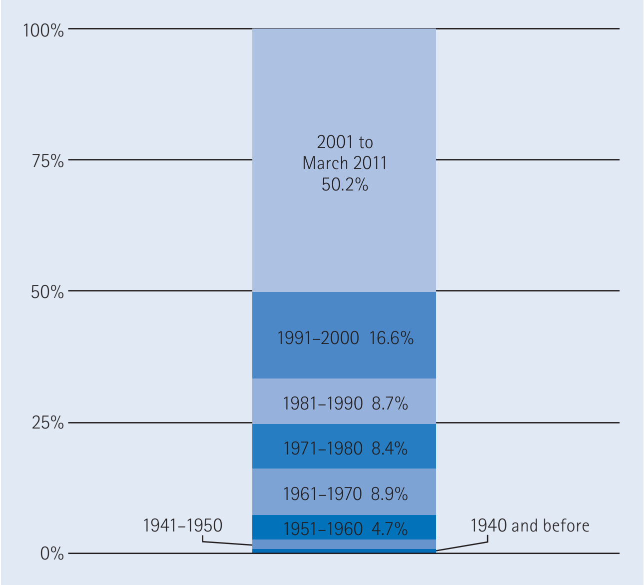
% foreign born in 2001 and 2011



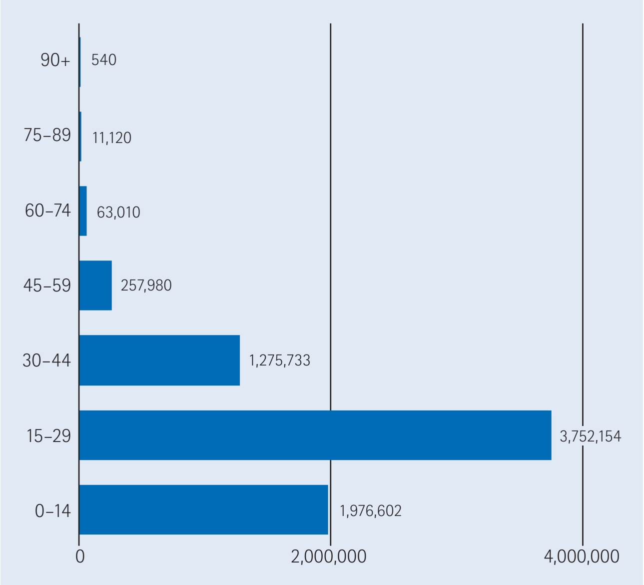
Top ten countries of birth (2011)



Most recent year of arrival (2011)



Age at arrival (2011)



Sources: Office for National Statistics (2012). International Migrants in England and Wales 2011. Office for National Statistics (2012). 2011 Census: Key Statistics for England and Wales, March 2011. Statistical Bulletin. Office for National Statistics (2012). Table QS802EW. 2011 Census: Age of arrival in UK, local authorities in England and Wales. Office for National Statistics (2012). Table QS801EW. 2011 Census: Year of arrival in UK, local authorities in England and Wales

More than two-thirds of foreign born residents (over 5 million people) arrived in the UK when they were aged 15-44 years old; almost two million were children under the age of 14[69, 70] (Box 3). This is partly explained by the fact that a substantial number of people migrate to work or study and some of them might have children accompanying them[69]. One per cent or 74,670 people arrived when they were aged 60 years or older. Further analysis of this group will be possible with further publications from the 2011 Census.

Half of the foreign born population of England who answered the 2011 Census arrived in the UK after 2001 – this is partly due to the accession of new countries to the European Union (EU) in 2004[39, 71]. Poland is an especially relevant case; in the past decade it became the second most reported country of birth among the foreign born population. Census data for England and Wales (shown together) report a nine-fold increase in the Polish population when comparing 2001 to 2011 (an increase from around 58,000 people in 2001 to over half a million in 2011)[69]. However, the top country of birth among the foreign born population is India, which in 2011 replaced the Republic of Ireland (the top country in 2001). Box 3 shows the top ten countries of birth for those born abroad – in 2011 these ten countries represented almost half (44.9%) of the foreign born population in England[69].

3.2 Current profile in Wales: ethnicity, language, religion, age and characteristics of the foreign born

Ethnicity in Wales

Census data show that in 2011 more than nine out of ten (93.2%) residents in Wales were White British (a higher proportion than the 79.8% in England), while 6.8% of the population (208,006 residents) was from a BAME group (Table 3). In 2011 Indian was the largest BAME group (0.6% of

Table 3 – Population by ethnic group in Wales in 2001 and 2011

Main groups	Subgroups	2001		2011	
		Number	(%)	Number	(%)
White[1]	English/Welsh/Scottish/Northern Irish/British	2,786,605	(96.0)	2,855,450	(93.2)
	Irish	17,689	(0.6)	14,086	(0.5)
	Gypsy or Irish Traveller		N/A	2,785	(0.1)
	Other White	37,211	(1.3)	55,932	(1.8)
Mixed/multiple ethnic groups	White and Black Caribbean	5,996	(0.2)	11,099	(0.4)
	White and Black African	2,413	(0.1)	4,424	(0.1)
	White and Asian	5,001	(0.2)	9,019	(0.3)
	Other Mixed	4,251	(0.1)	6,979	(0.2)
Asian/Asian British	Indian	8,261	(0.3)	17,256	(0.6)
	Pakistani	8,287	(0.3)	12,229	(0.4)
	Bangladeshi	5,436	(0.2)	10,687	(0.3)
	Chinese	6,267	(0.2)	13,638	(0.4)
	Other Asian	3,464	(0.1)	16,318	(0.5)
Black/African/Caribbean/Black British	African	3,727	(0.1)	11,887	(0.4)
	Caribbean	2,597	(0.1)	3,809	(0.1)
	Other Black	745	(0.0)	2,580	(0.1)
Other	Arab		N/A	9,605	(0.3)
	Any other ethnic group	5,135	(0.2)	5,663	(0.2)
Total	All ethnic groups	2,903,085	(100)	3,063,456	(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

the population or over 17,000 people), followed by Other Asian (16,318 people), White Irish (14,086) and Chinese (13,638). Similar to England, comparison with the 2001 Census shows that there was an increase in the number of residents across all BAME groups, with the exception of the White Irish. There was a decrease in the proportion of White British (from 96.0% to 93.2%), although there was an increase in numbers (68,845 additional people).

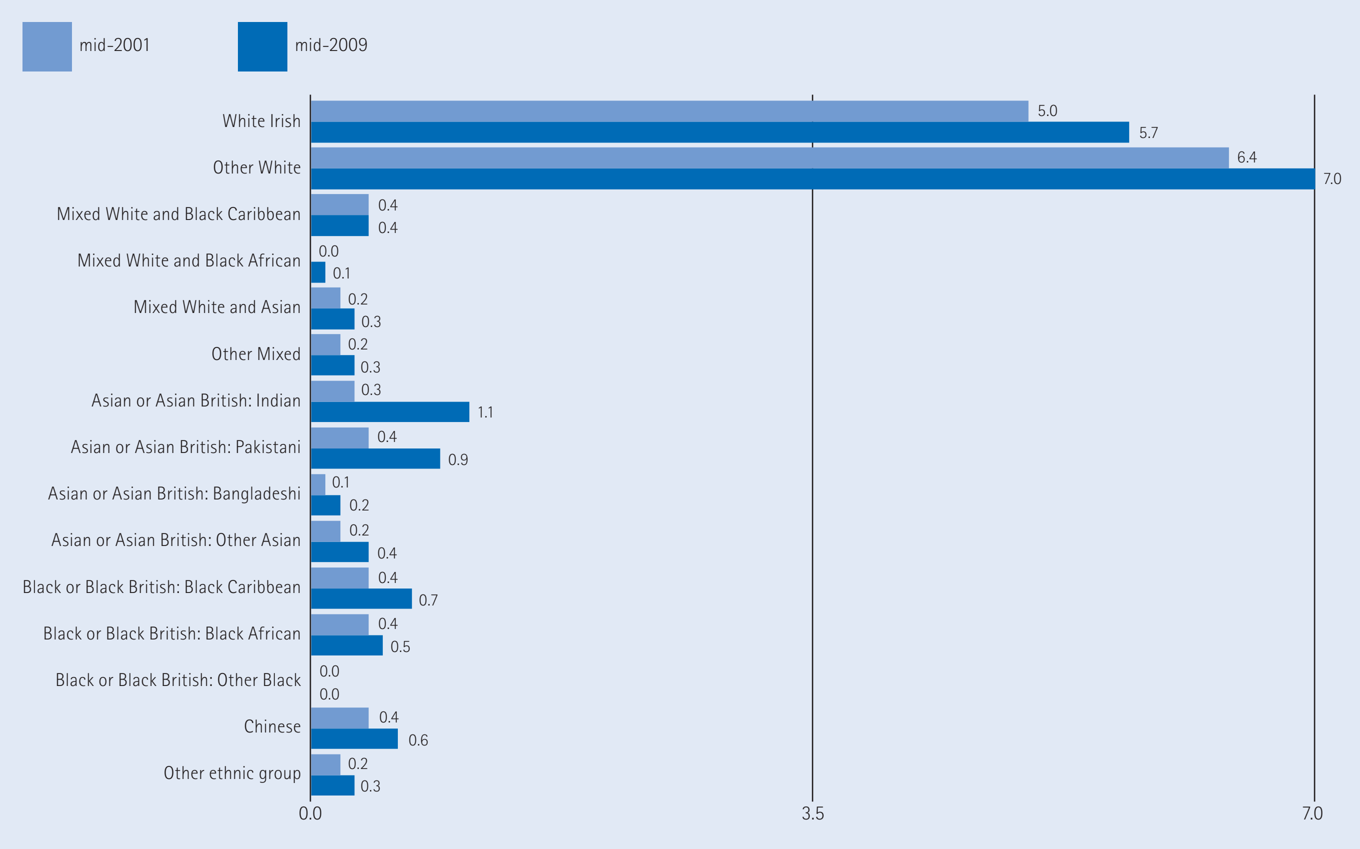
Age distribution of the BAME groups in Wales

Similar to England, ONS data show that in Wales most of the population (96.6%) aged 65+ is White British. In mid-2009 it was estimated that there were over half a million White British people aged 65+ (compared to over 18,000 amongst BAME groups)[60]. Data also show, however, that most ethnic groups have been ageing since mid-2001 (exceptions are Mixed White and Black Caribbean and Other Black in which numbers of older people remained roughly the same)[60, 61]. Amongst non-White BAME groups, the Indian (over one thousand people), the Pakistani (almost one thousand people) and the Black Caribbean (around 700 people) groups have the highest number of people aged 65+ (Figure 4). The group with the lowest number of older people is the Other Black (less than a hundred people)[72]. Similar to England, in Wales the White Irish are the group with the highest proportion of people aged 65+ (35.4% of its population), followed by the White British (19.0%) and Black Caribbean (12.3%)[60].

Religion in Wales

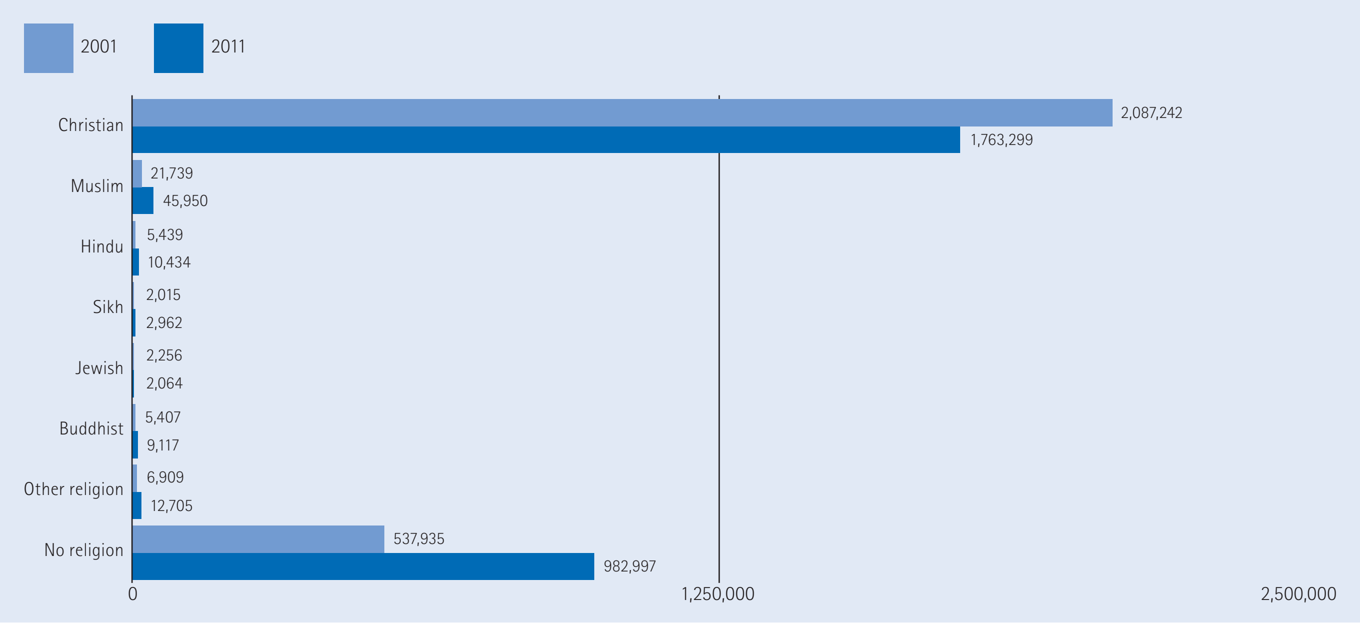
More than half (57.6%) of the population in Wales described themselves as Christian in 2011, while almost a third reported having no religion[63]. Over 233,000 people did not answer the question on religion (numbers not shown in Figure 5). The second most reported religion was Muslim, which represented 1.5% of the population in Wales. When comparing 2001 with 2011 there was an increase for all religions, except for

Figure 4 – Estimated number of people aged 65+ from BAME groups in Wales (in thousands)



Sources: Office for National Statistics (2011). Table EE4: Estimated resident population by ethnic group, age and sex, mid-2001. Rel. 8.0. Table EE4: Estimated resident population by ethnic group, age and sex, mid-2009. Rel. 8.0.

Figure 5 – Religion in Wales in 2001 and 2011



Source: Office for National Statistics (2013). 2001-2011 Census comparator tool. Key statistics interface v2.5

Jewish (decrease from 2,256 to 2,064 people) and Christian (decrease from almost 2.1 million to 1.7 million people) (Figure 5). There was an increase in those who reported having no religion (from over half a million to almost a million people).[58, 63]

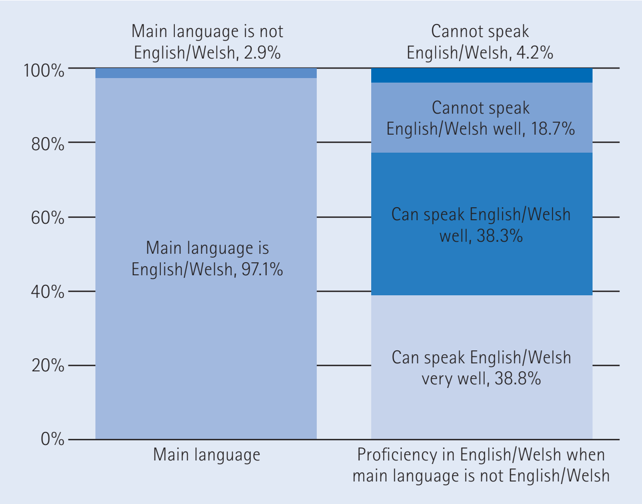
Language in Wales

In 2011, 97.1% of the population in Wales spoke English or Welsh as their first language. Similar to England, the second most spoken language was Polish (0.6% of residents or 17,001 people). This was followed by Arabic (6,800 people), Bengali (5,207) and Tagalog/Filipino (2,749 people)[65].

The overwhelming majority (77.1% or 65,131 people) of people who did not speak English as a first language could either speak it well or very well (Box 4). The remaining residents (19,305 people) whose main language was not English either could not speak English well or could not speak it at all[66].

Box 4 – Residents' top ten main languages and English proficiency in 2011 (Wales)

Top ten main languages	Number	(%)
English or Welsh	2,871,405	(97.1)
Polish	17,001	(0.6)
Arabic	6,800	(0.2)
Bengali (with Sylheti and Chatgaya)	5,207	(0.2)
Tagalog/Filipino	2,749	(0.1)
Portuguese	2,451	(0.1)
Urdu	2,350	(0.1)
French	2,073	(0.1)
German	2,050	(0.1)
Italian	1,694	(0.1)
All other languages	42,061	(1.4)
All residents aged 3 and over	2,955,841	(100)



Sources: Office for National Statistics (2012). Table QS204EW. 2011 Census: Main language (detailed), local authorities in England and Wales. Office for National Statistics (2012). Table QS205EW. 2011 Census: Proficiency in English, local authorities in England and Wales

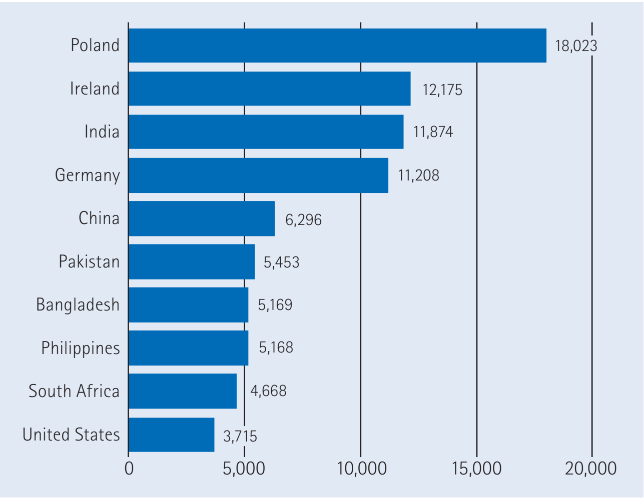
Foreign born populations living in Wales

In 2011, 5.5% of the population in Wales (167,871 people) was foreign born, an increase from 3.2% (or 92,263 people) in 2001[69]. More than three out of five foreign born residents (107,082 people) arrived in the UK when they were aged between 15–44 years, and almost a third (53,077 people) were children under the age of 14[69] (Box 5). A total of 1,652 people (or 1.0% of the foreign born population) arrived when they were aged 60 or older. More than half of the foreign born population (55.7%) living in Wales in 2011 arrived in the UK after 2001.

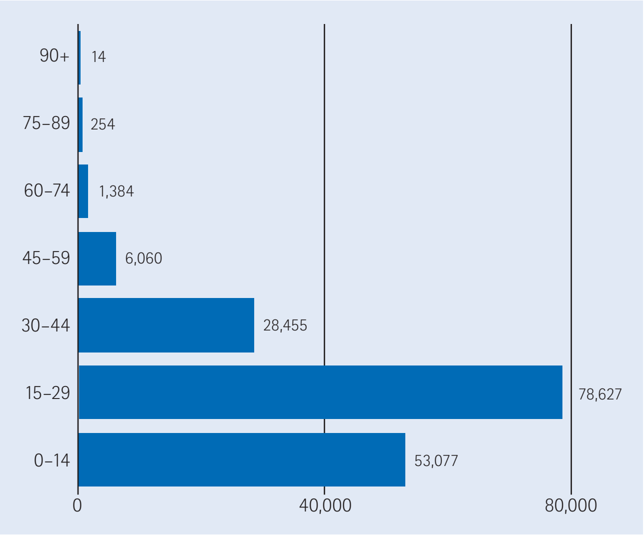
In 2011 Poland was the most reported country of birth (with 18,023 people or 10.7% of the foreign born population); this was followed by Ireland (12,175), India (11,874), Germany (11,208) and China (6,296). The top ten countries of birth are shown in Box 5; in 2011 half of people (49.9%) who were foreign born were born in one of these top ten countries[69].

Box 5 – Usual residents in Wales born outside the UK

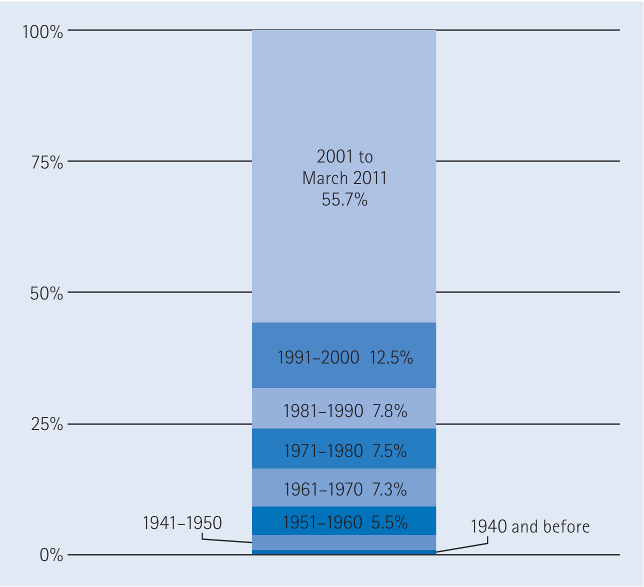
Top ten countries of birth amongst the foreign born (2011)



Age at arrival (2011)



Most recent year of arrival (2011)



Sources: Office for National Statistics (2012). International Migrants in England and Wales 2011. Office for National Statistics (2012). 2011 Census: Key Statistics for England and Wales, March 2011. Statistical Bulletin. Office for National Statistics (2012). Table QS802EW. 2011 Census: Age of arrival in UK, local authorities in England and Wales. Office for National Statistics (2012). Table QS801EW. 2011 Census: Year of arrival in UK, local authorities in England and Wales

3.3 Current profile in Scotland: ethnicity, religion and characteristics of the foreign born

In the past Scotland has attracted migrants from several parts of the world, especially from Pakistan, India, Italy, Poland and China. It also has one of the largest populations of asylum seekers[73]. Data from the 2011 Census on ethnicity are not yet available, but 2001 data show that White Scottish and Other White British together represented 95.5% of the population (over 4.8 million people)[74, 75] (Table 4). Other White were the largest ethnic group (1.5% of the population), followed by White Irish (1.0%), Pakistani (0.6%), Chinese (0.3%) and Indian (0.3%). Data from the 2001 Census also showed that the BAME groups had a younger age distribution than the White groups (except for the White Irish)[75].

