Koffman J, Bajwah S, Davies JM, Hussain JA. Researching minoritised communities in palliative care: An agenda for change. *Palliative Medicine,* 2022. Copyright © 2022 by the authors. DOI: doi.org/10.1177/02692163221132091

Researching minoritised communities in palliative care: an agenda for change

Jonathan Koffman [1], Sabrina Bajwah [2], Joanna M Davies [2] & Jamilla Akhter Hussain [3]

ABSTRACT

Background: Palliative care access, experiences and outcomes of care disadvantage those from ethnically diverse, Indigenous, First nation and First people communities. Research into this field of inquiry raises unique theoretical, methodological, and moral issues. Without the critical reflection of methods of study and reporting of findings, researchers may inadvertently compromise their contribution to reducing injustices and perpetuating racism.

Aim: To examine key evidence of the place of minoritised communities in palliative care research to devise recommendations that improve the precision and rigour of research and reporting of findings.

Methods: Narrative review of articles identified from PubMed, CINAHL and Google Scholar for 10 years augmented with supplementary searches.

Results: We identified and appraised 109 relevant articles. Four main themes were identified (i) Lack of precision when working with a difference; (ii) 'black box epidemiology' and its presence in palliative care research; (iii) the inclusion of minoritised communities in palliative care research; and (iv) the potential to cause harm. All stymie opportunities to 'level up' health gain across the palliative care spectrum.

Conclusions: Based on the findings of this review palliative care research must reflect on and justify the classification of minoritised communities, explore and understand intersectionality, optimise data quality, decolonise research teams and methods, and focus on reducing inequities

to level up end-of-life care experiences and outcomes. Palliative care research must be forthright in explicitly naming structural and systemic racism, describing its operation and engaging in non-judgmental debate on changes required.

What is already known about the topic?

- There is evidence that health experiences and outcomes of care disadvantage those from ethnically diverse, Indigenous, First nation and First people communities. Inequalities and inequity are well recognized but inadequately addressed.
- In the generation and reporting of research evidence, palliative care researchers play a vital part in influencing service provision, clinical practice and discussion of ways to reduce inequity. However, this is associated with significant methodological, conceptual and ethical challenges. Without honest discussion of these issues, progress remains stymied, and racism persists.

What does this paper add?

- Critical examination of palliative care research that has focused on ethnically diverse, Indigenous, First nation and First people communities identify a lack of precision in how terminology is employed. This compromises scientific rigour.
- Evidence of the harms inadvertently caused by current palliative care research practice is commensurate with structural, systemic and procedural racism.
- A detailed understanding of the underrepresentation of these communities in the palliative care research process can be mitigated by the decolonisation of research teams and methods used.

Implications for practice, theory, or policy

- The recommendations proposed by this review constitute the basis for guidance for the conception, conduct and reporting of ethnically diverse, Indigenous, First nation and First people communities in palliative care research.
- We suggest they serve as a guide for researchers undertaking studies that focus on these communities, for authors publishing them, as well as for reviewers and journal editors when evaluating the quality of the study design and the transparency of reporting.

BACKGROUND

Throughout history, individuals, families and groups have migrated from their original or previous homes for many reasons: as refugees to escape war, colonisation and domination by others, genocide, famine, political torture or other conflicts, for the prospect of educational, economic or social advantage, or to reunite with other family members[1]. Increasingly, globalization has brought with it an unparalleled number of people who have moved to high-income countries. From 2010 to 2020, North America and Europe received 25.9 million international migrants[2]. Migration has also witnessed mostly white people moving to countries where their colonisation has overwhelmed minoritised, Indigenous, First nation or First people communities, bringing with them systems and structures associated with social injustice[3]. The implications of this for palliative care are profound. Health and social care professionals, many of who themselves may come from a diverse range of ethnocultural backgrounds, will be providing care for those whose backgrounds are different to their own. Moreover, patients may arrive at a critical junction with different repertoires for how they comprehend illness, symptoms, expectations of care and make use of services[4].

In recent times, movements of the tectonic plates of the ethnocultural landscape in the United Kingdom, USA, Australia, New Zealand and many countries across Europe have exposed societal fissures that demand attention. 'Empire Windrush'[5], the response to acts of violence metered out to people of colour[6, 7] and the COVID-19 pandemic that exacted disproportionately high mortality among certain minority communities [4 8 9-12] have brought into sharper relief the inequity minority ethnic communities experience. Organisations, including those in palliative care[13], have made public commitments to listen more attentively and redress injustices. This was reiterated in the recent *Lancet Commission on the Value of Death*[4]. In a recent editorial in *Palliative Medicine*, three authors of this paper (JH, SB and JK) laid claim to the presence of racism in palliative care. They highlighted the imperative to collect and analyze data to monitor ethnic disparities and their intersection with other protected and social characteristics[14]. Most recently, the presence of racism is embedded across the entire health research landscape from question construction, racism in research commissioning, racism in academia and dissemination in peer-reviewed journals[15]. Like others[16] we believe there is no space for palliative care research to be complacent about this issue. The aim of this review is therefore to identify and critically appraise evidence to question the veracity of this assumption and where necessary formulate a methodological agenda for change.