According to the APS in 2009 all the White groups represented 67% of the population (which would mean a substantial decrease in the proportion of White people). Asian ethnic groups were estimated to represent 16%, Black 5%, Chinese 4% and others 6%; estimates for the Mixed category were considered to be unreliable[38]. It is difficult to make comparisons with the 2001 data because the presented ethnic categories are different from the ones shown in the 2001 Census (presented below). However, current available data on migration also suggest that the proportion of people from BAME groups has increased since 2001[73].

Religion and foreign born populations living in Scotland

Census data in 2001 showed that over two-thirds of the population in Scotland was Christian (Church of Scotland, Roman Catholic or other Christian), followed by Muslim (0.8%) (Box 6). Furthermore, 27.5% of the population declared not to have any religion[75, 76].

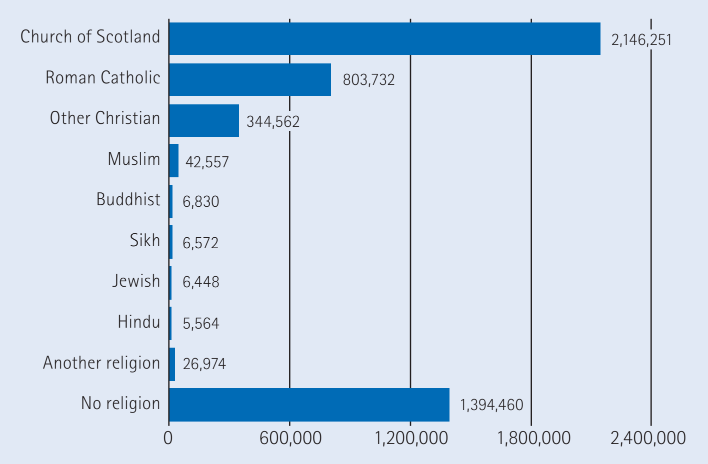
Until 2002, migration patterns were characterised by more people leaving than moving to Scotland[73]. In the past decade this has changed and in-migration from overseas has been increasing; from mid-2010 to mid-2011 it is estimated that 42,300 people had come to Scotland from overseas (while 16,900 people left Scotland to go overseas)[73]. Of the non-UK born population, the population born in the EU doubled from 69,000 people in 2004 to 154,000 in 2011. The ONS estimates that the population born outside the EU also increased during this period[73, 77]. The accession of the A8 countries (those born in Poland, Lithuania, Latvia, Slovakia, Estonia, Hungary, Slovenia and Czech Republic) to the EU in 2004 has contributed to this increase in migration[73, 77]. Most migrants (in both directions) are young; 71% of migrants from

Table 4 – Population by ethnic group in Scotland in 2001

Groups	Number	(%)
White Scottish	4,459,071	(88.1)
Other White British	373,685	(7.4)
White Irish	49,428	(1.0)
Any other White background	78,150	(1.5)
Indian	15,037	(0.3)
Pakistani	31,793	(0.6)
Bangladeshi	1,981	(0.0)
Chinese	16,310	(0.3)
Other South Asian	6,196	(0.1)
Caribbean	1,778	(0.0)
African	5,118	(0.1)
Black Scottish or any other Black background	1,129	(0.0)
Any mixed background	12,764	(0.3)
Any other background	9,571	(0.2)
All ethnic groups	5,062,011	(100)

Source: General Register Office for Scotland. 2001 Census: Table UV10 Ethnic Group (Scotland)

Box 6 – Religion and top ten countries of birth in Scotland (2001 Census and 2011 estimates)



Estimated top ten countries of birth (thousands)	Number (%)
Poland	67 (1.3)
India	24 (0.5)
Republic of Ireland	22 (0.4)
Germany	19 (0.4)
Pakistan	16 (0.3)
United States of America	15 (0.3)
South Africa	13 (0.3)
Canada	9 (0.2)
Australia	8 (0.2)
France	6 (0.1)

Sources: General Register Office for Scotland. 2001 Census: Table UV16 Current Religion (Scotland). Office for National Statistics (2012). Table A: Estimated population resident in the United Kingdom, by country of birth. Countries of the United Kingdom and Regions of England. January 2011 to December 2011.

overseas are aged 16–34 years old – compared to 25% of the resident population)[73].

Estimates show that, in 2011, 93.4% of the population in Scotland was born in the UK, a higher proportion when compared to England (86.2%), but lower than in Wales (94.5%)[78]. Poland and India were the top two countries among the foreign born population, but in an inverse direction when compared to England: Poland was the first (1.3% of the population or 67,000 people) while India was the second (0.5% of the population or 24,000 people)[78] (Box 6).

3.4 Current profile in Northern Ireland: ethnicity, language, religion and characteristics of the foreign born

Ethnicity in Northern Ireland

Reports on ethnicity in Northern Ireland suggest that the composition of BAME groups in this country is different from the one shown in England and Wales[68]. There is much less of a history of post-colonial immigration, for example. Settlement is reported to have happened in both urban and rural areas as opposed to just urban areas (as in England and Wales) with a wider spread of minority ethnic populations as a consequence[68]. Since 2004 there has been a substantial rise in migration from Central and Eastern Europe (as can also be observed in England and Wales), especially from the A8 nationals[68].

According to the Census, 98.2% of the population in Northern Ireland was White in 2011[79, 80] (Table 5); comparison with data from other UK countries is difficult since there are no White sub-categories. Data on White ethnic minorities are therefore not available. The Chinese was the largest non-White BAME group in 2011 (6,303 people or 0.3% of the resident population), followed by Indian (6,198 or 0.3%). Comparison with the 2001 Census shows that the number of people from a White ethnic group has increased, although this has not been accompanied by an increase in proportions. With the exception of the Irish Traveller, all other BAME groups have increased in number in the past ten years[80].

Religion in Northern Ireland

In 2011 the overwhelming majority of the population in Northern Ireland was Christian (almost 1.5 million people or 82.3% of the population), with Catholics (or Roman Catholics) as the largest group (40.8% of the population in this country). Other religions and philosophies (all religions other than Christian) represented 0.8% of the population (within which Muslims represented 25.8% with 3,832 residents and Hindus 16.0% with 2,382 residents). When comparing 2001 with 2011 we see that the number of people with Other religions has increased by 195.5% (from 5,028 residents

Table 5 – Population by ethnic group in Northern Ireland in 2001 and 2011

Ethnic groups	2001 Number	(%)	2011 Number	(%)
White	1,670,988	(99.2)	1,778,449	(98.2)
Chinese	4,145	(0.2)	6,303	(0.3)
Irish Traveller	1,710	(0.1)	1,301	(0.1)
Indian	1,567	(0.1)	6,198	(0.3)
Pakistani	666	(0.0)	1,091	(0.1)
Bangladeshi	252	(0.0)	540	(0.0)
Other Asian	194	(0.0)	4,998	(0.3)
Black Caribbean	255	(0.0)	372	(0.0)
Black African	494	(0.0)	2,345	(0.1)
Black other	387	(0.0)	899	(0.0)
Mixed ethnic group	3,319	(0.2)	6,014	(0.3)
Other ethnic group	1,290	(0.1)	2,353	(0.1)
All ethnic groups	1,685,267	(100)	1,810,863	(100)

Sources: Northern Ireland Statistics and Research Agency (2002). 2001 Census: Ethnic Group (administrative geographies). Northern Ireland Statistics and Research Agency (2013). Ethnic Group – Full Detail: QS201NI.

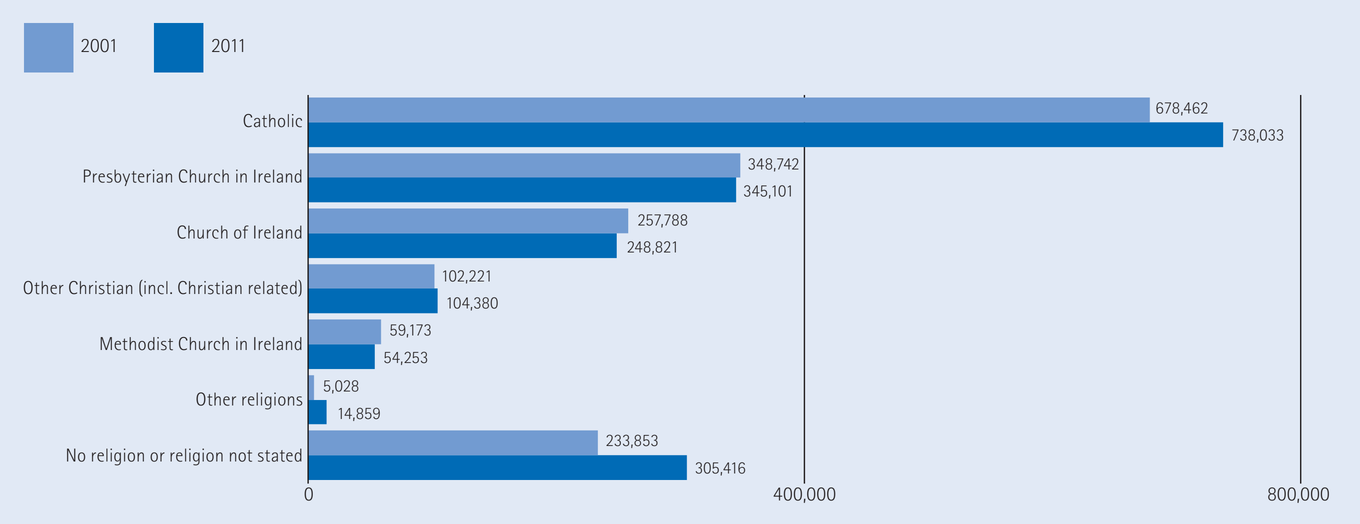
to 14,859); we also see a small increase for Other Christian (2.1% increase), Catholic (8.8% increase) and a more substantial increase for those who either reported having no religion or did not state their religion (30.6% increase in numbers, reaching over 300,000 people in 2011)[81, 82] (Figure 6).

Language in Northern Ireland

Similar to Wales, 96.9% of the population in Northern Ireland had English as their principal language in 2011. Following trends from England and Wales, the second main language was Polish (17,731 people or 1.0% of the population). This was followed by Lithuanian (6,250 people), Gaelic/Irish (4,130 people) and Portuguese (2,293 people) (Box 7). Although Chinese is not present in the top ten languages, when putting Mandarin Chinese, Cantonese and Chinese not specified together they sum up to 3,580 residents (occupying then the 5th place)[83].

Almost three out of four (73.5%) people who did not have English as their main language could either speak it well or very well, the remaining

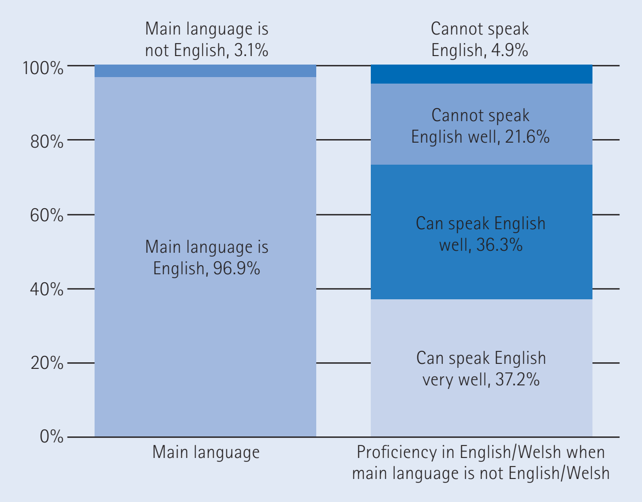
Figure 6 – Religion in Northern Ireland in 2001 and 2011



Sources: Northern Ireland Statistics and Research Agency (2002). 2001 Census: Religion (administrative geographies). Northern Ireland Statistics and Research Agency (2013). Religion – Full Detail: QS218NI.

Box 7 – Residents' top 10 main languages and English proficiency in 2011 (Northern Ireland)

Top ten main languages	Number	(%)
English	1,681,171	(96.9)
Polish	17,731	(1.0)
Lithuanian	6,250	(0.4)
Gaelic (Irish)	4,130	(0.2)
Portuguese	2,293	(0.1)
Slovak	2,257	(0.1)
Tagalog/Filipino	1,895	(0.1)
Latvian	1,273	(0.1)
Russian	1,191	(0.1)
Malayan	1,174	(0.1)
All other languages	16,346	(0.9)
All residents aged 3 and over	1,735,711	(100)



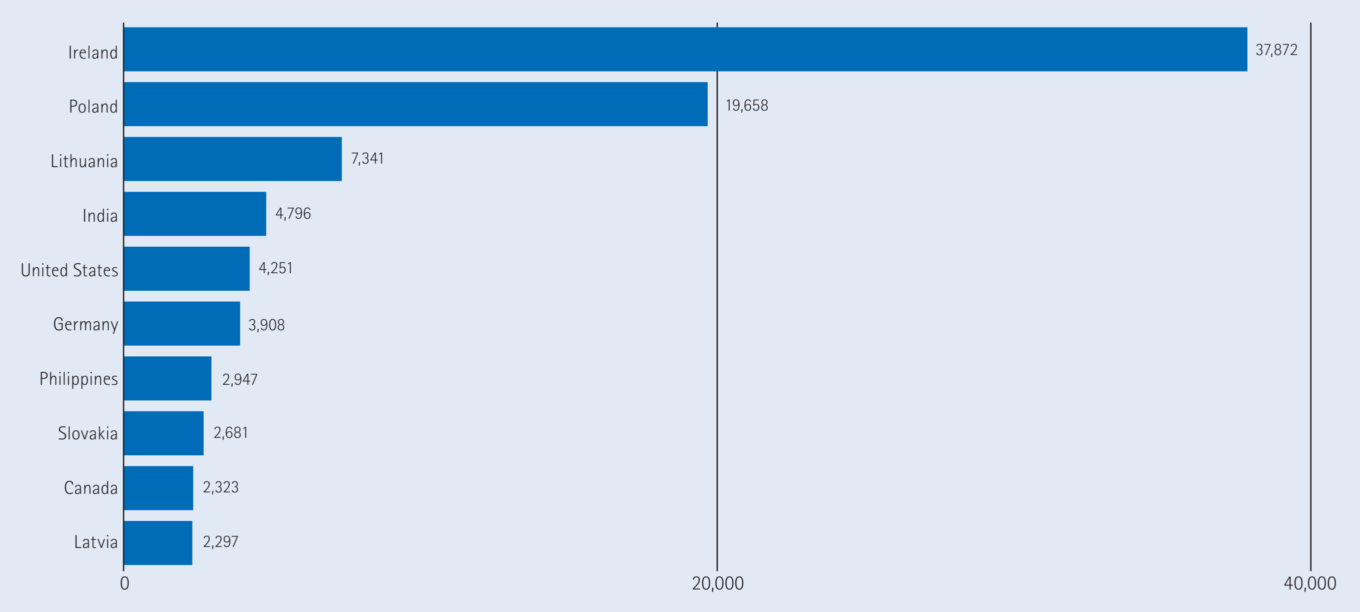
Source: Northern Ireland Statistics and Research Agency (2013). Main Language – Full Detail: QS210NI. Northern Ireland Statistics and Research Agency (2013). Proficiency in English: QS211NI (statistical geographies)

quarter (14,469 people) either could not speak English well or could not speak it at all[84]. Recently published statistics show that the top two languages when requesting interpreters in Health and Social Care are Polish (20,385 requests in 2011 compared to 1,025 in 2005) and Lithuanian (11,680 requests in 2011 compared to 1,140 in 2005)[85]. It is worth noting, however, that the growing demand for the service is likely to reflect the growing availability of these services over time[68].

Foreign born populations living in Northern Ireland

According to the 2011 Census the proportion of the resident population born outside Northern Ireland rose from 9% (151,000) in 2001 to 11% (202,000) in 2011[86]. When considering residents born outside of the UK, the proportion of foreign born was 6.6% or 119,186 residents[87]. The top country of birth amongst the foreign born population was Ireland (almost a third of the

Figure 7 – Top ten countries of birth among the foreign born in Northern Ireland in 2011



Source: Northern Ireland Statistics and Research Agency (2013). Country of Birth – Full Detail: QS206NI foreign born population or 37,872 residents). This was followed by Poland (16.5% or 19,658 people) and Lithuania (6.2% or 7,341 people)[87] (Figure 7). This is consistent with the observed increased levels of migration from the A8 countries in the past decade[68].

Recent estimates (2011) on age from the LFS show that the foreign born population is generally younger than the average Northern Ireland resident, with 82% under the age of 45 (compared with 62% of the overall population). Estimates for the foreign born over the age of 60 could not even be calculated because numbers were considered to be too small[88].

3.5 Projected profile: UK population projections by ethnicity

Our database search identified three recent population projections describing the possible changes in the ethnic composition of the UK population. All of them estimate an upward trend in the numbers and proportions of people from BAME groups in the future (with variations across groups according to different projections). They also estimate that in upcoming decades the BAME groups should represent a higher proportion of older people in the UK.

Wohland et al[46] developed five different projections for the UK up to the year 2051. Under their benchmark projection (named TREND-EF), all ethnic groups show potential growth between 2001 and 2031 (with the lowest growth for the White British Group by 4% and the highest for the Other Ethnic Group by 350%). By 2051 the White ethnic groups are estimated to represent 79% of the population and the non-White BAME groups would represent the remaining fifth of the population. The White British and the White Irish shares of the populations are expected to shrink, the Black Caribbean share is expected to remain stable (at 1%) while the other BAME groups all expand their population shares (including the Other White group, which show the greatest gain in terms of proportion of the overall population). Projections also estimate that all ethnic groups will be ageing, with the share of BAME populations that are elderly becoming comparable with the White British share of 17% in 2001 (except for the Mixed groups which are expected to have smaller shares of older people). These changes will have both important regional and within region variation (in population sizes, shares and concentration). Authors also estimate that the BAME groups will move into less deprived local authorities, will become less segregated and more spread throughout the UK (going beyond the big cities where they are currently concentrated).

Coleman's projections[47] were presented based on four immigration scenarios: standard (current patterns of immigration would continue in the future), natural change (no international migration of any kind in or out), reduced migration and balanced migration (zero net migration – same number of people in and out of the UK). Results from his standard scenario show each BAME group (except for the White Irish) growing considerably up to the year 2056 and representing a higher proportion of the population (with a consequent reduction for the White British, Irish and Scottish population). The Mixed ethnic group is expected to grow (primarily by acquiring population from the other groups) and become the largest BAME group, although it would reach this only after 2071. The Black Caribbean population is projected to become one of the smallest groups relative to the others (although without reduction in absolute numbers), along with the Other Black group. All ethnic groups are projected to age, although some groups would do so faster than others. The Mixed group would be the youngest, while the Black Caribbean is expected to be the most aged by 2056.

Lievesley[45] focused mainly on the future ageing of BAME populations in England and Wales. His projections show that although BAME groups have a younger age structure than the majority White British population, numbers of older people will substantially increase in the upcoming decades. The non-White minority ethnic groups are projected to represent 16.2% (9.3 million) of the population by 2016 and 20.1% by 2026 (12.3 million people) (Table 6). By 2051 the Other White is expected to be the most rapidly growing group in number among all minority ethnic groups (followed by Black African, Pakistani and Indian groups). The White British and White Irish are the groups with the least growth and the Mixed

Table 6 – Ageing of all ethnic groups in England and Wales (2016 and 2026)

Ethnic groups	2016			2026		
	Population	(% of total)	% aged 65+	Population	(% of total)	% aged 65+
White British	44,916,749	(78.6)	17.5%	45,300,442	(74.3)	20.2%
White Irish	503,503	(0.9)	32.3%	432,873	(0.7)	35.9%
White other	2,448,220	(4.3)	8.3%	2,998,347	(4.9)	10.7%
Mixed – White / Black Caribbean	555,381	(1.0)	1.0%	773,642	(1.3)	1.4%
Mixed – White / Black African	219,529	(0.4)	1.9%	311,324	(0.5)	3.2%
Mixed – White / Asian	508,806	(0.9)	2.2%	725,221	(1.2)	2.7%
Other Mixed	450,885	(0.8)	2.3%	653,349	(1.1)	2.8%
Indian	1,789,111	(3.1)	7.5%	2,199,270	(3.6)	10.6%
Pakistani	1,309,696	(2.3)	3.9%	1,701,099	(2.8)	5.8%
Bangladeshi	561,296	(1.0)	3.1%	756,559	(1.2)	4.2%
Other Asian	477,642	(0.8)	6.7%	623,593	(1.0)	9.6%
Black Caribbean	706,575	(1.2)	10.0%	796,168	(1.3)	13.4%
Black African	1,220,923	(2.1)	3.3%	1,682,274	(2.8)	6.6%
Other Black	143,157	(0.3)	3.1%	174,683	(0.3)	5.7%
Chinese	662,350	(1.2)	4.6%	900,015	(1.5)	7.9%
Other	692,759	(1.2)	4.6%	961,728	(1.6)	7.1%

Source: Lievesley (2010). Table 14. Ethnic Minority population projections to 2051. Chart 34. Age structure of ethnic minority groups, England and Wales, 2016. Chart 36. Age structure of ethnic minority groups, England and Wales, 2026. In: The future ageing of the minority ethnic population of England and Wales. Older BME People and Financial Inclusion Report.

groups are projected to have strong growth rates (although increase in numbers would be moderate due to low starting numbers). The Indian group is estimated to have a lower growth rate, although the increase in numbers would be substantial due to the size of the population. The Black Caribbean and Other Black groups are estimated to increase two to three-fold and the Black African group is projected to increase more than six-fold by 2051.

The author emphasises that in general by 2016 the minority ethnic population will have a younger population than the majority White British group (Table 6); this is especially true for the Mixed groups. The White Irish group is an exception; it is estimated that by 2016 nearly a third of their population will be aged 65+ (which is actually similar to the estimates published by the ONS for the year 2009). The Mixed ethnic groups will show a very young population, with less than 3% aged 65+. The Indian group is estimated to have 7.5% of its population aged 65+; this would be accompanied by an increase in the number of younger children. Pakistani and Bangladeshi groups will continue to show high fertility, with up to 40% of their population under the age of 15 and less than 4% of people aged 65+. The Black Caribbean group will also age, while the Black African and Other Black groups will stay the same, having less than 3% of people aged 65+ and about a third under the age of 15. The Chinese are estimated to have less than 5% of their population aged 65+ (Table 6).

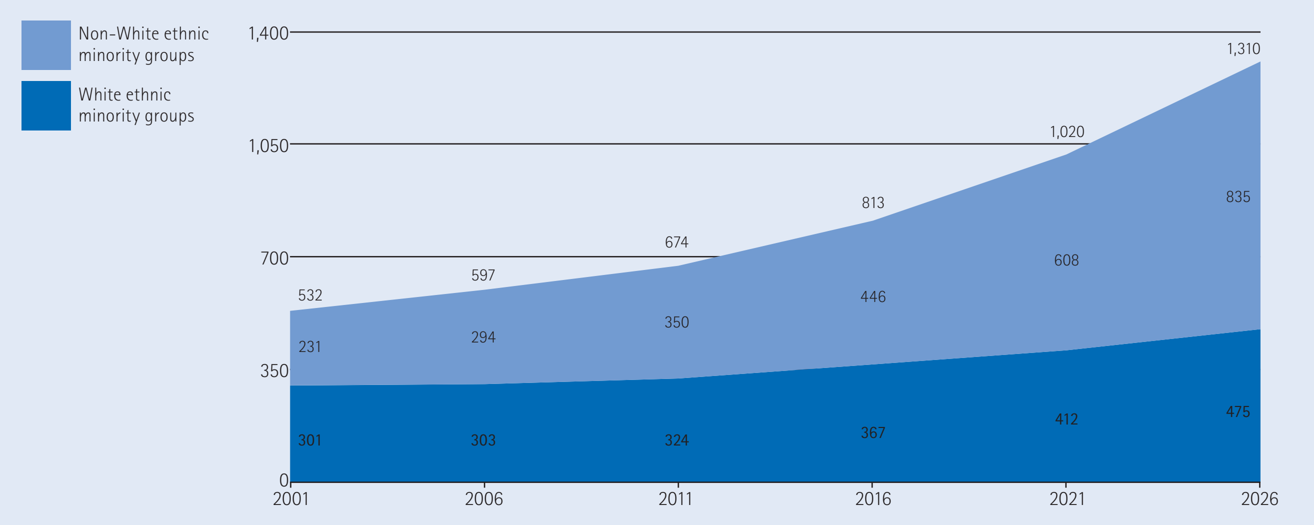
By 2026 most minority ethnic groups will still have a younger population structure, although there will be a substantial number of people aged 65+ (1.3 million people) and 70+ (almost half a million) (Box 8). In terms of numbers, the White Other (over 300,000 people) and the Indian (over 200,000 people) will be the BAME groups with the biggest population over the age of 65 (Box 8). The White Irish are estimated to have the highest proportion of people aged 65+ (35.9%), followed by the Black Caribbean (13.4%), White Other (10.7%), Indian (10.6%) and Other Asian (9.6%) (Table 6).

Box 8 – The ageing of minority ethnic groups according to Lievesley (2010)

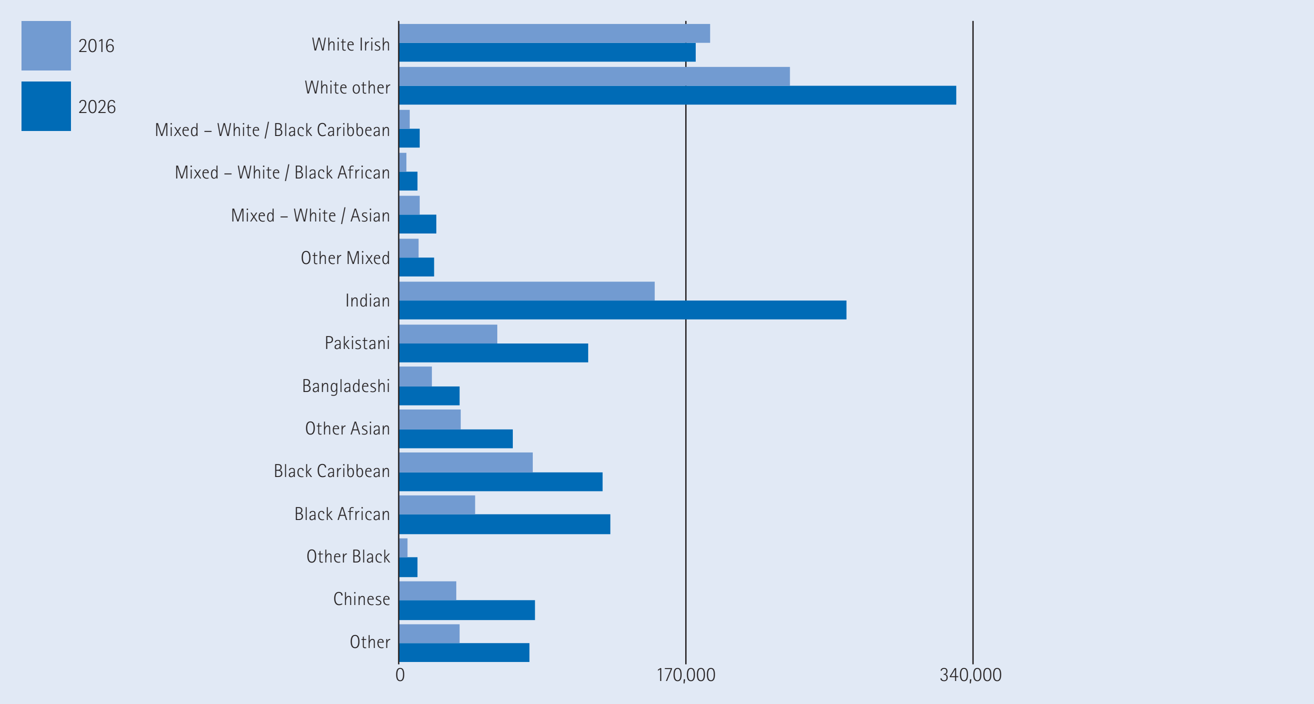
Number of people over the age of 50 by year (5-year trends up to 2026, in thousands)

Years	All minority ethnic groups			Non-White minority ethnic groups		
	50+	65+	70+	50+	65+	70+
2001	1,317	532	340	659	231	132
2006	1,556	597	376	868	294	172
2011	1,920	674	441	1,166	350	225
2016	2,412	813	510	1,541	446	269
2021	3,063	1,020	640	2,015	608	355
2026	3,857	1,310	822	2,572	835	496

Projected increase in number of 65+ (thousands)



BAME populations aged 65+ in 2016 and 2026



Source: Lievesley (2010). Table 14. Ethnic Minority population projections to 2051. Table 15. The future older ethnic minority population of England and Wales (thousands). In: The future ageing of the minority ethnic population of England and Wales. Older BME People and Financial Inclusion Report.

Summary of key points from Section 3

- Official Census data identify that the numbers and proportion of people from BAME groups is increasing in all the UK countries. This is especially true in England; in 2011 they represented a fifth of the total population (10.7 million people). This trend is expected to continue.
- In both England and Wales there was a reduction in the number of people who considered themselves Christian, an increase for all other religions and also for those who reported having no religion.
- Although the majority of people who do not have English as their main language can speak it very well or well, almost 900,000 people in the UK cannot speak English well or at all.
- Ethnic groups are not evenly distributed across England; London has the largest concentration of people from BAME groups but the North East has the least diversity. In some areas (for example a number of boroughs in London) there is evidence that BAME groups comprise the majority population while White British people represent only a fifth of the total population.
- While people from BAME groups are typically younger than the White British and White Irish peers there is evidence that some groups have experienced demographic changes during the last decade. There are, however, wide variations across BAME groups. In 2009 it was estimated that about 707,300 residents from BAME groups were aged 65+ in England and over 18,000 in Wales.
- Recent population projections identify that ageing trends are expected to continue. By 2026 it is estimated that there will be over 1.3 million people from BAME groups aged 65 or older, many of whom may experience life limiting illnesses that could benefit from care.

Issues to consider

- The number of people from BAME groups and those from religions other than Christianity are increasing. Approximately 900,000 residents in the United Kingdom do not speak English. Moreover, those from BAME populations are ageing, and many will experience life-limiting illness, including cancer. This trend is expected to continue with significant implications on the delivery of high quality culturally appropriate care – this must incorporate attention to peoples' background, beliefs, needs and preferences in relation to their place of care and location of death, amongst many other issues.

4. Literature reviews on palliative and end of life care for BAME groups

After the overview of the demographic characteristics and projected changes for BAME populations in the UK, we now move to what is known about palliative and end of life care provided to them. This Section presents the results from the systematic review on the current state of palliative and end of life care provision for BAME groups, focusing on disparities, unmet needs and recommendations to improve care.

4.1 Results

We identified 27,459 records in databases after removing duplicates and studies published before 1992. We excluded 26,317 records in stage 1 (screening titles), 851 records in stage 2 (screening abstracts) and 253 records in stage 3 (screening full-text) as they did not meet our inclusion criteria. Five papers which had reached stage 3 were excluded because the full publication was not available for full-text screening. A total of 29 records were included; one record was an abstract with preliminary results from a full-text review (these two records were considered as one review). Tracking of reference lists, discussion with an expert and searches at the NHS library added 17 reviews. As a result, there were 45 included reviews. More detailed information on the results of the selection process is presented in figure A18 in the Appendix.

4.2 Information on included studies

Details from all the 45 included studies are available in Table A19 in the Appendix. Key characteristics shown in the table are summarised below.

All but one review were published after 2000; two-thirds (n=30) of them were published in or after 2005. More than half of the reviews referred to minority ethnic groups living in countries other than the UK: 21 in the USA, two in Australia, one in Canada and one described data from several countries but did not include minority ethnic groups living in the UK. Seven studies focused on BAME groups in the UK and 13 included evidence from minority ethnic groups living in the UK and also other countries. Most reviews (n=37) either provided evidence for more than one minority ethnic group or referred to minority ethnic groups in general, while eight reviews provided evidence for a specific group. Minority ethnic categories were not consistent across or within reviews (e.g. use of African Caribbean, Black Caribbean or Caribbean), an issue raised by some authors when reporting evidence[89–94].

Most studies (n=36) either approached palliative and end of life care in general or covered more than one medical condition, while eight reported only on cancer and one only reviewed data for HIV/AIDS patients (Table A19 in the Appendix). The most commonly mentioned conditions were cancer (mentioned in 31 studies), dementia (mentioned in seven studies) and HIV/AIDS (three studies). Four studies focused on older people in general (Table A19 in the Appendix). The majority (n=43) of the reviews focused on reporting data from primary studies, but two focused on analysing data from reviews[25, 90].

Less than half (n=17) of the included studies were systematic reviews, eight were critical reviews following some aspects of a systematic approach (e.g. use of a search strategy, inclusion and exclusion criteria), 18 were narrative reviews not following a systematic approach and two were reports from the UK government (Table A19 in the Appendix).

4.3 Methodological quality

The 25 reviews which were either systematic, or had followed a systematic approach (Table A19 in the Appendix), were scrutinised for quality. Overall, quality of reviews was considered to be acceptable. However, certain individual quality criteria were not met by a substantial number of studies. Box A20 in the Appendix shows the complete quality assessment of reviews and their most common flaws.

4.4 Key findings on the current state of palliative and end of life care provision

Analysis of the included reviews identified disparities and unmet needs both in relation to access to, and actual provision of, palliative care services. Key findings are summarised in Figure 8. Aspects such as inadequate monitoring/coding of ethnicity, lack of adequate translation services, structural inequities in society and their consequences (such as cultural mistrust) and assumptions/stereotypes based on culture and ethnicity were found to permeate these key themes at different levels. These aspects are discussed alongside evidence on disparities and unmet needs; core issues on recording ethnicity and assumptions underlying research and practice are highlighted in Table 7 because is it vital to be aware of them when interpreting the findings. It is also worth noting that disparities are not necessarily equivalent to unmet needs or inequities in care. Causes of disparities are complex and varied; evidence does not always present them in contrast with actual needs and preferences from minority ethnic groups.

Table 7 – Core issues regarding ethnic monitoring and assumptions regarding ethnicity

Ethnic monitoring	Core assumptions in research and practice
• Recent, making it difficult to compare data across time[92] • Not compulsory[92] • Does not reach all groups[92] • Definitions vary, no consensus on the use of terms[92, 93] • Use of proxies (e.g. place of birth instead of ethnicity, ignoring second and third generations) has limitations[89, 92] • Incomplete identification in medical/national records[25, 89, 95, 96] • Very little reliable information nationally (UK) on access and uptake[89, 91, 97] and also on professionals from minority ethnic groups[89] • Poor level of data for incidence/prevalence of conditions by minority ethnic group[89, 97] • Misunderstandings and failure to see the applicability of collecting data and indirect racial discrimination[98]	• Research with a monocultural perspective[92] • Habit to 'blame the victim' (e.g. people who mistrust the system are inherently mistrustful)[92, 99] • Habit to shift the burden of change to the patient[100] (e.g. by using the 'hard to reach' stereotype – they are the ones who are not accessible, not us)[101] • Lack of appreciation of heterogeneity of ethnic groups (minority or majority)[89, 102] • Think that all in a particular ethnic group (minority or majority) share the same values[89, 90, 93, 98, 101, 103–105] (e.g. on religion, food preferences, family values and decision making) • Not appreciate that same beliefs can be shared by different groups[101] • Use of culture and ethnicity as predictors of behaviour[93] • Lack of self-awareness of one's own beliefs and values underpinning attitudes[89, 96] • Lack of awareness that ethnicity is something that everyone possesses[25]

4.4.1 Unmet needs and disparities in access to palliative and end of life care

A common theme across studies was the low uptake of palliative and end of life care services for BAME groups. Potential explanatory factors for the low uptake included lack of referrals, lack of knowledge about services or about what palliative care involves and religious traditions and family values in conflict with the idea of palliative/hospice care. Other factors included structural barriers such as geographical location of inpatient hospices and social segregation, previous bad experiences when in receipt of care and demographic/epidemiological characteristics of BAME populations. These issues are discussed next.

Low uptake

Low uptake of palliative/hospice care services amongst minority ethnic groups has been repeatedly and consistently reported across several countries, especially in the UK and the USA, across different healthcare settings (such as services in the community, in inpatient hospices and in care homes)[25, 53, 89, 91, 92, 96–98, 100, 104, 106–120]. Exceptions to low uptake, however, are also reported. For example, indigenous Australians dying of cancer had greater use of palliative care services (hospital or community based) than other Australians according to Cunningham et al[95]. Ramey et al[113] reported that several studies examining only specific cancer diagnoses found no significant differences between Caucasian and African American patients or even reported increased use amongst African American patients. Connolly et al[53] reported that the care setting, the patient's condition and its severity might influence entering care, with minority ethnic groups with severe dementia living in a nursing home being equally or more likely to receive hospice care.

Lack of referrals, lack of knowledge and lack of information

Lack of referrals to palliative care in inpatient hospices/day care services was pointed out as one of the main reasons for low uptake[25, 28, 89, 97, 108, 115, 120, 121]. Reasons for this are multiple and include, amongst others, an assumption that family would provide care at home for cultural reasons, had the resources to provide the care/would risk stigma if they did not do so[97, 100, 104, 120], or lastly, fears of criticism from patients and relatives on 'giving up'[28, 89]. Referrals to palliative home care services (instead of referral to care in institutional settings) were more likely to happen for similar reasons[104, 121].

Lack of knowledge of what hospice/palliative care involves or how it works and low awareness/no information about existing services has also been highlighted[25, 28, 89, 91, 92, 97, 100, 101, 103, 108, 109, 113–117, 119], mostly for patients, but also for care providers[89, 100, 115, 116], including GPs[89], which in turn affects the number of referrals to palliative care. In the UK, Black Caribbeans reported not having received sufficient information about services more often than White peers; South Asian patients also reported receiving little information about relevant hospice care services[104].

The lack of information on relevant services in different languages and formats and across care settings/services is perceived as a barrier to knowledge/awareness, referral and consequently access to hospice care[25, 28, 91, 97, 98, 104, 108, 114, 115]. Lack of cultural equivalents for words such as 'palliative' and 'hospice' (or negative connotation of equivalents) has been pointed out as a particular problem[103, 104]. Poor skills in written and spoken English may also influence low uptake[103, 115]. This lack of knowledge may help to generate mistrust about the services[98, 113], and contribute to the thought that services (such as specific diets and space for their religious practices) are not available nor accessible to all[89, 93, 96, 98, 108, 114, 115, 117], have low quality[104, 111, 115] or inferior quality compared to aggressive care[117].

Religious and family issues

Religious traditions and family roles might also be seen as incompatible with palliative/hospice care[90, 100, 109, 113, 116, 117]. Accepting a terminal prognosis might imply giving up faith in God's power, or acceptance that it is really the end[28, 111, 117]. The patient's family might feel responsible for providing care[28, 89, 100, 116], although authors warned against assuming that family support was available since this is not always the case[25, 89, 105]. This assumption that minority ethnic groups 'look after their own' has been widely criticised[89, 101, 104, 115, 120]. Authors highlighted that demographic changes, presence of smaller families, more women working outside the house and socioeconomic circumstances (such as poor housing) might make home care challenging. Further, lack of referral at an appropriate time might generate acute admission to hospital when a patient is in a critical condition and their family cannot cope with the care[120].

The idea of open disclosure was described as Anglo-centric by authors and not appropriate or even offensive for some patients[89, 98, 122]. Some groups might avoid disclosing prognosis and diagnosis in order to protect the patient or avoid distress[52, 89, 123], although popular conceptions about the Chinese view to avoid open disclosure was questioned by Payne et al's review on Chinese views regarding end of life care[103]. Gunaratnam has also raised doubts about the belief that minority ethnic groups are more anxious about talking about death and dying[115].

Structural, demographic and epidemiological issues

Structural issues have also been identified as barriers[25, 92]. These include the fact that inpatient hospices are often (but not universally) located in White, middle class areas[92, 111] or services (healthcare in general and palliative care) are not available in more rural/remote areas[95, 100, 113, 123]. Social segregation[107] and social exclusion[115] in general, disparities in the cancer continuum[102] such as lower levels of cancer knowledge amongst minority ethnic groups[91, 97], can also indirectly affect access to palliative and end of life care.

Previous negative experiences in accessing general healthcare services that include instances of racism (individual and institutional), insensitivity and lack of cultural awareness[89, 91, 92, 97, 101, 104, 108], socio-economic factors (such as income, education, deprivation, lack of health insurance)[28, 92, 100, 108, 109, 111, 113, 116, 117, 121], heterogeneity in palliative care provision ('postcode lottery')[115] have also been pointed out as key factors influencing low uptake.

Finally, differences in age[25, 89, 91, 113, 114, 121] and medical condition[25, 28, 89, 91, 114] were presented as explanatory factors for differences in access to palliative care, since minority ethnic groups have a younger age structure compared with the White majority and also have a lower prevalence of certain types of cancer/more chronic conditions (in a context where palliative care is mostly provided for those with cancer). However, authors highlighted that these were not the main reasons for the lower uptake, and a few emphasised that not only is the minority ethnic population ageing, but also that changes in lifestyle and acculturation are changing the prevalence of cancer amongst these populations[25, 97, 115, 120].

4.4.2 Unmet needs and disparities when in receipt of palliative and end of life care

Most of the evidence on disparities and unmet needs for BAME populations when in receipt of palliative and end of life care referred to poor communication between healthcare professionals and the patient/family. The delivery of full and accessible information is crucial for impeccable assessment, and delivery of timely interventions to people at the end of life and their families. Moreover, these interactions rely heavily on high quality communication between health and social care professionals and patients and their families. The inability to engage in communication not only affects access to palliative care services but has been shown to be a source of serious problems in clinical consultations and the cause of misunderstandings amongst patients, family members and healthcare providers[37, 124].

Another widely discussed area involved differences regarding end of life decisions (such as a lower use of advance care planning documents and more choices of aggressive treatment). Reports on differences regarding health outcomes were less common, although a few authors described differences regarding treatment of pain, place of death and satisfaction with care.

Communication

Poor communication has been identified as a serious problem when providing care to minority ethnic groups[25, 89, 92, 99, 101, 102, 104, 119]; this is associated with lack of sensitivity to cultural and religious issues (and consequent poor understanding of needs)[92, 101, 102, 119] and lack of translation resources[25, 90, 101, 102, 104, 115]. Elkan et al emphasised that barriers to appropriate communication between healthcare professionals, patients and their families can lead to poor experiences of care[101]. There is some evidence that medical doctors are less empathetic with minority ethnic groups[102]. Minority ethnic groups have also felt that they have been mistreated because of a lack of respect or recognition of their ethnicity or gender[104]. Cemlyn et al reported that lack of cultural familiarity in hospitals may make patients from Gypsy and Traveller communities feel threatened and scared[119]. Some authors reported situations in which religious needs were unmet (such as lack of space/time for praying, no support for required rituals at the time of death or space for bigger families to mourn or weep if needed)[89, 101, 115]. Poor communication and lack of sensitivity to cultural issues can also make it difficult to assess symptoms and explain medications[89, 99], cause problems when trying to diagnose anxiety and depression (described as physical symptoms due to problems with stigmatisation)[104] and can impede a doctor's ability to assess the patient's mental competence to make informed decisions[123].

Some authors reported that communication can become more difficult when the cultural background of the doctor, nurse and patient differ[122] or when inequalities in power (which are already present in a doctor-patient relationship) are intensified by communication difficulties when a patient speaks poor English, or is from a different cultural background[104]. A dearth of minority medical doctors and other health professionals who could be more understanding[89, 100], a low number of female doctors for Muslim women and not many advocates for a wide variety of ethnicities are also pointed out as problems[101].

Similar to factors associated with access to care, language barriers are reported as a problem when receiving care, affecting comprehension of information and communication[101]. There are reports of lack of appropriate translation, interpreting facilities, availability of appropriate interpreters and advocacy schemes[90, 101, 102, 104, 115]. This can lead to relying on family members for translation and can generate issues such as relatives willingly or unwillingly censoring information, problems with sharing sensitive data and children skipping school to help with translations[25, 101, 104, 123]. There are also issues with professional interpreters who lack experience dealing with people with a terminal illness or have limited knowledge of palliative care services, operational issues such as difficulties in knowing when to book them and limited resources to find them[104]. Provision of linkworkers and advocate schemes have been described as patchy, disconnected and limited by low awareness of their need, low pay, low status and the lack of professional recognition of a proper career[89].

These communication problems are detrimental not only for patients and their family carers, but also cause considerable uncertainty for professionals caring for minority ethnic patients. Gunaratnam reports that this inability to communicate with minority ethnic patients and families can cause dissatisfaction and stress amongst professionals[115]. Poor communication can also lead to nurses having negative feelings and distancing themselves from patients[89], can result in hesitancy and inertia and consequently failure to do what is best for the patient[96].

Difficulties in communication are enhanced by an apparent scarce availability of training to help professionals address diversity, cultural values and health beliefs[90, 104], with hospice care providers also unaware of available cultural competency training[104]. Much of the training available involves 'fact-files' or 'cookbook approaches', which are heavily criticised for creating myths, stereotyping behaviours[25, 89, 90, 97, 104] and assuming that everyone from the same minority ethnic group behaves the same way. The 'fact-files' may also make professionals afraid to take risks in case they 'got it wrong'[89]. Several authors mentioned the importance of 'cultural competence training'[89, 98, 100, 103, 108, 109, 115, 125], while Evans et al warned that there is still no clear definition of what this should involve[23].

End of life decisions

Findings on end of life decisions were mainly shown in studies published in the USA (with most of the evidence about African Americans), although a few authors referred to UK BAME groups[103, 122]. Substantial evidence reports that minority ethnic groups are less likely to complete advance directives (known as advance decisions to refuse treatment in England) than the majority White[52–54, 93, 99, 111, 112, 123, 125–128]. They are also less likely to complete living wills (known as advance decision to refuse treatment and advance statements in England), have a Durable Power of Attorney (known as Lasting Power of Attorney in England) or a healthcare proxy and to indicate a wish for physician-assisted suicide[93, 99, 100, 109, 122, 125, 127, 129]. They are more likely to desire life-sustaining treatment and aggressive treatments such as artificial nutrition and cardiopulmonary resuscitation[25, 54, 93, 100, 102, 105, 113, 116–118, 122, 125, 126, 129], even when there is no hope for recovery. Evidence also suggests that minority ethnic doctors preferred aggressive care when presented with a hypothetical scenario[52, 100, 102, 105, 111, 112, 126–129]. There are reports of exceptions, however, with Korean Americans being positive about life-sustaining treatments, though not for themselves[54, 93, 122, 125]. Limited evidence shows that minority ethnic caregivers/surrogates of dementia patients in long-term care facilities and in the community were more likely to have made a decision to provide aggressive care (to admit to hospital and to perform surgery)[53]. The importance of ethnicity in end of life decisions seems to remain when accounting for other variables such as age, education or socio-economic status[125, 126, 129].

Reasons for these differences are complex and sometimes contradictory. The most commonly discussed issues were mistrust regarding the healthcare system[52, 54, 99, 100, 105, 111, 112, 117, 118, 122, 125, 126, 128–130], the importance of religion[54, 111, 127] and difficulties in trying to apply the Western model of autonomy to different cultures[90, 93, 96, 103, 122, 123, 128]. Mistrust seems to be influenced by the legacy of centuries of abuse and discrimination which results in a fear of being prematurely deprived of life or receiving sub-optimal treatment[95, 100, 105, 111]. It seems to affect both decisions to undertake aggressive treatment and decisions not to use advance care planning[129]. Completing an advance care planning document could give 'an excuse to limit treatment'[99] or allow minority groups to die in instances where their conditions could potentially have improved with an intervention[126, 128]. There is also the feeling that nothing in written legal documents would be followed[130].

Religion also has a fundamental influence in shaping treatment decisions at the end of life[90, 111, 127]. God may be seen as the only one with the power to decide life and death, the one capable of making miracles[111, 127]. Moreover, life-limiting interventions might be perceived as hastening death which is sometimes forbidden[127].

The Western values underpinning decisions at the end of life have also been discussed[52, 90, 93, 100, 111, 125, 128]. The idea of autonomy, right to self-determination and control over dying is not a universal value[93] and it is not shared in all parts of the world[100]. Many patients might prefer involvement in decision making by families and health professionals[52, 90, 96, 100, 105, 118, 123, 128]. The concept of advance care planning documents is not universally accepted[52] and might be seen as an 'intrusive legal mechanism' interfering with the family responsibility to care for their loving ones[93, 128], a violation of one's sense of identity and family[100]. In some cultures where the patient is protected from hearing their diagnosis while the family receives the information, discussing advance care planning might actually harm patients and their families[104, 122, 125].

Health outcomes, home death and satisfaction with care

Authors usually reported outcomes for minority ethnic groups using a narrative approach, with no meta-analysis or pooling of data/numbers, which represents a limitation of the original studies, not the reviews. Reporting ethnicity in intervention studies is the exception rather than the rule[131]. Evidence from three main outcomes was emphasised: pain[53, 89, 99, 100, 105, 106, 109, 116, 125], home death[98, 106, 110, 119, 123, 129] and satisfaction with care[89, 98, 104, 107, 113].

Most of the studies discussing pain are from the USA. They consistently show that minority ethnic groups show a significantly higher score for pain (even without a significant difference in opioid intake)[53, 109], are more likely to report under-treatment for pain or receive inadequate pain management[99, 100, 109, 116, 125] and die a more painful death in palliative care[105]. However, studies also highlighted that pain management was generally inadequate for patients from all ethnicities[109, 116]. Suffering pain was also related to the availability of opioid medication, which seems to be scarce in the USA in regions with higher concentrations of minority ethnic groups[99, 100, 109, 112, 116]. Other barriers to providing adequate pain management included a lack of awareness from health professionals that different people may have different attitudes and responses to pain[89, 116, 117]. Some may refuse pain medication because they wish to be conscious when dying or see enduring pain as a spiritual commitment or a test of faith[89, 100, 109, 117, 132] or might be concerned about becoming addicted to potent opioids[109, 112]. Pain severity might also be underestimated if verbal assessment of pain is expressed by different language speakers[89]; lack of interpreters may make it difficult to communicate pain and symptom control through using sign languages and diagrams[104].

Regarding place of death, there is some evidence that minority ethnic groups die at home less often [98, 106, 110, 119, 123, 129]. In the USA, Whites are more likely to die at home than non-Whites[110, 129]. In Canada, Kelly and Minty reported that most Aboriginal patients do not die at home (even though this seems to be their wish)[123]. In the UK, Caribbeans were less likely to say that caregivers or patients were given sufficient choice about the location of their death[98]. There also appears to be little support for Gypsies and Travellers to die at home (which also appears to be their wish)[119]. It is difficult to contrast this evidence with minority ethnic preferences for their place of death in order to confirm unmet needs since evidence on preferences for BAME groups is not widely available. There is some evidence that Chinese people living in the UK have a preference for hospital care (so hope could be maintained)[104] and have concerns about being in a hospice[25]. Moreover, those who are Bangladeshi in the UK often prefer repatriation to their country of origin (although this should never be assumed since preference is dependent on multiple factors, and this trend has been changing)[25, 89]. Limited evidence from the USA identifies a preference among African Americans to die at home [108].

Other reviews reported lower quality of care for minority ethnic groups in care homes[107], individual suffering[104], and less satisfaction with hospice care when compared to other groups[89, 113]. Caregivers of African Caribbean patients in the UK also reported a more problematic caregiving role at the end of life and more distress with patient symptoms[120]; care ratings by this group were also reported to be lower across several healthcare categories (such as receiving reassurance and support, being given a choice about treatment and greater dissatisfaction with care)[98]. There is also some evidence to suggest that those who were not satisfied with the services were more likely to suffer bereavement-related problems[89]. A minority of reviews reported no differences in outcomes in adjustment or role strain, personal strain or emotional strain (for African American caregivers of people with dementia)[53] and in quality of life across different minority ethnic groups[109].

4.5 Ways forward: Recommendations for policy, practice and research and best practices from reviews

The reviews reported a series of recommendations/measures to improve palliative and end of life care for minority ethnic groups, with most of them referring to practice and research. These are summarised in Tables 8, 9 and 10.

In terms of policy, authors recognised the importance of addressing both social and health disparities across the whole continuum of care in order to improve end of life care[53, 100, 105, 126, 130]. It was recommended that policies integrated values from all ethnic groups[52, 112, 115, 126, 128], instead of only the White majority, with the understanding that the involvement from BAME groups when developing strategies was a requirement for this to happen[95, 119, 126]. Authors also highlighted the need to provide palliative and end of life care for non-cancer patients[28, 89, 104] in order to reach the BAME community; some emphasised the need to improve ethnic monitoring at a national level[89, 98].

Recommendations for practice included the importance of training, especially regarding cultural competency, effective communication and translation services[56, 69, 70, 78, 85, 88, 93, 95, 96, 101]. Being sensitive and non-judgemental when having conversations was also seen as crucial to allow effective communication and meet patients' needs and preferences[76, 85]. Related to this was the widely recommended caution about avoiding stereotypes and treating each patient as an

Figure 8 – 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 prevalence 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 and insufficient availability of opioid medication (mostly USA data)
  - 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

individual (instead of a member from a certain group)[56, 72, 76, 77, 83, 93, 94, 99, 101, 106]. There were many recommendations to improve access, all involving direct interaction with BAME communities (such as outreach measures or recruitment of healthcare workers and volunteers from BAME groups)[89, 100, 104, 108, 109, 115].

Recommendations for research highlighted several research gaps regarding provision of palliative and end of life care for BAME communities. Many authors focused on the need to have more studies assessing the effectiveness of interventions on improving access or health outcomes[56, 84, 89, 98, 102] instead of more studies describing differences in the use of services. This would help us understand better whether disparities equate with unmet needs or inequities[121], which is not always clear with the current available evidence. The need to assess care currently being provided to BAME groups was also emphasised[28, 104, 113, 120]. Authors recommended more studies about needs and preferences from BAME patients, especially those who are usually not represented in research (such as White Irish, Gypsy or Irish Traveller and refugees)[89, 90, 104, 119]. There was the awareness that different research methodologies (such as developing prospective studies, carrying out multivariate analysis and using standardised measures) was required in order to build this knowledge[52, 89, 113, 116], and that ethnicity needs to be better captured when doing studies with BAME

Table 8 – Recommendations for policy from included reviews

Recommendations for policy

Making use of knowledge and supporting its development:

- Policy to be based upon systematic reviews to reflect the current evidence/minimise bias[25]
- Improve ethnic monitoring[89, 98], include White groups and religions[89] and provide data locally[98]

Reaching out, listening to and involving BAME communities:

- Ensure policies and end of life care programmes integrate values and preferences from minority ethnic groups instead of only those from the dominant culture[52, 112, 115, 126, 128]
- Involve minority ethnic groups when planning policy strategies to improve care at the end of life[95, 119, 126] and create public awareness campaigns[100]
- Provide high-quality palliative and end of life care for cancer and non-cancer patients[28, 89, 104]

Policies at a national level:

- Address social[115] and health disparities across the continuum of care[53, 100, 105, 126, 130]; fund national initiatives to improve access to healthcare[100]; and develop procedures to eliminate discriminatory practices[100]
- Create a national training strategy for bilingual health and support workers, but retain flexibility for local needs[89]
- Create nationally validated qualifications for the training of advocates, linkworkers and interpreters[89]
- Make information about palliative care available in different languages at a national level[89]

Table 9 – Recommendations for practice from included reviews

Recommendations for practice

Staff training[89, 98-100, 103, 104, 108, 109, 115, 125]:

- Train bilingual support workers, advocate and linkworkers to be sources of information[89]
- Cultural competency training for medical/nursing students[89, 125] and palliative care staff[89, 98, 100, 108, 109, 115 103]
- Communication skills training for palliative and end of life care staff and interpreters[98, 99, 104, 109]
- Interdisciplinary learning for health and social care workers, attorneys, and clergy providing palliative care[100]
- Two-way education between specialists and generalists to provide better access to palliative care[115]

Open, non-judgemental and ongoing communication[99, 127]:

- Carefully listen to patients and families[99, 127]; ask how they wish to hear and discuss medical information[112]; be respectful when practices are not acceptable to them[98, 127]; respond to their views[115], and provide necessary support (dietary, religious, family involvement)[89, 98, 105, 127, 133]
- Address each patient and family individually[98, 123], but apply general principles of good practice to all, regardless of ethnicity[101]
- Provide advocacy, intervention and support for family/friends[89, 115]
- Beware of stereotypes, be aware of differences within the same group[90, 93, 98, 101, 103–105, 112, 127, 128] and of own personal biases[93, 103, 112]
- Establish anti-racism/anti-discriminatory policies[89, 106] and create a code of conduct for staff and patients[89]

Reaching, listening to and involving BAME communities:

- Develop outreach measures to provide information about services[108, 115]: seek out agencies providing services to BAME communities, conduct presentations about hospice care[108]; develop community-based partnerships[89, 109] and encourage BAME communities[89, 104] and volunteer organisations[89] to participate
- Recruit individuals from BAME communities[89, 100, 108, 109], including bilingual volunteers[89, 108], have BAME representatives in the board of directors, advisory councils[108] and management committees[89]
- Provide information using various media to address all literacy levels[89, 108, 115]
- Have pain charts, dictionaries and phrase books for use in the absence of interpreters[89]

Building and sharing knowledge:

- Use robust research findings to inform practice[128] and ensure appropriate capture of ethnicity data[119, 120] to support research[120]
- Share experiences of good practice and recommendations with others[89]
- Develop a system of information provision for hospital consultants and GPs about available palliative care services for BAME communities[89]

populations[52, 89, 96, 120, 121]. Although several authors recommended cultural competency training, Evans et al[104] and Cox et al[122] were the only authors to show concerns about the need to better define what cultural-competent training means and the need of more evidence to explicate 'culturally sensitive care'. The issue was further highlighted by Evans et al in a recent systematic review focusing on cultural competence[94]. The authors emphasised that more research is needed in comparing different cultural competency approaches and assessing their impact on patient outcomes. They also warned that terms, definitions and models of cultural competency in the British literature lack clarity and consequently can complicate implementation[25, 94].

In addition to giving recommendations, a few authors gave examples of local practices designed to address disparities and meet the needs of BAME populations[89, 95, 101, 106, 109, 115, 119]. There is no requirement to report best practices in reviews, so a low number of authors doing this should not be seen as surprising. Some authors presented 'current practices' and therefore there was no description of their actual impact. Other practices were shown to have positive results, but since they were displayed as boxes or examples (instead of being part of the studies assessed by the reviews); there was very limited evidence on whether these practices were systematically proven to be effective. Authors in one review created a model of culture to be used to integrate cultural knowledge into clinical practice, but provided no information on whether the model had been tested[112]. Despite these limitations, the examples given are summarised in Table A21 in the Appendix; these help to show that initiatives are usually locally-based instead of being part of a national programme to improve care locally, an issue raised by Elkan et al[101]. Another issue raised was the fact that programmes were short-term, which could potentially only have a short-term effect on improving care[119].

Table 10 – Recommendations for research from included reviews

Recommendations for research

Self-awareness and understanding of the current social context:

- Be aware of own cultural biases[92], stereotypes[90, 92], be culturally knowledgeable and sensitive and consider the broader social context when analysing data[92]

Better understanding cultural competency:

- Develop a consensus on what cultural competency training means/what programmes it should involve[104]; produce more empirical evidence to explicate culturally sensitive care[122]
- Assess whether cultural competency training has an effect on patient outcomes[89, 104]

More evidence on needs, experiences and health outcomes for BAME populations:

- Assess different needs, experiences and opinions of a diversity of BAME groups[89, 90, 104, 119]; include White minorities[89, 104], Gypsies and Travellers[119] and refugees[89]
- More accurate information on patient needs[28, 89, 96, 97], pain control and coping, preferences for care[52, 89, 103, 111], patient/carer views[96, 121], more bereavement studies[89], more on the role of primary healthcare teams as gatekeepers[28], more on palliative care provided in the community and in care homes[89, 96]
- Explore fully how spiritual beliefs underlie preferences/decisions at the end of life regarding treatment[89, 111, 113, 127]

More evidence on the effect of interventions on health outcomes – moving from descriptive studies:

- Assess the effect of patient/medical doctor conversations[102]
- Evaluate interventions to address disparities, inequalities and unmet needs at the end of life[91, 97, 104, 117, 120]
- Test communication techniques[93], pain treatments[109]; and interventions addressing patients' spiritual needs[127]
- Evaluate the actual care provided to BAME groups[28, 104, 113, 120]
- Move beyond patterns of service use[121]; determine whether disparities lead to differences in outcomes[98, 102, 113, 120, 121, 129] and adequately estimate need[121]

Including ethnicity more often as a variable in studies – and analysing it appropriately:

- Improve ethnicity data capture[52, 89, 96, 120] and include it more often as a variable in studies[121]
- More studies using representative samples, standardised and psychometrically sound measures[52, 116], more prospective studies of patients[52, 89, 113] and retrospectives of carers[89]
- More multivariate analyses that consider factors such as socioeconomic status and patient characteristics[52, 121]

Summary of key points from Section 4

- Reviews show a series of unmet needs and disparities in palliative and end of life care for BAME groups regarding access to, and receipt of care
- Issues such as inadequate coding and monitoring of ethnicity, social inequities in society, lack of translation services and making assumptions based on cultural stereotypes permeate these reported unmet needs and disparities
- In terms of access, evidence exists of poor access to palliative and end of life care for BAME groups when compared to the White majority (or White British in the UK). Associated factors included lack of referrals, lack of awareness/information from patients and professionals about available services, assumptions that care is not available, or that the family will provide care
- Inequities in the provision of palliative and end of life care are dominated by three key themes: communication, end of life decisions, and health outcomes
- Evidence of poor communication exists and is associated with lack of cultural sensitivity, poor translation services and scarce availability of training to help professionals address diversity
- Evidence on end of life decisions identified that minority ethnic groups were less likely to complete advance care planning documents and more likely to desire aggressive and life-sustaining treatments. This theme was associated with religious issues and in some instances cultural mistrust resulting from discrimination/mistreatment. Authors also highlighted that advance care planning is often based on Western values of autonomy and self-determination – these are not applicable to groups with a family/community approach to decision making
- Evidence on health outcomes is often absent. Where available, reports focus on worse pain outcomes (mostly USA data), differences in location of death (with patients from BAME groups less likely to die at home that the White majority/White British), and perceptions of lower satisfaction with healthcare at the end of life
- In addition to reporting unmet needs and disparities, reviews also provided several recommendations for policy, practice and research
- These recommendations included improvements in ethnic monitoring, involvement of BAME groups in developing policies, addressing social inequities, and developing policies and strategies at a national level (such as training and translated sources of information)
- Recommendations for practice included staff training (e.g. communication skills and cultural competency), open communication (avoiding stereotypes), reaching BAME communities, sharing experiences of good practice and improving the capture of ethnicity data
- Recommendations for future research focus on the elements of cultural competency and its benefits for BAME populations, studies examining the effectiveness of care provided to BAME groups, identification of BAME end of life needs including preferences, and better inclusion of ethnicity as a variable in studies

Issues to consider

- Data identify that palliative and end of life care for BAME groups has the potential for improvement. Evidence also highlights that there is much that we still do not know about care (for example health outcomes, experiences and unmet needs). Poor ethnic monitoring and coding of ethnicity exacerbate problems.
- Whilst recommendations exist for improving the care provided to BAME groups actual examples of best practice are much less common. Well-funded, rigorous research executed by skilled researchers is urgently required.

5. Take home messages

Equity is the core ethical principle underpinning discussion of ethnicity and healthcare. An equitable service would meet equal needs equally, but this requires a diversity in the organisation of services, to ensure uniformity in access, use and quality at the point of delivery[134]

This report made use of the most up-to-date demographic data for BAME populations in the UK. To our knowledge this is the first non-official Census publication to analyse the 2011 Census data. Adequate and current demographic data are crucial to understand local and national profiles of BAME populations. We also systematically identified and appraised evidence to describe the current state of palliative and end of life care provision for BAME populations, including available recommendations for policy, practice and research. The transparent/structured approach allowed us to summarise current evidence in a way that we hope will be useful for planning initiatives to improve palliative and end of life care for BAME populations.

5.1. Limitations of report and current evidence

Before discussing the implications of the data presented here it is important to acknowledge report limitations. These limitations regard the demographic data and the review on unmet needs and disparities for BAME groups.

Demographic data

Analysis of population trends by comparing Censuses is limited due to changes in ethnic categories, and use of different categories for different UK countries. Furthermore, since the UK ethnic composition is diverse and not evenly distributed across regions, the main ethnic categories from the Census might not be as relevant in some UK areas (although detailed data provided by the Census might be useful in these cases). Despite these limitations, using Census data is still the best way to estimate the ethnic composition of the UK population.

Report writing coincided with the release of some of the 2011 Census data, but unfortunately it was not possible to have access to aggregated tables (for example, cross-tabulating religion and ethnicity, or age and English proficiency). This would have allowed for a much richer analysis of the characteristics of BAME populations in the UK. Tables describing ethnic groups by age will be especially important in understanding the ageing of BAME groups and updating population projections. Relevant Census 2011 data for Scotland had not yet been made available and our analysis was restricted to less recent population estimates. Census data are only available every 10 years; the next couple of years will present the perfect opportunity for thoroughly analysing up-to-date information about BAME populations in the UK.

Another limitation refers to the population projections shown in the report. These were developed before the release of the 2011 Census data, and were based on less recent population estimates. Furthermore, the ONS has recently reported that migration levels have been underestimated in the past decade[135]. With new demographic data being released, it is timely to develop new projections based on the most recent estimates.

Due to the scope of the report we did not present a Section on epidemiology according to different ethnic groups; we also have not included a Section on social disparities in society. Both are crucial to understanding the findings presented here. Epidemiological information is important to estimate both current and future needs of palliative and end of life care for BAME populations. Furthermore, in order to fully understand the relationship between ethnicity and health we need to take into account the different forms of social disadvantage experienced by BAME groups and the ways in which racism can influence their health[136].

This report has also not discussed current initiatives which can potentially improve our understanding of the current state of palliative and end of life care for BAME groups in the UK, although we reported on best practices mentioned in the included reviews. The Cicely Saunders Institute is currently analysing 27 years (1984–2010) of death registration data in England (over 13 million records) and in the near future will publish trends in cause of death and place of death according to country of birth (as part of the GUIDECARE project: www.csi.kcl.ac.uk/guidecare.html). The national VOICES survey in 2011 was completed by 22,292 bereaved relatives across England, assessing the quality of care delivered to people in the last three months of their lives[137]. Data were collected on patients' ethnicity and the ONS provided country of birth information based on death registrations; VOICES results taking into account ethnicity should be published at a later date. The NEoLCIN (now part of Public Health England: www.endolifecare-intelligence.org.uk) is combining data from Hospital Episode Statistics (HES) (which contain information on patients' ethnicity) with mortality data from death certificates (which have data on cause of death and country of birth). Since January 2012 the National Records of Scotland requires every informant registering a death to indicate the ethnic group of the deceased[138]; this will allow for different analyses of mortality trends in the future. These studies and initiatives will help to shed light on unmet needs and disparities and could also highlight potential regional disparities in care according to ethnicity.

Systematic review

Other report limitations refer to the review on the current state of palliative and end of life care provision for BAME populations. Time and resource constraints influenced our decision to focus on reviews (instead of primary studies). We have attempted to cover reviews which were not published in peer reviewed journals (by checking the NHS Ethnicity and Health Library, reference lists of included studies and contacting an expert in the field). However, since we did not contact relevant organisations to enquire about other publications it is possible that we missed some which could be eligible for inclusion. We know this happened in at least one case: we tried to track an online publication found in the reference list of one included review[91] and the publication could not be found because the publishing organisation had ceased to exist and their website had been deactivated. We are also aware that there is a wide range of grey literature about experiences and needs from BAME communities, and since we focused on reviews these were only covered if our included reviews mentioned them, which was the case for some studies about UK populations[25, 89, 104, 115].

Our search strategy focused on identifying unmet needs, barriers and disparities. As a consequence, we did not cover studies which only reported on needs and preferences for BAME groups. This was not the aim of this review (although we reported needs and preferences when data were available from our included reviews), but such data could have helped to better associate disparities with unmet needs. Selective reporting of negative results and publication bias may have also influenced our findings and conclusions.

We made the decision not to exclude studies when their methodological quality could not be assessed or when reviews were considered to have low quality after assessment. We feel that by removing the 20 reviews which could not be assessed (because they did not follow a systematic approach) we would have excluded evidence from smaller studies and grey literature, which are very important sources of palliative and end of life care evidence for BAME groups. For example, by doing so two core reports published by the UK National Council for Palliative Care would have been excluded[89, 115]. By including these reviews we might have increased bias in our analysis since we do not know which methods they followed to select and analyse their evidence. However, it is difficult to estimate in which direction this bias happened. The included reviews which followed a systematic approach were shown to have acceptable quality (only four of them had mid-range major to extensive flaws), but many have also presented key shortcomings, especially regarding four items: not making it clear if their literature search was comprehensive, not making it clear whether bias in the selection of studies was avoided, not reporting criteria for assessing the validity of included studies and not assessing the validity of studies using appropriate criteria. Even considering these limitations, we feel it is best to include all reviews if the aim is to describe the current state of palliative and end of life care provision for BAME populations. The alternative would be to miss too much of the available evidence. It is important to highlight, however, that research on palliative and end of life care for BAME groups, similar to research in any other area, can only benefit from being more transparent when reporting methods of selecting and analysing data.

Finally, including reviews from non-UK minority ethnic populations might make it more challenging to generalise evidence to the UK population. Different countries can have different health systems, criteria for providing palliative care, different ethnic groups and socioeconomic characteristics. However, we felt that providing evidence from other countries would be useful to identify both differences and similarities regarding unmet needs for minority ethnic groups. Furthermore, most of the studies with non-UK populations focused on end of life care decisions (such as completing advance decisions to refuse treatment) and different outcomes for pain, which are areas in which UK studies are lacking. We feel that these reviews complemented UK data and helped to shed light on areas not yet widely investigated. Importantly, there is already a recently published systematic review appraising the provision of end of life care for minority ethnic groups which focuses only on UK studies reporting on the UK population[25]. We felt that there would be little use in doing a similar review unless we widened our scope, looked for evidence published after this review and thoroughly presented the authors' recommendations for practice, policy and research.

5.2 Where do we go from here?

We identified that both assessing demographic data and appraising evidence on access to, and the provision of, palliative and end of life care for BAME groups is not short of limitations. For both there are difficulties when trying to compare data. There are issues regarding out of date estimates for the former, and several problems due to different aims and studied populations and varied (or unknown) qualities of evidence for the latter. Nonetheless, the evidence allows us to discuss some issues which have considerable importance for future palliative and end of life care planning.

There is growing evidence that both the numbers and proportions of people from BAME groups are increasing in the UK, although there are wide variations across groups and these are unequally distributed across the UK. In 2011 the BAME groups represented a fifth of the entire population in England with proportions in the other UK countries also increasing. Population projections suggest that BAME groups will represent an even larger proportion of the UK population in the future. Provisional data and projections show us that these groups are not only ageing, but that the trend is expected to continue in the upcoming decades. Evidence also suggests that the incidence of cancer is expected to increase for different BAME groups. It is known that older people are more likely to suffer from cancer and chronic conditions such as dementia[27]; crucial decisions are now being made to fund health and social care for an escalating number of older people in the UK in the near future. Ageing people from BAME groups will be an important part of this picture[139]. Although in terms of proportion they will be the minority (when compared to the White British), they will, nevertheless, represent a substantial number of people in need of care at the end of life. Furthermore, in some parts of the UK, they are very likely to represent the majority of the population.

When analysing the evidence on palliative care and end of life care provision we identified a number of disparities and unmet needs both with access to, and receipt of care. For example, information about hospice services can be scarce; assumptions about how one should behave are common, lack of cultural awareness seems to be a problem and communication leaves much to be desired. The need for more adequate translation services was highlighted. There are differences in terms of place of death and reports of low satisfaction with care. There is yet much that needs to be known about needs and preferences of BAME groups, especially for some populations which are not widely researched. Common suggestions for improvements include more training in cultural competency and communication skills, wider availability of translation services and advocates. Involvement with the community and recruiting people from BAME groups was also strongly encouraged. At the same time, evidence was lacking on the effectiveness of cultural competency training, and also on interventions designed to improve health outcomes for patients.

If we contrast demographic data with the evidence it is difficult not to reflect on how care that is currently being reported as inadequate will be able to meet the needs and preferences of an increasing number of people from BAME groups in the future. Furthermore, there are other issues worth mentioning. White minority groups are not widely researched. A third of the White Irish population is estimated to be aged 65+, yet this group was mentioned in only one review. Likewise, only one review provided evidence for Gypsy or Irish Traveller communities (which have an estimated population of almost 60,000 people in England according to the 2011 Census) and this review reported unmet needs on a wide range of services, from education to end of life care. We identified that almost 900,000 people in the UK currently either do not speak English well, or cannot speak it at all. Depending on how many people from this group are older people (something that will only be confirmed with future releases of ONS data), there might be an even higher demand for translation services in the future. It is also worth noting that about two-thirds of the population in England and Wales reported having a religion, and it is possible that a number of these would have special needs/requirements at the end of life. Numbers in Northern Ireland are even higher, while numbers for Scotland are less recent. On the other hand, the increasing number of people reporting no religion highlights the need to avoid assumptions/stereotypes when caring for patients.

Variations in the distribution of BAME groups and specific religions in the UK raise other questions. 'Pockets of good practice'[101] are usually located in areas with a higher concentration of minority ethnic groups, such as Birmingham, Leicester or London. Although we recognise the importance of having local projects to improve care, we feel that a nationwide initiative to promote and disseminate best practices is needed. Without this initiative, there is the risk that those from BAME groups/belonging to a particular religion who live in less ethnic diverse areas (for example the North East) might not benefit from them.

We believe it is out of the scope of this report to establish a plan of action or define future priorities for the provision of palliative and end of life care for minority ethnic groups living in the UK. We do, however, offer evidence that relevant stakeholders and policy makers may wish to consider in order to improve care. We suggest studying and evaluating the recommendations presented in Tables 8, 9 and 10, in addition to the summary of recommendations from UK studies reported by Evans et al[25]. To avoid repetition, we do not mention these here again, although we add a few more below.

A national plan funding studies to examine the effectiveness of interventions to improve care that includes a representative number of people from BAME groups is urgently needed. While the field of palliative and end of life care in general has established a strong body of evidence on preferences, revealed evidence of the effectiveness of palliative care and is now building evidence on the cost-effectiveness of care[140, 141], we observed that the studies assessing care for BAME populations still have a long way to go in all these areas. There is also the need to widely publish and disseminate best practices, which would involve collaborations with both practice and research. As previously mentioned, while we agree that each region may have different needs according to the characteristics of its population, we feel that a structured, coordinated national strategy is needed. This should be done as part of a strategy to provide the best palliative and end of life care possible for all, regardless of their ethnicity.

We also suggest the implementation of health promotion palliative care programmes for younger people from all ethnic groups (which would reach a substantial number of foreign born at younger ages). There are examples in Australia of school authorities developing place of death education as a part of their secondary school curriculum. This approach encourages students to address the issues around death as they arise in the subjects studied and to engage in reflective conversation about dying, death and bereavement in order to reduce misapprehension and fear[142]. In the UK, Sue Ryder has developed a School Project to promote awareness of, and local engagement with local specialist palliative care services from a younger age (in the Bradford and Airedale District areas), as part of a community engagement project funded by the Department of Health[143]. The initiative has been done twice and feedback has been positive. Similar approaches may be considered and adapted to other parts of the UK.

We encourage local organisations and local stakeholders to make the most of the available data on ethnicity, checking the ONS, NISRA and NRS websites for local and national information which is available for free. We recommend the systematic examination of procedures which are shown to produce positive results during daily practice in order to demonstrate their effectiveness. There is the need to move from evidence which is often anecdotal to build up evidence which can be disseminated, adapted and made further applicable to different populations.

Finally, in terms of research there is the need to assess not only health outcomes for patients (such as satisfaction with care and symptom control), but also for family caregivers (such as caregiver burden and grief). Further analysis of aggregated data from the 2011 Census and development of new population projections is required. We hope that research can work in integration with both policy and practice, helping with the design of interventions and analysis of evidence while being guided on which areas are most relevant for equitable provision of palliative and end of life care, now and in the future.

6. Appendices

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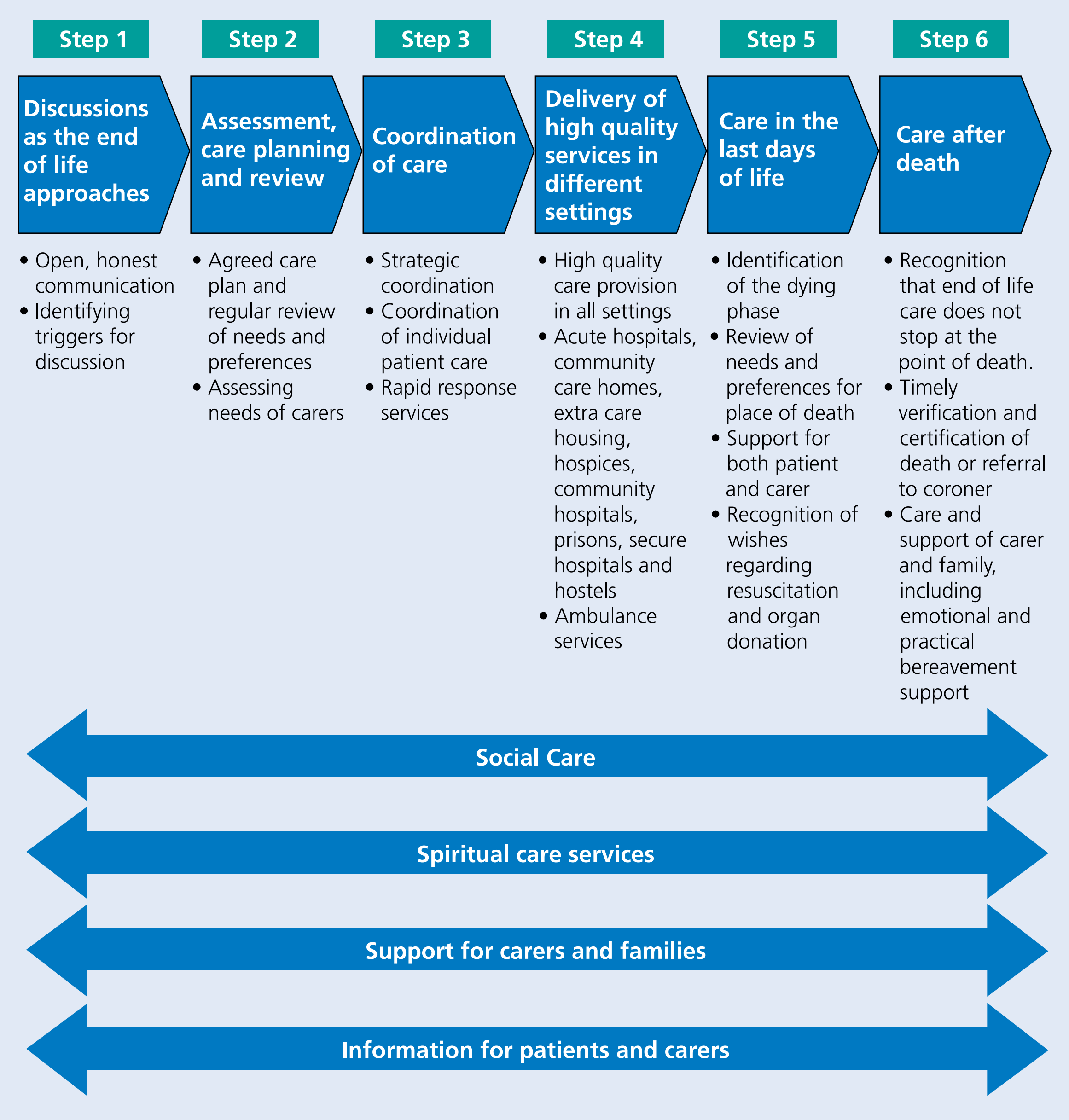
Figure A1 – End of Life Care Pathway



Step 1

Discussions as the end of life approaches

- Open, honest communication
- Identifying triggers for discussion

Step 2

Assessment, care planning and review

- Agreed care plan and regular review of needs and preferences
- Assessing needs of carers

Step 3

Coordination of care

- Strategic coordination
- Coordination of individual patient care
- Rapid response services

Step 4

Delivery of high quality services in different settings

- High quality care provision in all settings
- Acute hospitals, community care homes, extra care housing, hospices, community hospitals, prisons, secure hospitals and hostels
- Ambulance services

Step 5

Care in the last days of life

- Identification of the dying phase
- Review of needs and preferences for place of death
- Support for both patient and carer
- Recognition of wishes regarding resuscitation and organ donation

Step 6

Care after death

- Recognition that end of life care does not stop at the point of death.
- Timely verification and certification of death or referral to coroner
- Care and support of carer and family, including emotional and practical bereavement support

Social Care

Spiritual care services

Support for carers and families

Information for patients and carers

Sources: Department of Health (2008). End of Life Care Strategy – Promoting high quality care of all adults at the end of life: Department of Health. End of Life Care Pathway. Available from: http://www.endoflifecare.nhs.uk/care-pathway.aspx

Table A2 – Glossary of terms used in the report

Terms used in the report
Advance decision to refuse treatment (ADRT): An advance decision to refuse treatment (ADRT) is a decision to refuse a specific treatment made in advance by a person who has capacity to do so. This decision only applies at a future time when that person lacks capacity to consent to, or refuse, the specified treatment. This is set out in section 24 of the Mental Capacity Act. Specific rules apply to advance decisions to refuse life-sustaining treatment[144]. ADRT is a term commonly used in England, while 'advance directives' is a term commonly used in the USA. In the report we used the terms interchangeably and adopted the term 'advance care planning documents' when referring to data from both countries.
Advance care planning (ACP): Advance care planning is a voluntary process of discussion and review to help an individual who has capacity to anticipate how their condition may affect them in the future and, if they wish, set on record: choices about their care and treatment and / or an advance decision to refuse a treatment in specific circumstances, so that these can be referred to by those responsible for their care or treatment (whether professional staff or family carers) in the event that they lose capacity to decide once their illness progresses[144].
BAME: Acronym for 'Black, Asian and Minority Ethnic groups'. This refers to all ethnic groups other than White British as reported by the UK Censuses (1991, 2001 and 2011).
End of life care: Care that helps all those with advanced, progressive and terminal conditions to live as well as possible until they die. It enables the supportive and palliative care needs of both person and family to be identified and met through the last phase of life and into bereavement. It includes physical care, management of pain and other symptoms and provision of psychological, social care as well as spiritual and practical support[9].
Ethnicity: Ethnicity can be defined as a collective awareness of shared origins of descent. It refers to a sense of identity as a member of a group and to difference from others. It is often attributed on the basis of physical characteristics such as skin colour. Ethnicity is a socially constructed resource based upon religion, language and nationality[145]. In this report it was reported based on ethnic categories from the UK Censuses (1991, 2001 and 2011).
Lasting Power of Attorney or Durable Power of Attorney: This allows a trusted family member or friend to make personal welfare decisions, such as those around treatment, on someone's behalf, and in their best interests if they ever lose capacity to make those decisions themselves[146]. The term 'Lasting Power of Attorney' is commonly used in England, while 'Durable Power of Attorney' is used in the USA.
Minority ethnic groups: These are used as a synonym to BAME groups in the UK and also describes minority ethnic groups in countries other than the UK. In these cases the term refers to any group other than the majority White.
Palliative care: Palliative care improves the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement. Palliative care is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications[147].

Table A3 – Census question on English proficiency (England, Wales and Northern Ireland)

English proficiency in 2011
What is your main language? ☐ English[1] (go to 20) ☐ Other, write in (including British[2] sign language) How well can you speak English? ☐ Very well ☐ Well ☐ Not well ☐ Not at all

[1] English or Welsh in Wales

[2] British/Irish sign languages in Northern Ireland

Source: original Census questionnaires available from: http://cdu.mimas.ac.uk/2011/documentation/questions/index.html

Table A4 – Questions on ethnicity in Northern Ireland and Scotland

Northern Ireland (2001 and 2011)[1]	Scotland (2001)[2]
Census 2001 – To which of these ethnic groups do you consider you belong? 3 one box only **Census 2011** – What is your ethnic group? Tick one box only ☐ White ☐ Chinese ☐ Irish Traveller ☐ Indian ☐ Pakistani ☐ Bangladeshi ☐ Black Caribbean ☐ Black African ☐ Black Other ☐ Mixed ethnic group, write in ☐ Any other ethnic group, write in	What is your ethnic group? Choose ONE Section from A to E, then **3** the appropriate box to indicate your cultural background. **A White** ☐ Scottish ☐ Other British ☐ Irish ☐ Any other White background, *please write in* **B Mixed** ☐ Any Mixed background, *please write in* **C Asian, Asian Scottish or Asian British** ☐ Indian ☐ Pakistani ☐ Bangladeshi ☐ Chinese ☐ Any other Asian background, *please write in* **D Black, Black Scottish or Black British** ☐ Caribbean ☐ African ☐ Any other Black background, *please write in* **E Other ethnic background** ☐ Any other background, *please write in*

[1] In Northern Ireland, the only differences between the 2001 and the 2011 Censuses are the questions asked and the '3' symbol, which was replaced in 2011 by the word 'tick'. All ethnic categories remained the same.

[2] Ethnic categories have changed in Scotland in the 2011 Census, these are not shown here as we are not reporting on 2011 ethnicity data for Scotland (not available at the time of this publication).

Source: original Census questionnaires available from http://cdu.mimas.ac.uk/2011/documentation/questions/index.html, http://www.nisra.gov.uk/archive/census/Householdform.pdf and http://www.gro-scotland.gov.uk/files/hseform.pdf

Table A5 – Census questions on religion in England and Wales

Census 2001	Census 2011
What is your religion?	What is your religion?
This question is voluntary	This question is voluntary
3 one box only	☐ No religion
☐ None	☐ Christian[2] (including Church of England, Catholic, Protestant and all other Christian denominations)
☐ Christian (including Church of England[1], Catholic, Protestant and all other Christian denominations)	☐ Buddhist
☐ Buddhist	☐ Hindu
☐ Hindu	☐ Jewish
☐ Jewish	☐ Muslim
☐ Muslim	☐ Sikh
☐ Sikh	☐ Any other religion, write in
☐ Any other religion, *please write in*	______________________________
______________________________	

[1] In Wales it is stated 'Church of Wales' instead of 'Church of England'

[2] In Wales, brackets say 'all denominations' instead of listing denominations.

Source: Original Census questionnaires available from http://cdu.mimas.ac.uk/2011/documentation/questions/index.html and www.ons.gov.uk/ons/guide-method/census/census-2001/about-census-2001/census-2001-forms/index.html

Table A6 – Census questions on religion in Northern Ireland

Census 2001	Census 2011
8) Do you regard yourself as belonging to any particular religion?	What religion, religious denomination or body do you belong to?
☐ Yes (go to 8a)	☐ Roman Catholic
☐ No (go to 8b)	☐ Presbyterian Church in Ireland
8a) What religion, religious denomination or body do you belong to?	☐ Church of Ireland
☐ Roman Catholic	☐ Methodist Church in Ireland
☐ Presbyterian Church in Ireland	☐ Other, write in
☐ Church of Ireland	______________________________
☐ Methodist Church in Ireland	☐ None
☐ Other, please write in	
______________________________	

Source: original Census questionnaires available from http://cdu.mimas.ac.uk/2011/documentation/questions/index.html and http://www.nisra.gov.uk/archive/census/Householdform.pdf

Table A7 – Census question on religion in Scotland

Census 2001

What religion, religious denomination or body do you belong to?

☐ None
☐ Church of Scotland
☐ Roman Catholic
☐ Other Christian, please write in

____

☐ Buddhist

☐ Hindu ☐ Jewish
☐ Muslim ☐ Sikh

☐ Another religion, please write in

____

Source: Original Census questionnaires available from http://www.gro-scotland.gov.uk/files/hseform.pdf

Table A8 – Databases and search terms

Databases	Search terms
Web of Science with conference proceedings (1992 to Jan 2013) Inspec (1992 to Jan 2013) Journal Citation Reports (1992 to Jan 2013) MEDLINE (1992 to Jan 2013) PsycINFO (1992 to Jan 2013) EMBASE (1992 to Jan 2013) ASSIA (1987–2010)[1] CINAHL (1992 to Jan 2013) Cochrane reviews (1992 to Jan 2013)	(United Kingdom OR UK OR Britain OR England OR Wales OR Scotland OR Northern Ireland OR United States OR Canada OR Australia OR New Zealand or South Africa) AND (palliative OR terminal OR end of life OR end of life OR death OR dying OR continu* care OR advance directive* OR hospice* OR supportive care) AND (cultur* OR intercultural OR cross-cultural OR transcultural OR ethnic* OR migrant* OR minorit* OR diversit* OR Muslim* OR Jew* OR Christian* OR Sikh* OR Buddh* OR Hindu* OR India* OR Pakistan* OR black OR white OR Caribbean* OR Africa* OR Bangladesh* OR Irish OR British OR Chinese OR Asia* OR depriv* OR access OR barrier* OR obstacle* OR equit* OR inequ* OR equal* OR Afro* OR Arab* OR Burma OR Burmese OR China OR Egypt* OR Gujerat* OR Gujarat* OR Hong Kong OR Islam* OR Iran* OR Malaysia* OR Mauritius OR Middle East OR Oriental OR Philippin* OR Singapor* OR Sri Lank* OR Vietnam* OR race* OR raci* OR Latin* OR Hispan* OR Maor* OR indigenous)

[1] It was not possible to filter records from ASSIA from 1992 onwards while doing searches, records published before 1992 were removed manually when screening all records

Table A9 – Inclusion and exclusion criteria for reviews

Inclusion criteria	Exclusion criteria
• Qualitative or quantitative reviews (published in peer reviewed journals or grey literature) reporting on the provision of palliative/end of life care for the adult population for one or more minority ethnic groups (as a main or specific subgroup) by: a) Describing their unmet needs and/or b) Reporting disparities in care, regardless of whether this is perceived as an unmet need and/or c) Presenting recommendations, successful practices and measures used to reduce disparities	• Reviews about children (under the age of 18) from BAME groups • Languages other than English • Reviews that report only epidemiological data for BAME populations (e.g. incidence, prevalence and mortality for specific conditions), but do not address palliative and end of life care • Reviews that report general unmet needs for ethnic minorities (e.g. housing and education), but not in palliative and end of life care • Reviews that report unmet needs/preferences/priorities in healthcare (i.e. prevention, curative treatment; aggressive chemotherapy, transplant), but not in palliative and end of life care • Commentaries, editorials, toolkits, guidelines, overviews and purely descriptive papers that briefly describe a BAME group (even if reporting on palliative and end of life care), but do not present themselves as reviews

Table A10 – Index of scientific quality applied to systematic and critical reviews with a systematic approach

Oxman and Guyatt's index of the scientific quality of research overviews

1. Were the search methods used to find evidence (original research) on the primary question(s) stated?

☐ yes ☐ partially ☐ no

2. Was the search for evidence reasonably comprehensive?

☐ yes ☐ can't tell ☐ no

3. Were the criteria used for deciding which studies to include in the overview reported?

☐ yes ☐ partially ☐ no

4. Was bias in the selection of studies avoided?

☐ yes ☐ can't tell ☐ no

5. Were the criteria used for assessing the validity of the included studies reported?

☐ yes ☐ partially ☐ no

6. Was the validity of all studies referred to in the text assessed using appropriate criteria (either in selecting studies for inclusion or in analysing the studies that are cited)?

☐ yes ☐ can't tell ☐ no

7. Were the methods used to combine the findings of the relevant studies (to reach a conclusion) reported?

☐ yes ☐ partially ☐ no

8. Were the findings of the relevant studies combined appropriately relative to the primary question the overview addressed?

☐ yes ☐ can't tell ☐ no

9. Were the conclusions made by the authors supported by the data and/or analysis reported in the overview?

☐ yes ☐ partially ☐ no

10. How would you rate the scientific quality of the overview?

extensive flaws		major flaws		minor flaws		minimal flaws
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7

Guidance: If the methods that were used are reported incompletely relative to a specific item, score the item as 'partially'. If there was no information provided regarding what was done relative to a particular question, score it as 'can't tell'. For question 8, if no attempt was made to combine findings, and no statement is made regarding the inappropriateness of combining findings, check 'no'. For a review to be scored as 'yes' on question 9, data must be reported that supports the main conclusions regarding the review's primary question(s) The score for question 10, the overall scientific quality, should be based on your answers to the first nine questions.

Source: Egger et al (2001). Systematic reviews in Health Care. Meta-analysis in context. London: BMJ Publishing House

Box A11 – An analysis of the English and Welsh population by ethnic group since 1991

Important methodological information

Census 1991 data needed adjustments to be compared with other Censuses because changes were made to the way the ONS dealt with missing data/under-enumeration (adjustments for people who did not answer the question on ethnicity)[148]. Adjusted data for 1991 were published by the ONS and were only available as showing England and Wales together[148]. Comparability issues between other Censuses (2001 and 2011) can be seen in the methods Section of this report.

According to the Office for National Statistics, the only comparable categories when checking 1991 and 2001 data are White (as a main group), Indian, Pakistani, Bangladeshi and Chinese. Because of changes in categories there is less stability for the Black Caribbean and Black African groups; Other Black, Other Asian and Other ethnic groups have the least stability[148] and comparison is even more limited. Total population for groups other than White is not comparable across decades because of changes in ethnic categories. The White sub-categories were offered for the first time in 2001, while 1991 data shown for the Other Asian category were created from write-in responses to Any Other Ethnic Group[148].

Ethnicity in England and Wales since 2001

Data since 1991 for England and Wales show that since 1991 both the numbers and proportion of the White group have reduced (8% in proportion or approximately 390,000 fewer people in this group)[57, 64, 148]. This reduction occurred mainly for the White British group (7% in percentual points) and the White Irish groups (0.3% reduction in percentual points). When checking other comparable groups, we see an increase in numbers and proportions for all ethnic groups within the Asian/Asian British category. Importantly, despite difficulties in comparing individual ethnic categories, data clearly show that in the past 20 years England and Wales have become substantially more ethnically diverse.

Population by ethnic group in England and Wales in 1991, 2001 and 2011 (thousands)

Main groups	Subgroups	1991[1]		2001		2011	
		Number	(%)	Number	(%)	Number	(%)
White[2]	English/Welsh/Scottish/Northern Irish/British		N/A	45,533.7	(87.5)	45,134.7	(80.5)
	Irish		N/A	641.8	(1.2)	531.1	(0.9)
	Gypsy or Irish Traveller		N/A		N/A	57.7	(0.1)
	Other White		N/A	1,345.3	(2.6)	2,485.9	(4.4)
	Total White	**47,876.6**	**(94.1)**	**47,520.9**	**(91.3)**	**48,209.4**	**(86.0)**
Mixed/multiple ethnic groups	White and Black Caribbean		N/A	237.4	(0.5)	426.7	(0.8)
	White and Black African			78.9	(0.2)	166.0	(0.3)
	White and Asian			189.0	(0.4)	341.7	(0.6)
	Other Mixed			155.7	(0.3)	290.0	(0.5)
Asian/Asian British	Indian	855.1	(1.7)	1,036.8	(2.0)	1,413.0	(2.5)
	Pakistani	469.0	(0.9)	714.9	(1.4)	1,124.5	(2.0)
	Bangladeshi	166.6	(0.3)	280.8	(0.5)	447.2	(0.8)
	Chinese	152.3	(0.3)	227.0	(0.4)	393.1	(0.7)
	Other Asian	198.7	(0.4)	241.3	(0.5)	835.7	(1.5)
Black/African/Caribbean/Black British	African	220.1	(0.4)	479.7	(0.9)	989.6	(1.8)
	Caribbean	514.0	(1.0)	563.9	(1.1)	594.8	(1.1)
	Other Black	182.8	(0.4)	96.1	(0.2)	280.4	(0.5)
Other	Arab		N/A		N/A	230.6	(0.4)
	Any other ethnic group	289.8	(0.6)	219.8	(0.4)	333.1	(0.6)
Total	All ethnic groups	50,888.1	(100)[3]	52,041.9	(100)	56,075.9	(100)

[1] 1991 data adjusted for Census under-enumeration by the ONS using OPCS/GRO(S) 1994 factors

[2] Ethnic groups shown are the ones used by the 2011 Census. Comparison between Censuses is limited (see methods Section).

[3] Sum might not add to totals due to rounding.

Sources: Office for National Statistics (2006). A guide to comparing 1991 and 2001 Census ethnic group data. Office for National Statistics (2012). Ethnicity and National Identity in England and Wales 2011. Office for National Statistics (2003). Table KS06: Ethnic group. Office for National Statistics (2012). Table KS201EW. Ethnic group

Table A12 – Population by ethnic group (in thousands) in English regions in 2001 and 2011

Ethnic groups	Year	North East Number	(%)	North West Number	(%)	Yorkshire & Humber Number	(%)	East Midlands Number	(%)	West Midlands Number	(%)	East of England Number	(%)	London Number	(%)	South East Number	(%)	South West Number	(%)
White English/Welsh/Scottish/ Northern Irish/British	2001	2,425.6	(96.4)	6,203.0	(92.2)	4,551.4	(91.7)	3,807.7	(91.3)	4,537.9	(86.2)	4,927.3	(91.4)	4,287.9	(59.8)	7,304.7	(91.3)	4,701.6	(95.4)
	2011	2,431.4	(93.6)	6,141.1	(87.1)	4,531.1	(85.8)	3,871.2	(85.4)	4,434.3	(79.2)	4,986.2	(85.3)	3,669.3	(44.9)	7,359.0	(85.2)	4,855.7	(91.8)
White Irish	2001	8.7	(0.3)	77.5	(1.2)	32.7	(0.7)	35.5	(0.9)	73.1	(1.4)	61.2	(1.1)	220.5	(3.1)	82.4	(1.0)	32.5	(0.7)
	2011	8.0	(0.3)	64.9	(0.9)	26.4	(0.5)	28.7	(0.6)	55.2	(1.0)	55.6	(1.0)	176.0	(2.2)	73.6	(0.9)	28.6	(0.5)
White Gypsy or Irish Traveller	2001		N/A		N/A		N/A		N/A		N/A		N/A		N/A		N/A		N/A
	2011	1.7	(0.1)	4.2	(0.1)	4.4	(0.1)	3.4	(0.1)	4.7	(0.1)	8.2	(0.1)	8.2	(0.1)	14.5	(0.2)	5.6	(0.1)
Other White	2001	21.1	(0.8)	75.0	(1.1)	57.1	(1.2)	57.2	(1.4)	63.3	(1.2)	136.5	(2.5)	594.9	(8.3)	221.9	(2.8)	81.2	(1.6)
	2011	34.4	(1.3)	151.6	(2.1)	130.0	(2.5)	143.1	(3.2)	139.4	(2.5)	260.3	(4.5)	1,034.0	(12.6)	380.7	(4.4)	156.5	(3.0)
Mixed White and Black Caribbean	2001	2.8	(0.1)	22.1	(0.3)	18.2	(0.4)	20.7	(0.5)	39.8	(0.8)	19.9	(0.4)	71.0	(1.0)	23.7	(0.3)	13.3	(0.3)
	2011	5.9	(0.2)	39.2	(0.6)	33.2	(0.6)	40.4	(0.9)	68.5	(1.2)	37.2	(0.6)	119.4	(1.5)	46.0	(0.5)	25.7	(0.5)
Mixed White and Black African	2001	1.7	(0.1)	9.9	(0.1)	4.1	(0.1)	3.4	(0.1)	3.7	(0.1)	6.1	(0.1)	34.2	(0.5)	9.5	(0.1)	3.9	(0.1)
	2011	3.6	(0.1)	18.4	(0.3)	9.3	(0.2)	8.8	(0.2)	9.2	(0.2)	15.4	(0.3)	65.5	(0.8)	22.8	(0.3)	8.6	(0.2)
Mixed White and Asian	2001	4.7	(0.2)	17.2	(0.3)	14.2	(0.3)	11.2	(0.3)	18.2	(0.3)	17.4	(0.3)	59.9	(0.8)	30.0	(0.4)	11.2	(0.2)
	2011	8.0	(0.3)	30.5	(0.4)	26.0	(0.5)	21.7	(0.5)	32.6	(0.6)	32.2	(0.6)	101.5	(1.2)	58.8	(0.7)	21.4	(0.4)
Other Mixed	2001	3.0	(0.1)	13.3	(0.2)	8.5	(0.2)	7.9	(0.2)	11.6	(0.2)	14.6	(0.3)	61.1	(0.9)	22.6	(0.3)	8.9	(0.2)
	2011	4.9	(0.2)	22.8	(0.3)	16.0	(0.3)	15.3	(0.3)	21.4	(0.4)	27.3	(0.5)	118.9	(1.5)	40.2	(0.5)	16.3	(0.3)
Asian/Asian British: Indian	2001	10.2	(0.4)	72.2	(1.1)	51.5	(1.0)	122.4	(2.9)	178.7	(3.4)	51.0	(0.9)	437.0	(6.1)	89.2	(1.1)	16.4	(0.3)
	2011	15.8	(0.6)	107.4	(1.5)	69.3	(1.3)	168.9	(3.7)	218.4	(3.9)	86.7	(1.5)	542.9	(6.6)	152.1	(1.8)	34.2	(0.6)
Asian/Asian British: Pakistani	2001	14.1	(0.6)	117.0	(1.7)	146.3	(2.9)	27.8	(0.7)	154.6	(2.9)	38.8	(0.7)	142.8	(2.0)	58.5	(0.7)	6.7	(0.1)
	2011	19.8	(0.8)	189.4	(2.7)	225.9	(4.3)	48.9	(1.1)	227.3	(4.1)	66.3	(1.1)	223.8	(2.7)	99.3	(1.1)	11.6	(0.2)
Asian/Asian British: Bangladeshi	2001	6.2	(0.2)	26.0	(0.4)	12.3	(0.2)	6.9	(0.2)	31.4	(0.6)	18.5	(0.3)	153.9	(2.1)	15.4	(0.2)	4.8	(0.1)
	2011	11.0	(0.4)	45.9	(0.7)	22.4	(0.4)	13.3	(0.3)	52.5	(0.9)	33.0	(0.6)	222.1	(2.7)	28.0	(0.3)	8.4	(0.2)
Asian/ Asian British: Chinese	2001	6.1	(0.2)	26.9	(0.4)	12.3	(0.2)	12.9	(0.3)	16.1	(0.3)	20.4	(0.4)	80.2	(1.1)	33.1	(0.4)	12.7	(0.3)
	2011	14.3	(0.6)	48.1	(0.7)	28.4	(0.5)	24.4	(0.5)	31.3	(0.6)	33.5	(0.6)	124.3	(1.5)	53.1	(0.6)	22.2	(0.4)
Asian/ Asian British: Other Asian	2001	3.2	(0.1)	14.7	(0.2)	12.3	(0.2)	11.8	(0.3)	20.9	(0.4)	13.4	(0.2)	133.1	(1.9)	23.5	(0.3)	4.9	(0.1)
	2011	13.7	(0.5)	46.8	(0.7)	40.0	(0.8)	37.9	(0.8)	75.0	(1.3)	58.9	(1.0)	398.5	(4.9)	119.7	(1.4)	29.1	(0.5)
Black/African/Caribbean/Black British: African	2001	2.6	(0.1)	15.9	(0.2)	9.6	(0.2)	9.2	(0.2)	12.0	(0.2)	17.0	(0.3)	378.9	(5.3)	24.6	(0.3)	6.2	(0.1)
	2011	11.0	(0.4)	59.3	(0.8)	46.0	(0.9)	41.8	(0.9)	64.3	(1.1)	69.9	(1.2)	573.9	(7.0)	87.4	(1.0)	24.2	(0.5)
Black/African/Caribbean/Black British: Caribbean	2001	0.9	(0.0)	20.4	(0.3)	21.3	(0.4)	26.7	(0.6)	82.3	(1.6)	26.2	(0.5)	343.6	(4.8)	27.5	(0.3)	12.4	(0.3)
	2011	1.2	(0.0)	23.1	(0.3)	23.4	(0.4)	28.9	(0.6)	86.8	(1.5)	33.6	(0.6)	344.6	(4.2)	34.2	(0.4)	15.1	(0.3)
Black/African/Caribbean/Black British: Other Black	2001	0.4	(0.0)	5.3	(0.1)	3.3	(0.1)	3.6	(0.1)	9.8	(0.2)	5.3	(0.1)	60.4	(0.8)	4.9	(0.1)	2.3	(0.0)
	2011	1.1	(0.0)	15.5	(0.2)	10.9	(0.2)	10.8	(0.2)	31.1	(0.6)	13.9	(0.2)	170.1	(2.1)	14.4	(0.2)	10.1	(0.2)
Other ethnic group: Arab	2001		N/A		N/A		N/A		N/A		N/A		N/A		N/A		N/A		N/A
	2011	5.9	(0.2)	24.5	(0.3)	21.3	(0.4)	9.8	(0.2)	18.1	(0.3)	10.4	(0.2)	106.0	(1.3)	19.4	(0.2)	5.7	(0.1)
Other ethnic group: any other ethnic group	2001	4.2	(0.2)	13.3	(0.2)	9.5	(0.2)	7.4	(0.2)	14.1	(0.3)	14.5	(0.3)	113.0	(1.6)	29.3	(0.4)	9.3	(0.2)
	2011	5.2	(0.2)	19.7	(0.3)	19.6	(0.4)	16.0	(0.4)	31.8	(0.6)	18.5	(0.3)	175.0	(2.1)	31.8	(0.4)	9.9	(0.2)
All ethnic groups	2001	2,515.4	(100)	6,729.8	(100)	4,964.8	(100)	4,172.2	(100)	5,267.3	(100)	5,388.1	(100)	7,172.1	(100)	8,000.7	(100)	4,928.4	(100)
	2011	2,596.9	(100)	7,052.2	(100)	5,283.7	(100)	4,533.2	(100)	5,601.9	(100)	5,847.0	(100)	8,173.9	(100)	8,634.8	(100)	5,288.9	(100)

Source: Office for National Statistics (2012). Ethnicity and National Identity in England and Wales 2011. Office for National Statistics (2003). Table KS06: Ethnic group. Office for National Statistics (2012). Table KS201EW. Ethnic group

Table A13 – Estimated population by age and ethnic group (in thousands) in England in mid-2009

Sub-categories	0-14 Number (%)	15-44 Number (%)	45-54 Number (%)	55-64 Number (%)	65-74 Number (%)	75-84 Number (%)	85+ Number (%)	All ages Number (%)
White British	7,299 (17.0)	16,467.4 (38.4)	5,924.7 (13.8)	5,474.9 (12.8)	3,956.6 (9.2)	2,668.1 (6.2)	1,102.5 (2.6)	42,893.3 (100)
White Irish	29.1 (5.2)	163.9 (29.4)	85.4 (15.3)	98.4 (17.6)	97.9 (17.5)	63.6 (11.4)	19.9 (3.6)	558.1 (100)
Other White	220.2 (11.8)	1,106.0 (59.4)	224.4 (12.1)	145.2 (7.8)	91.6 (4.9)	55.1 (3.0)	19.2 (1.0)	1,861.8 (100)
Mixed White and Black Caribbean	133.1 (44.2)	141.3 (46.9)	16.0 (5.3)	5.0 (1.7)	3.3 (1.1)	2.0 (0.7)	0.8 (0.3)	301.3 (100)
Mixed White and Black African	54.2 (42.5)	56.9 (44.6)	9.8 (7.7)	4.1 (3.2)	1.6 (1.3)	0.8 (0.6)	0.2 (0.2)	127.5 (100)
Mixed White and Asian	126.6 (43.3)	129.6 (44.3)	18.3 (6.3)	9.0 (3.1)	5.3 (1.8)	2.8 (1.0)	0.9 (0.3)	292.4 (100)
Other Mixed	95.1 (40.4)	107.2 (45.5)	16.6 (7.0)	9.2 (3.9)	4.5 (1.9)	2.1 (0.9)	0.7 (0.3)	235.5 (100)
Asian or Asian British: Indian	234.1 (16.6)	775.2 (54.8)	180.0 (12.7)	118.8 (8.4)	68.3 (4.8)	31.1 (2.2)	6.7 (0.5)	1,414.1 (100)
Asian or Asian British: Pakistani	275.8 (27.8)	536.6 (54.2)	84.6 (8.5)	47.8 (4.8)	30.3 (3.1)	13.3 (1.3)	2.3 (0.2)	990.7 (100)
Asian or Asian British: Bangladeshi	111.5 (29.0)	214.2 (55.7)	28.5 (7.4)	13.7 (3.6)	11.7 (3.0)	4.2 (1.1)	0.6 (0.2)	384.3 (100)
Asian or Asian British: Other Asian	73.8 (19.5)	209.6 (55.5)	45.4 (12.0)	28.2 (7.5)	14.1 (3.7)	5.7 (1.5)	1.2 (0.3)	377.7 (100)
Black or Black British: Black Caribbean	96.0 (15.8)	272.6 (44.7)	112.8 (18.5)	44.0 (7.2)	51.5 (8.5)	27.6 (4.5)	4.8 (0.8)	609.4 (100)
Black or Black British: Black African	180.3 (22.9)	456.8 (58.0)	93.8 (11.9)	33.7 (4.3)	16.8 (2.1)	5.2 (0.7)	1.0 (0.1)	787.5 (100)
Black or Black British: Other Black	39.4 (31.6)	62.7 (50.4)	14.3 (11.5)	3.7 (3.0)	2.7 (2.2)	1.3 (1.0)	0.3 (0.2)	124.5 (100)
Chinese	55.4 (12.6)	284.2 (64.7)	50.7 (11.5)	28.8 (6.6)	13.4 (3.0)	5.7 (1.3)	1.2 (0.3)	439.5 (100)
Other ethnic group	52.0 (12.6)	267.2 (64.8)	50.2 (12.2)	28.1 (6.8)	10.6 (2.6)	3.2 (0.8)	0.7 (0.2)	412.1 (100)
All ethnic groups	9,075.7 (17.5)	21,251.7 (41.0)	6,955.2 (13.4)	6,092.7 (11.8)	4,380.0 (8.5)	2,891.6 (5.6)	1,162.9 (2.2)	51,809.7 (100)

Source: Office for National Statistics (2011). Table EE4: Estimated resident population by ethnic group, age and sex, mid-2009. Rel. 8.0. Sums may not add up to totals due to rounding.

Table A14 – Estimated population aged 65+ (men) and 60+ (women) by ethnic group (in thousands) and English regions in mid-2009

Sub-categories	North East Number (%)	North West Number (%)	Yorkshire & Humber Number (%)	East Midlands Number (%)	West Midlands Number (%)	East of England Number (%)	London Number (%)	South East Number (%)	South West Number (%)
White British	511.6 (97.6)	1,281.6 (94.4)	961.9 (94.9)	836.3 (93.6)	987.4 (90.9)	1,097.9 (92.8)	760.6 (71.4)	1,584.4 (93.0)	1,143.3 (95.6)
White Irish	3.0 (0.6)	28.1 (2.1)	11.7 (1.2)	13.5 (1.5)	28.9 (2.7)	22.6 (1.9)	57.6 (5.4)	30 (1.8)	13.9 (1.2)
Other White	3.6 (0.7)	15.4 (1.1)	11.5 (1.1)	12.8 (1.4)	12.7 (1.2)	25.2 (2.1)	64.4 (6.0)	39.5 (2.3)	19.3 (1.6)
Mixed White and Black Caribbean	0.2 (0.0)	0.7 (0.1)	0.5 (0.0)	0.5 (0.1)	0.8 (0.1)	0.7 (0.1)	2.4 (0.2)	0.9 (0.1)	0.6 (0.1)
Mixed White and Black African	0.1 (0.0)	0.5 (0.0)	0.2 (0.0)	0.2 (0.0)	0.2 (0.0)	0.3 (0.0)	1.2 (0.1)	0.6 (0.0)	0.3 (0.0)
Mixed White and Asian	0.2 (0.0)	0.7 (0.1)	0.6 (0.1)	0.6 (0.1)	0.7 (0.1)	1.2 (0.1)	3.8 (0.4)	2.2 (0.1)	0.9 (0.1)
Other Mixed	0.2 (0.0)	0.7 (0.1)	0.5 (0.0)	0.5 (0.1)	0.6 (0.1)	1.1 (0.1)	3.3 (0.3)	1.8 (0.1)	0.8 (0.1)
Asian or Asian British: Indian	1.5 (0.3)	7.8 (0.6)	6.1 (0.6)	14.9 (1.7)	20.1 (1.9)	9.9 (0.8)	52.3 (4.9)	14.5 (0.9)	4.1 (0.3)
Asian or Asian British: Pakistani	1.2 (0.2)	7.9 (0.6)	9.5 (0.9)	3.0 (0.3)	10.5 (1.0)	3.9 (0.3)	12.1 (1.1)	5.9 (0.3)	1.6 (0.1)
Asian or Asian British: Bangladeshi	0.4 (0.1)	1.8 (0.1)	1.1 (0.1)	0.7 (0.1)	2.3 (0.2)	2.1 (0.2)	9.1 (0.9)	1.5 (0.1)	0.6 (0.1)
Asian or Asian British: Other Asian	0.4 (0.1)	1.5 (0.1)	1.2 (0.1)	1.5 (0.2)	2.3 (0.2)	2.6 (0.2)	12.2 (1.1)	3.6 (0.2)	1.1 (0.1)
Black or Black British: Black Caribbean	0.3 (0.1)	4.4 (0.3)	4.6 (0.5)	5.3 (0.6)	14.6 (1.3)	6.6 (0.6)	48.5 (4.6)	7.3 (0.4)	3.6 (0.3)
Black or Black British: Black African	0.3 (0.1)	1.7 (0.1)	1.1 (0.1)	1.1 (0.1)	1.4 (0.1)	2.7 (0.2)	17.1 (1.6)	3.5 (0.2)	1.4 (0.1)
Black or Black British: Other Black	0.1 (0.0)	0.4 (0.0)	0.2 (0.0)	0.3 (0.0)	0.5 (0.0)	0.5 (0.0)	2.3 (0.2)	0.6 (0.0)	0.3 (0.0)
Chinese	0.6 (0.1)	2.9 (0.2)	1.6 (0.2)	1.6 (0.2)	1.7 (0.2)	3.6 (0.3)	8.7 (0.8)	4.3 (0.3)	2.0 (0.2)
Other ethnic group	0.4 (0.1)	1.2 (0.1)	1.1 (0.1)	1.1 (0.1)	1.3 (0.1)	2.0 (0.2)	9.4 (0.9)	3.5 (0.2)	1.6 (0.1)
All ethnic groups	524.1 (100)	1,357.3 (100)	1,013.5 (100)	893.8 (100)	1,085.9 (100)	1,182.9 (100)	1,065 (100)	1,704.1 (100)	1,195.3 (100)

Source: Office for National Statistics (2011) Table EE2: Estimated resident population by ethnic group, age and sex, mid-2009. Rel. 8.0. Note: Estimates shown here are reported for those aged 60+ (women) and 65+ (men) as published by the ONS. Hence, overall numbers for England shown in Figure 2 for all aged 65+ do not match the totals shown here (showing numbers for both 60+ and 65+).

Table A15 – Religion by English regions in 2001 and 2011

Regions	Year	Christian		Buddhist		Hindu		Jewish		Muslim		Sikh		Other religion		No religion		Not stated	
		Number	(%)	Number	(%)	Number	(%)	Number	(%)	Number	(%)	Number	(%)	Number	(%)	Number	(%)	Number	(%)
North East	2001	2,014,608	(80.1)	3,097	(0.1)	4,370	(0.2)	3,151	(0.1)	26,925	(1.1)	4,780	(0.2)	3,886	(0.2)	276,196	(11.0)	178,429	(7.1)
	2011	1,753,334	(67.5)	6,316	(0.2)	7,772	(0.3)	4,503	(0.2)	46,764	(1.8)	5,964	(0.2)	6,668	(0.3)	607,700	(23.4)	157,865	(6.1)
North West	2001	5,249,686	(78.0)	11,794	(0.2)	27,211	(0.4)	27,974	(0.4)	204,261	(3.0)	6,487	(0.1)	10,625	(0.2)	705,045	(10.5)	486,681	(7.2)
	2011	4,742,860	(67.3)	20,695	(0.3)	38,259	(0.5)	30,417	(0.4)	356,458	(5.1)	8,857	(0.1)	19,166	(0.3)	1,397,916	(19.8)	437,549	(6.2)
Yorkshire & Humber	2001	3,627,774	(73.1)	7,188	(0.1)	15,797	(0.3)	11,554	(0.2)	189,089	(3.8)	18,711	(0.4)	9,624	(0.2)	699,327	(14.1)	385,769	(7.8)
	2011	3,143,819	(59.5)	14,319	(0.3)	24,074	(0.5)	9,929	(0.2)	326,050	(6.2)	22,179	(0.4)	16,517	(0.3)	1,366,219	(25.9)	360,627	(6.8)
East Midlands	2001	3,003,475	(72.0)	7,541	(0.2)	66,710	(1.6)	4,075	(0.1)	70,224	(1.7)	33,551	(0.8)	9,863	(0.2)	664,845	(15.9)	311,890	(7.5)
	2011	2,666,172	(58.8)	12,672	(0.3)	89,723	(2.0)	4,254	(0.1)	140,649	(3.1)	44,335	(1.0)	17,918	(0.4)	1,248,056	(27.5)	309,443	(6.8)
West Midlands	2001	3,823,235	(72.6)	9,760	(0.2)	56,668	(1.1)	4,977	(0.1)	216,184	(4.1)	103,870	(2.0)	10,895	(0.2)	647,718	(12.3)	394,001	(7.5)
	2011	3,373,450	(60.2)	16,649	(0.3)	72,247	(1.3)	4,621	(0.1)	376,152	(6.7)	133,681	(2.4)	25,654	(0.5)	1,230,910	(22.0)	368,483	(6.6)
East of England	2001	3,886,778	(72.1)	12,065	(0.2)	31,386	(0.6)	30,367	(0.6)	78,931	(1.5)	13,365	(0.2)	15,471	(0.3)	902,145	(16.7)	417,632	(7.8)
	2011	3,488,063	(59.7)	22,273	(0.4)	54,010	(0.9)	34,830	(0.6)	148,341	(2.5)	18,213	(0.3)	24,981	(0.4)	1,631,572	(27.9)	424,682	(7.3)
London	2001	4,176,175	(58.2)	54,297	(0.8)	291,977	(4.1)	149,789	(2.1)	607,083	(8.5)	104,230	(1.5)	36,558	(0.5)	1,130,616	(15.8)	621,366	(8.7)
	2011	3,957,984	(48.4)	82,026	(1.0)	411,291	(5.0)	148,602	(1.8)	1,012,823	(12.4)	126,134	(1.5)	47,970	(0.6)	1,694,372	(20.7)	692,739	(8.5)
South East	2001	5,823,025	(72.8)	22,005	(0.3)	44,575	(0.6)	19,037	(0.2)	108,725	(1.4)	37,735	(0.5)	28,668	(0.4)	1,319,979	(16.5)	596,896	(7.5)
	2011	5,160,128	(59.8)	43,946	(0.5)	92,499	(1.1)	17,761	(0.2)	201,651	(2.3)	54,941	(0.6)	39,672	(0.5)	2,388,286	(27.7)	635,866	(7.4)
South West	2001	3,646,488	(74.0)	11,299	(0.2)	8,288	(0.2)	6,747	(0.1)	23,465	(0.5)	4,614	(0.1)	18,221	(0.4)	825,461	(16.7)	383,851	(7.8)
	2011	3,194,066	(60.4)	19,730	(0.4)	16,324	(0.3)	6,365	(0.1)	51,228	(1.0)	5,892	(0.1)	29,279	(0.6)	1,549,201	(29.3)	416,850	(7.9)
All England	2001	35,251,244	(71.7)	139,046	(0.3)	546,982	(1.1)	257,671	(0.5)	1,524,887	(3.1)	327,343	(0.7)	143,811	(0.3)	7,171,332	(14.6)	3,776,515	(7.7)
	2011	31,479,876	(59.4)	238,626	(0.5)	806,199	(1.5)	261,282	(0.5)	2,660,116	(5.0)	420,196	(0.8)	227,825	(0.4)	13,114,232	(25.1)	3,804,104	(7.2)

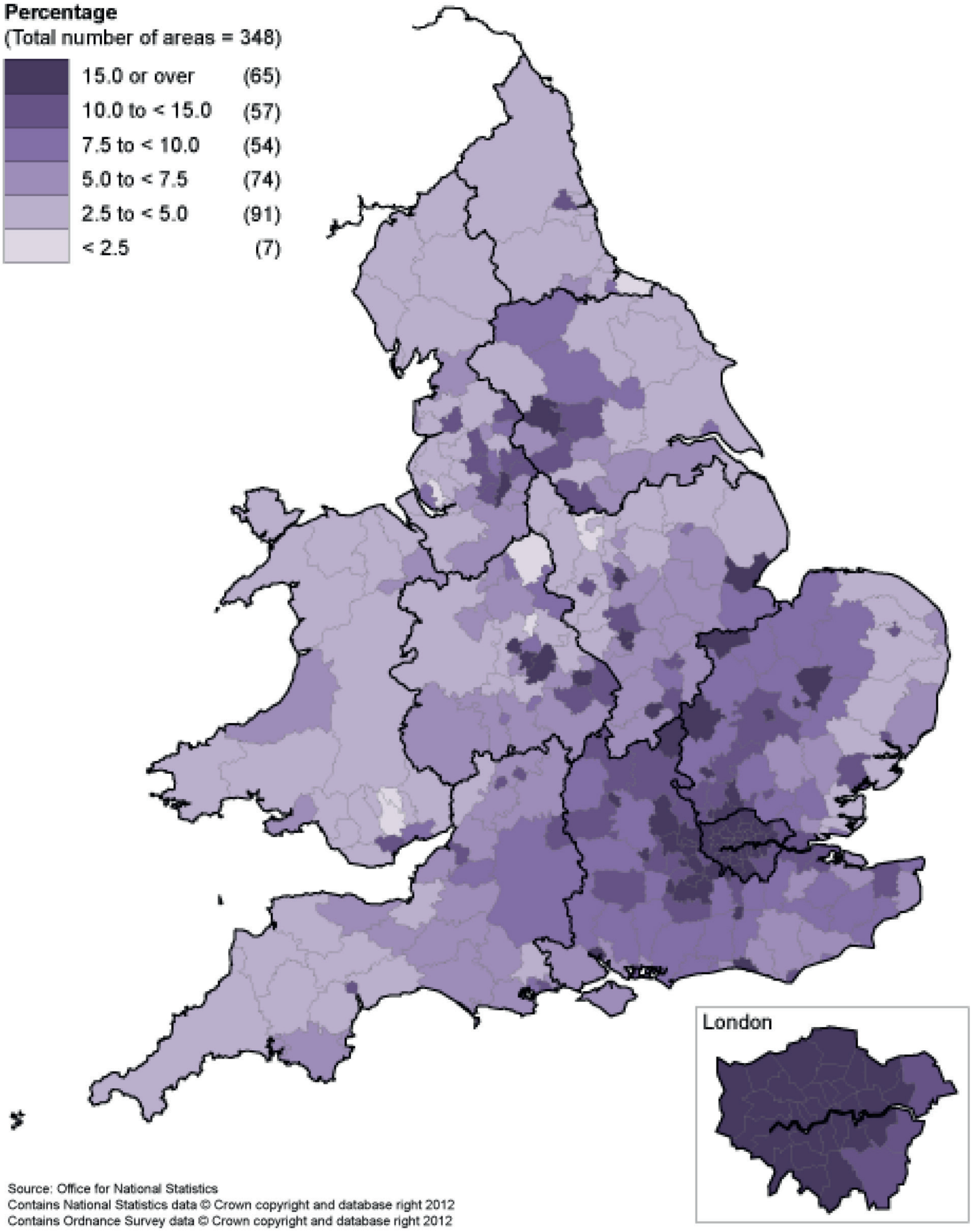
Source: Office for National Statistics (2013). 2001-2011 Census comparator tool. Key statistics interface v2.5

Table A16 – English proficiency by English regions (2011) – Residents aged 3 years or older

Regions	Main language is English		Main language is not English								Total residents aged 3 and over	
			Can speak English very well		Can speak English well		Cannot speak English well		Cannot speak English			
	Number	(%)	Number	(%)	Number	(%)	Number	(%)	Number	(%)	Number	(%)
North East	2,435,635	(97.2)	28,783	(1.1)	27,650	(1.1)	12,007	(0.5)	2,317	(0.1)	2,506,392	(100)
North West	6,446,819	(94.9)	131,068	(1.9)	130,578	(1.9)	69,718	(1.0)	13,724	(0.2)	6,791,907	(100)
Yorkshire & Humber	4,783,865	(94.1)	104,260	(2.1)	115,293	(2.3)	67,614	(1.3)	14,159	(0.3)	5,085,191	(100)
East Midlands	4,101,046	(93.8)	95,822	(2.2)	105,884	(2.4)	56,723	(1.3)	11,288	(0.3)	4,370,763	(100)
West Midlands	5,001,880	(92.8)	134,457	(2.5)	144,645	(2.7)	87,657	(1.6)	19,375	(0.4)	5,388,014	(100)
East of England	5,317,554	(94.5)	130,200	(2.3)	118,244	(2.1)	53,402	(0.9)	9,392	(0.2)	5,628,792	(100)
London	6,083,420	(77.9)	763,502	(9.8)	643,410	(8.2)	271,693	(3.5)	47,917	(0.6)	7,809,942	(100)
South East	7,832,436	(94.2)	223,997	(2.7)	180,188	(2.2)	65,638	(0.8)	11,600	(0.1)	8,313,859	(100)
South West	4,934,125	(96.5)	77,317	(1.5)	69,687	(1.4)	25,410	(0.5)	4,211	(0.1)	5,110,750	(100)
All England	46,936,780	(92.0)	1,689,406	(3.3)	1,535,579	(3.0)	709,862	(1.4)	133,983	(0.3)	51,005,610	(100)

Source: Office for National Statistics (2012). Table QS205EW. 2011 Census: Proficiency in English, local authorities in England and Wales

Figure A17 – Foreign born residents by local or unitary authority in England and Wales (2011)



Source: Office for National Statistics
Contains National Statistics data © Crown copyright and database right 2012
Contains Ordnance Survey data © Crown copyright and database right 2012

Source: Office for National Statistics (2012). International Migrants in England and Wales 2011

Figure A18 – Review flowchart

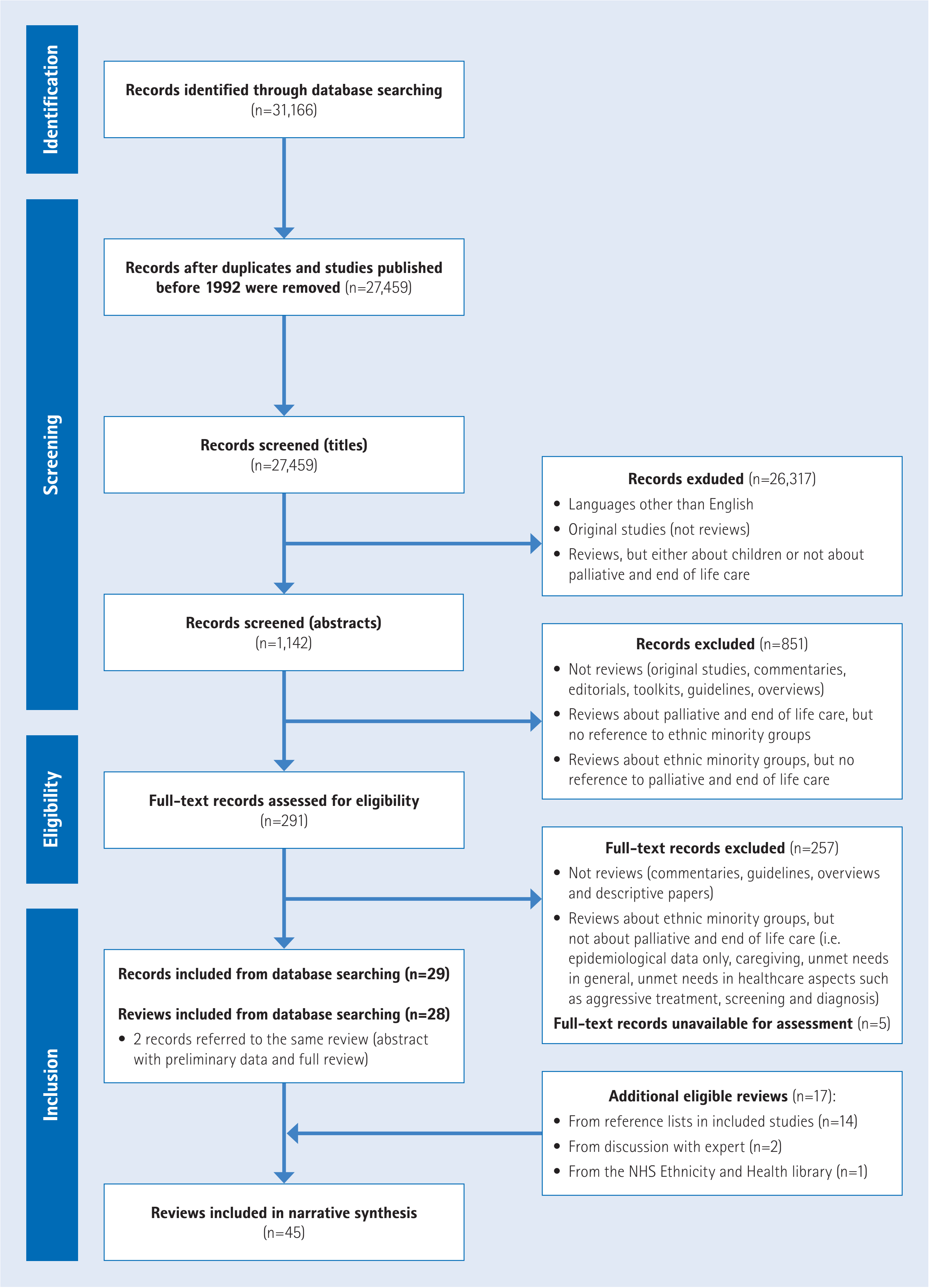


Table A19 – Details of included reviews

Authors and year, country Method	Country of population, minority ethnic groups, diagnosis at the end of life	Aim of review	Quality: extensive to minimal flaws
Ahmed et al 2004[28], UK Systematic review	Various (including UK), >1 group CHD, stroke, cancer, non-specific conditions	Identify and assess the current evidence to determine what is known about how patients and their families access specialist palliative care; identify any obstacles and barriers to such care and highlight any gaps in the evidence base	Minimal flaws
Anderson et al 2009[109], USA Critical review (systematic approach)	USA, >1 group ACH, COPD, Cancer, chronic pain, non-specific conditions	Evaluate critically the recent literature on racial and ethnic disparities in pain and to determine how far we have come toward reducing and eliminating disparities in pain	Mid-range major to minor flaws
Atkinson et al 2001[91], UK Systematic review	UK, >1 group Multiple conditions (e.g. cancer, diabetes), non-specific conditions	Produce an overview of current findings on ethnicity and health service access; provide information on the demographic profile of London and comment on how this is predicted to change; identify gaps in the evidence and make recommendations for research	Minimal flaws
Badger et al 2009[96], UK Narrative review (non-systematic)	UK, >1 group Older people living in care homes	Summarise the current research evidence on cultural issues relating to ethnicity in end of life care in care homes	N/A
Baker 2002[126], USA Narrative review (non-systematic)	USA, >1 group Older people, non-specific conditions	Review literature during the decade that followed the passage of the PSDA including research exploring ethnic factors in the completion of advance directives (including barriers to completing advance directives by minority populations)	N/A
Barrett 2005[105], USA Narrative review (non-systematic)	USA, >1 group Non-specific conditions	Provide insights into the documented pattern of African Americans to use ADs; offer practical suggestions for clinical caregivers working with African Americans to enhance culturally sensitive caregiving and the utilisation of ADs amongst African Americans	N/A
Brooke 2011[133], Australia Systematic review	Australia, >1 group Older people residing in residential aged-care facilities	Identify evidence-based practice guidelines to support the care needs of Aboriginal and Torres Strait Islander clients residing in residential aged-care facilities	Minor flaws
Cemlyn et al 2009[119], UK Systematic review	UK, >1 group (shown as 'Gypsy and Traveller communities') Non-specific conditions	Draw together the evidence from Gypsies' and Travellers' experiences in order to set out clearly the full extent of inequalities and discrimination; provide a basis for action to address the inequalities, including on issues which the policy agenda often neglects	Mid-range major to minor flaws
Cohen 2008[110], USA Systematic review	USA, >1 group Cancer, AIDS, non-specific conditions	To examine the evidence regarding differences in hospice use amongst minority patients versus White patients	Mid-range major to minor flaws
Connolly et al 2012[53], UK Systematic review	USA, >1 group Dementia and cancer	Investigate differences in interventions used at the end of life, verify potential barriers to providing good end of life care to people with dementia from ethnic minorities (including attitudes/experiences of people with dementia and their caregivers)	Mid-range minor to minimal flaws
Cox et al 2006[122], UK Critical review (systematic approach)	UK and USA, >1 group HIV, cancer, non-specific conditions	Consider the implications of Black and Minority ethnic people's cultural diversity on the Do Not Attempt Resuscitation decision making process and to make recommendations for ethically sound practice within the healthcare system	Mid-range extensive to major flaws

Table A19 continued

Authors and year, country Method	Country of population, minority ethnic groups, diagnosis at the end of life	Aim of review	Quality: extensive to minimal flaws
Cunningham et al 2008[95], Australia Systematic review	Australia, Indigenous Australian Cancer	Give an up-to-date assessment of cancer in Indigenous Australians, their demographic and socioeconomic context; patterns of incidence, mortality, treatment, and survival; key risk factors; screening participation; and their views on cancer and cancer treatment	Mid-range major to minor flaws
Degenholtz et al 2003[129], USA Narrative review (non-systematic)	USA, >1 group Cancer, dementia, non-specific conditions	Examine the extent to which racial differences in the use of the intensive care unit reflects the pattern of disproportionate burden described by the Institute of Medicine. Also address the association amongst race, individual preferences, and use of end of life care.	N/A
DoH 2008[98], UK Equality Impact Assessment report with a narrative review (non-systematic)	UK, >1 group Non-specific conditions	Try to understand more where and why the service is failing to deliver a good quality service in some cases	N/A
Elkan et al 2007[101], UK Critical review (systematic approach)	UK and USA, >1 group Cancer	Explore the views and experiences of cancer service users from minority ethnic groups	Mid-range major to minor flaws
Evans et al 2011[25], Spain, UK and the Netherlands Systematic review	UK, >1 group Cancer, non-malignant diseases, non-specific conditions	Evaluate the reviews of the literature concerning minority ethnic groups and end of life care in the UK and discuss selected issues	Minimal flaws
Evans et al 2012[104], Spain, UK and the Netherlands Systematic review	UK, >1 group Cancer, non-specific conditions	Systematically identify and review all original studies relating to minority ethnic groups and end of life care in the UK, critically examine the quality of studies, determine key themes across studies, identify current knowledge gaps	Minimal flaws
Firth 2001[89], UK Narrative review (non-systematic)	Various (including UK), >1 group Multiple conditions (e.g. cancer, stroke), non-specific conditions	Review the literature on minority ethnic groups in end of life care and discuss selected issues	N/A
Gunaratnam 2006[115], UK Narrative review (non-systematic)	UK and USA, >1 group Cancer, stroke, dementia, non-specific conditions	Bring together established and developing work on older people, ethnicity and palliative care, drawing attention to the palliative care needs and experiences of elders from groups most commonly referred to in the UK as being 'minority ethnic'	N/A
Haley et al 2002[118], USA Narrative review (non-systematic)	USA, >1 group Multiple chronic (e.g. dementia), terminal (e.g. cancer) conditions	Examine the role of families in end of life decisions and care throughout the course of disease progression	N/A
Harding et al 2005[106], UK and USA Systematic review	USA, >1 group HIV patients	Promote adequate palliation for patients with HIV disease through the identification of inequalities in HIV palliative care and the associated barriers to access	Mid-range major to minor flaws
House of Commons Health Committee 2004[114], UK Report (non-systematic)	UK and USA, >1 group Cancer, non-specific conditions	Examine the extent to which the needs and wishes of patients of different ages are taken into account, including their care choices, ethnicity, cultural and spiritual beliefs	N/A
Johnson 2001[97], UK Narrative review (non-systematic)	Various (including UK), >1 group Cancer	Review the available literature on palliative care, cancer and minority ethnic communities	N/A

Table A19 continued

Authors and year, country Method	Country of population, minority ethnic groups, diagnosis at the end of life	Aim of review	Quality: extensive to minimal flaws
Johnson et al 2005[127], USA Systematic review	USA, African Americans Cancer, non-specific conditions	Identify a spiritual belief system that may guide the end of life treatment decisions of African Americans	Minor flaws
Johnstone and Kanitsaki 2009[128], Australia Narrative review (non-systematic)	Various (including UK), >1 group Cancer, non-specific conditions	Give a cross-cultural examination of the mainstream bioethical foundations of ACP/ADs and their possible implications when applied without modification in a culturally diverse society	N/A
Jones 2005[90], UK Systematic review	Various (including UK), >1 group Non-specific conditions	Investigate qualitative literature on end of life and ethnicity/race/diversity	Mid-range major to minor flaws
Kagawa-Singer et al 2010[112], USA Narrative review (non-systematic)	USA, >1 group Cancer	Suggest a definition of culture to serve as the basis for a framework that incorporates culture and identifies promising strategies to augment clinical skills with culturally sensitive communication; and to show how the incorporation of culture could reduce cancer health disparities along the entire cancer care continuum	N/A
Kelly and Minty 2007[149], Canada 'Critical review' (systematic approach)	Canada, Aboriginal Non-specific conditions	Understand some of the cross-cultural issues in providing palliative care for aboriginal patients	Major flaws
Krakauer et al 2002[125], USA Narrative review (non-systematic)	USA, >1 group Cancer, non-specific conditions	Explore barriers to optimum end of life care that particularly affect minority patients	N/A
Kwak and Haley 2005[52], USA Critical review (systematic approach)	Various (not including UK), >1 group Cancer, dementia, non-specific conditions	Provide a critical review of what is known about diversity and end of life decision making research, identify gaps in literature, and to provide recommendations for future research, practice and policy	Minor flaws
Lees and Papadopoulos 2000[92], UK Critical review (systematic approach)	UK and USA, >1 group Cancer	Bring together the evidence from recently published studies concerning cancer and men, with a focus on men from minority ethnic groups, migrant men or their descendants	Mid-range major to minor flaws
Payne et al 2003[116], USA Narrative review (non-systematic)	USA, >1 group Breast cancer	Identify racial disparities in the palliative care of patients with cancer and their impact on quality of life for African-American women	N/A
Payne et al 2005[103], UK Systematic review	Various (including UK), Chinese Cancer, non-specific conditions	Describe key contributing factors and issues for Chinese people facing death and draw out implications for the culturally competent practice in palliative care	Major flaws
Ramey and Chin 2012[113], USA Systematic review	USA, >1 group Cancer, non-specific conditions	Determine if the disparity in hospice utilisation between African American and Caucasians persisted when restricted to examining hospice use amongst cancer patients; determine the degree to which clinical/demographic factors, healthcare system barriers, or patient preferences may contribute to hospice use in this population	Major flaws
Redman et al 2008[120], UK Critical review (systematic approach)	UK, >1 group Cancer	Review research literature on health that addressed ethnicity, race and health, identifying commonalities and differences between and within ethnic groups in the UK	Minor flaws

Table A19 continued

Authors and year, country Method	Country of population, minority ethnic groups, diagnosis at the end of life	Aim of review	Quality: extensive to minimal flaws
Talamantes et al 1995[108], USA Narrative review (non-systematic)	USA, >1 group Older people, non-specific conditions	Give an overview of health/demographic characteristics for the Hispanic elder population; address family caregiving issues surrounding terminal illness; understand resource use; make recommendations for the provision of information/education about hospice services	N/A
Trice and Prigerson 2009[102], USA Narrative review (non-systematic)	Various (including UK), >1 group Cancer	Review end of life communication between oncologists and advanced cancer patients, highlighting differences by race and ethnicity, and the end of life outcomes associated with this communication	N/A
Underwood et al 2005[130], USA Critical review (systematic approach)	USA, African Americans Non-specific conditions	Review, analyse and critique the outcomes reported involving the nursing research aimed toward reducing and/or eliminating health-related disparities amongst African Americans	Mid-range major to minor flaws
Volker 2005[93], USA 'Literature review' (non-systematic)	USA, >1 group Non-specific conditions	Examine how the concepts of patient control and ethnicity may influence end of life care decisions	N/A
Walshe et al 2009[121], UK Systematic review	Various (including UK), >1 group Cancer, dementia, non-specific conditions	Search guided by the questions: do adult patient (or carer) characteristics affect access to, or utilisation of, community palliative care services?	Mid-range minor to minimal flaws
Washington et al 2003[117], USA Systematic review	USA, African American Non-specific conditions	Identify research methods/designs being used to explore barriers to utilisation of hospice care by African Americans; identify obstacles to increased African American participation and tested interventions designed to increase the number of African Americans using hospice	Mid-range major to minor flaws
Werth et al 2002[99], USA Narrative review (non-systematic)	USA; >1 group Cancer, non-specific conditions	Highlight some of the ways in which culture can affect end of life care and decision making	N/A
White et al 2012[107], USA Narrative review (non-systematic)	USA, >1 group Non-specific conditions	Synthesise findings from the health services research literature and present a framework that extends a seminal model of segregation and health disparities to address segregation as a fundamental cause of racial disparities in healthcare	N/A
Wicher and Meeker 2012[111], USA Systematic review	USA, African Americans Cancer, dementia, non-specific conditions	To examine and synthesise the state of the science from published research focused on end of life preferences and the influences on those preferences amongst African Americans	Mid-range major to minor flaws
Winston et al 2004[100], USA Narrative review (non-systematic)	USA, >1 group Cancer, non-specific conditions	Explore some of the barriers to the utilisation of hospice and palliative care for African Americans, and how those barriers might be eliminated	N/A

Abbreviations: UK – United Kingdom. USA – United States of America. CHD – coronary heart disease. ACH – advanced congestive heart failure. COPD – chronic obstructive pulmonary disease. N/A – not applicable. AD – advance directives. AIDS – Acquired Immune Deficiency Syndrome . HIV – Human Immunodeficiency Virus.

Box A20 – Methodological assessment of reviews

Most reviews clearly specified which search methods they had used, except for two of them[103, 109]. However, it was only clear in only about half of reviews that their search had been comprehensive[25, 28, 53, 90, 91, 95, 101, 104, 110, 119, 121, 123, 133]. Most reviews explicitly described their criteria for including studies, except for six of them[92, 103, 119, 122, 123, 133]. Only seven reviews made it clear whether bias was avoided when selecting studies[28, 53, 91, 95 25, 104, 117] (e.g. by assessing studies according to criteria or using two different researchers to do the assessment). Only a third (n=8) fully specified their criteria for assessing how valid the results they included were[25, 28, 53, 91, 104, 120, 121, 127], although 60% (n=15) of reviews attempted to critically examine the evidence while presenting it[25, 28, 52, 53, 91, 104, 109–111, 113, 120, 121, 127, 130, 133]. Only seven studies did not explicitly explain the processes of how they combined findings from their included studies (e.g. meta-analysis, narrative synthesis, interpretative synthesis)[52, 53, 95, 106, 110, 122, 123]. All reviews presented their findings according to what they had specified as their research objectives and all but one[122] had conclusions which were clearly supported by their data/analysis. Overall, 10 (40%) of the reviews were considered to have between minor and minimal flaws[25, 28, 52, 53, 91, 104, 120, 121, 127, 133, 11] (44%) had from mid-range major to minor flaws[90, 92, 95, 101, 106, 109–111, 117, 119, 130] and four reviews (16%) were considered to have either major flaws[103, 113, 123] or mid-range major to extensive flaws[122].

Quality assessment of systematic reviews and critical reviews with a systematic approach

Author and year	1. Search methods stated	2. Search for evidence comprehensive	3. Inclusion and exclusion criteria stated	4. Bias in selection avoided	5. Criteria reported for assessing validity	6. Validity assessed using appropriate criteria	7. Methods used to combine findings reported	8. Findings combined relative to research question	9. Conclusions supported by data	10. Quality (1–7)
Ahmed et al 2004[28]	yes	yes	yes	yes	yes	yes	yes	yes	yes	7
Anderson et al 2009[109]	partially	can't tell	yes	can't tell	no	yes	yes	yes	yes	4
Atkinson et al 2001[91]	yes	yes	yes	yes	yes	yes	yes	yes	yes	7
Brooke 2011[133]	yes	yes	partially	can't tell	partially	yes	yes	yes	yes	5
Cemlyn et al 2009[119]	yes	yes	no	can't tell	no	can't tell	yes	yes	yes	4
Cohen 2008[110]	yes	yes	yes	can't tell	no	yes	no	yes	yes	4
Connolly et al 2012[53]	yes	yes	yes	yes	yes	yes	no	yes	yes	6
Cox et al 2006[122]	yes	can't tell	no	can't tell	no	can't tell	partially	yes	partially	2
Cunningham et al 2008[95]	yes	yes	yes	yes	no	can't tell	no	yes	yes	4
Elkan et al 2007[101]	yes	yes	yes	can't tell	no	can't tell	yes	yes	yes	4
Evans et al 2011[25]	yes	yes	yes	yes	yes	yes	yes	yes	yes	7
Evans et al 2012[104]	yes	yes	yes	yes	yes	yes	yes	yes	yes	7
Harding et al 2005[106]	yes	can't tell	yes	can't tell	no	can't tell	partially	yes	yes	4
Johnson et al 2005[127]	yes	can't tell	yes	can't tell	yes	yes	yes	yes	yes	5
Jones 2005[90]	yes	yes	yes	can't tell	no	can't tell	yes	yes	yes	4
Kelly and Minty 2007[123]	yes	yes	no	can't tell	no	can't tell	no	yes	yes	3
Kwak and Haley 2005[52]	yes	can't tell	yes	can't tell	partially	yes	yes	yes	yes	5
Lees and Papadopoulos 2000[92]	yes	can't tell	partially	can't tell	no	can't tell	yes	yes	yes	4
Payne et al 2005[103]	partially	can't tell	no	can't tell	no	can't tell	yes	yes	yes	3
Ramey and Chin 2012[113]	yes	can't tell	yes	can't tell	no	yes	no	yes	yes	3
Redman et al 2008[120]	yes	can't tell	yes	can't tell	yes	yes	yes	yes	yes	5
Underwood et al 2005[130]	yes	no	yes	can't tell	no	yes	yes	yes	yes	4
Walshe et al 2009[121]	yes	yes	yes	can't tell	yes	yes	yes	yes	yes	6
Washington et al 2003[117]	yes	no	yes	yes	no	can't tell	yes	yes	yes	4
Wicher and Meeker 2012[111]	yes	can't tell	yes	can't tell	no	yes	yes	yes	yes	4

Table A21 – Examples of best practices

Author and year	Examples of best practices
Anderson et al 2009[109]	Authors gave examples of clinical trials designed to empower minority group patients to be active partners in their pain management and concluded that individualised education combined with role playing and specific suggestions for pain treatments is a 'promising intervention'.
Cemlyn et al 2009[119]	Authors reported successful practices to reduce inequities in healthcare in general for Gypsy and Traveller communities, without focusing on palliative care. Effective strategies included the employment of specialist health outreach staff to work with Gypsies and Travellers; a project involving visits from outreach workers to identify health needs and priorities (and put in support and training around those needs). Other practices included a booklet for health staff on Gypsies' and Travellers' cultural values (with information on how to support them to access healthcare) and an information booklet which stressed practitioners' responsibility for engaging with their patients and ensuring they were familiar with instructions (e.g. medication). Authors mentioned other projects which involved engagement with residents and emphasised the importance of joint service planning (health providers and members of the community working together) for a project to be successful. They finalised by highlighting that the short-term nature of many projects is a major concern, since there is the risk to lose any improvement when the projects finish, and suggest the need to create a national strategy to reduce health inequalities.
Cunningham et al 2008[95]	Cunningham et al referred to the Northern Territory Well Women's screening programme, which seems to have resulted in a decrease in the number of Indigenous Australian women with cervical cancer in the Australian's Northern Territory (no further information on the programme is given)
Elkan et al 2007[101]	Elkan et al state that there has been much work in the UK to develop initiatives to better respond to the needs of BAME groups. Authors referred to Deepak's report 'Beyond the Barriers'[150] which describes efforts being made to improve cancer information and support to BAME communities, but highlighted that these initiatives represent 'pockets of good practice' instead of being widely embedded throughout services in the UK.
Firth 2001[89]	Firth referred to several examples of potential good practice in her review. Examples of ongoing projects at the time of her publication included the Warwickshire Health Authority Project, which aimed to specifically address the palliative care needs of BAME patients in the area, the 'No Exclusion Project' (also in Warwickshire) investigating the coordination of translators and interpreters; a London-wide health advocacy initiative funded by the NHS and the King's Fund; work in Birmingham University Hospital to develop a 'culturally sensitive pain tool' to help patients assess pain in different languages; a Muslim bereavement service in London with the aim to train Muslims to be bereavement visitors (but also to have a wider role giving advice when required). Firth also referred to the Acorn Children's Hospice in Birmingham, reporting that it has had successful outreach in the minority ethnic communities through the provision of videos in different languages and through visits to groups, clubs and community leaders. There was also reference to a multidisciplinary specialist healthcare service for BAME elders in Streatham (London) which was gradually accepted by the Local Asian community through the efforts of a specialist health visitor and a screening clinic with an interpreter who also accompanied patients to hospital and GP appointments.
Gunaratnam 2006[115]	Gunaratnam referred to several UK projects to address the local needs of BAME groups. These included a joint project between St Gemma's Hospice and Sue Ryder Care (Wheatfields) (results are not presented), the creation of Macmillan Ethnic Minorities Liaison Officers in Bradford (with the results of improved communication between professionals and service users, more accurate needs assessment and increase in the use of hospice services by people from South-Asian groups), the Bengali Cancer Awareness and Advocacy Project to raise awareness of cancer and increase access to service for Bengali people (results are not presented) and a training course on communication and cultural awareness in London for all healthcare professionals caring for cancer patients (one of the outcomes was a significant improvement in self-confidence levels at the end of the course).
Harding et al 2005[106]	Harding et al referred to several demonstration projects and an evaluation centre in the USA which was funded to deliver palliative care to hard-to-reach and underserved populations with HIV/AIDS. The service involved mobile palliative care teams in community settings and community-based residential units. There was no further information on whether the service has proven to be effective. Authors also gave examples of two specialist UK-based palliative care services, but without further information on their effectiveness to improve care.
Kagawa-Singer et al 2010[112]	Authors developed a theoretical Ecologic Model of Culture, provided recommendations for integrating cultural knowledge into clinical practice, described different levels of cultural assessment and provided ethnic specific cancer support resources at the end of their publication. There was no further information on whether the proposed model has been tested.

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Acknowledgements

This research report has been developed and produced with valued contributions from the Department of Health, Help the Hospices, King's College London, Leicestershire Social Care Development Group, the National Council for Palliative Care and the Race Equality Foundation. Their contributions through membership of the BAME project group have been extremely valuable in producing this report in addition to shaping and delivering the project overall. We thank Gerry Mahaffey and Ian Gittens from Marie Curie Cancer Care and Katie Lindsey from Public Health England for their invaluable help during the whole project. We could not have written this report without the help and feedback from Claire O'Neill, Phil McCarvill, Sabine Best and Teresa Tate at Marie Curie Cancer Care; Alice Rigby, Heather Richardson, Jabeer Butt, Julia Verne, Julie Alexander, Kerry Archer-Dutton, Naz Hussein, Nicola Bowtell and Simon Chapman from the BAME Project Group.

We thank Cicely Saunders International and the Cicely Saunders Institute for their constant support. Special thanks to Dan Sims at King's College London, Barbara Gomes, Sian Best, Fliss Cheek and Gao Wei at the Cicely Saunders Institute. We thank everyone who attended the event: 'Delivering inclusive end of life care services that meet the expectations, preferences and needs of people from Black, Asian and other Minority Ethnic (BAME) backgrounds' on the 10th April 2013. The participants' very pertinent comments and constructive criticism helped us to produce the final version of this report. We thank the ONS, NISRA, NRS, Coleman, Wohland et al, the Runnymede Trust and the Centre for Policy on Ageing for making their data available free of charge. We also thank King's Library Services for helping us to access literature not available online. We thank Libby Osborn and the authorship team (Jennie Popay, Helen Roberts, Amanda Sowden, Mark Petticrew, Lisa Arai, Mark Rodgers, Nicky Britten, Katrina Roen and Steven Duffy) for providing us with the 'Guidance on the Conduct of Narrative Synthesis in Systematic Reviews' (a product from the ESRC Methods Programme). Finally, we are extremely grateful to Sophia Blake at the Cicely Saunders Institute, Malvina Rossi and Rhiannon Smith at Marie Curie Cancer Care for proofreading this report.

Disclaimer

Data presented derive from different sources, but the report reflects the authors' views.

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