METHOD

This review follows a narrative methodology suited to a question of this nature[17]. This was enhanced through a systematic sampling approach to address the research question whilst mitigating some of the limitations of this approach by using clearly defined search criteria, data extraction and analysis process[18 19].

Search strategy

A search of the peer-reviewed literature was conducted which involved the following PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Google Scholar electronic databases from March 2012-March 2022 (table 1). This search was augmented with an electronic search of key palliative care journals. Finally, bibliographies from articles were cross-searched to identify any supplementary papers relevant to the review aim.

Table 1: Databases and search terms for narrative review

Database	Controlled vocabulary	Search Terms	
PubMed	MeSH	“Palliative” [Mesh] OR “Palliative Care” [MeSH] OR “Terminally ill” [Mesh] “Terminal care” [MeSH] OR “Hospices” [Mesh] OR “Hospice Care” [MeSH] AND “Ethnicity” [MeSH] OR “Ethnic” [MeSH] OR “Race” [MeSH] OR “Racial” [MeSH] OR “Culture” [Mesh] OR “Indigenous” [MeSH] OR “First Nation” [MeSH] OR ”First People” [MeSH]) AND “Research” [MeSH] OR “Study” [MeSH] OR “Studies” [MeSH]	11,707
CINAHL	Major headings	MM "Hospice and Palliative Nursing") OR (MM "Palliative Care" OR MH "Terminal Care" OR MM "Hospice Care" OR MH "Palliative Medicine" OR "Palliative" OR "Terminally Ill" OR "Hospice" OR MH "Hospice" or "Palliative care" or "End of Life Care" or "Terminal Care") AND MH "Ethnic Minorities" OR "Racial " OR “Indigenous” OR MM “First Nation” OR MH “First People” AND MH "Research" OR "Research Study"	42,738
Google Scholar	Major headings	"Palliative Care" OR "Hospice Care" OR "Terminal Care" AND "Ethnic Minorities" OR "Race OR "Ethnicity OR “First Nation” OR “First People” OR “Indigenous” AND "Research Study"	12,700

Criteria for inclusion and exclusion

All searches were limited to full-text articles published in English-language, peer-reviewed journals. Articles were included where content directly informed the focus and objective of the narrative review, including discussion papers and scientific papers reporting qualitative and or quantitative research. Papers were excluded if their focus was not directly relevant to one of the search terms.

Article management and review

The categorisation and storage of articles were managed using EndNote X9 bibliographic software. Articles were read and re-read with observations made to inform the review. As noted by Coughlan[18] this represents an effective approach to facilitating the integration of both theoretical and empirical literature. Further synthesis of the literature was then organised into themes for critical discussion.

For transparency, the interpretation of evidence for this narrative review was mediated through the respective cultural lenses of the authors. Specifically, JK is a White British Jewish social scientist with a track record of conducting research in transcultural palliative care and equity, JMD is a White British social scientist with expertise in social determinants of health and palliative care equity, SB is a British Pakistani Muslim and a palliative care clinician and senior lecturer and works in an inner-London hospital serving a population where 50% of patients are from ethnically diverse communities and JAH is a British Pakistani Palliative Care Consultant working in Bradford, a northern UK city where 33% of the population come from ethnically diverse communities.

RESULTS

A total of 109 articles were used to identify four themes: (1) lack of precision when working with difference; (2) 'black box epidemiology' and its presence in palliative care research; (3) the inclusion of minoritised communities in palliative care research; and (4) the potential to cause harm.

Lack of precision when working with difference

Research on race, ethnicity, Indigenous, First peoples and First nation communities creates conceptual, methodological and moral challenges[1]. Recently, more attention has been drawn to how terminology on difference is theorised, operationalised and has evolved in research[20, 21]. The collection of sociodemographic variables is often poorly thought out concerning the outcome or phenomena being studied, vaguely defined, and inappropriately considered interchangeable[22, 23]. Good quality research requires carefully considered terminology and measures to reveal inequities and convey respect.

Race relies on an erroneous belief that people can be categorised according to shared physical and biological characteristics such as skin colour, facial features, and other hereditary traits. This framework for categorising people has been largely discredited with a clear demonstration that genetic variations between racial groups are small, inconsequential, inaccurate and misleading[24]. Instead, we see race as a social representation created to devise social groupings related to physical appearance to create and maintain a power hierarchy between groups and enforce systems of privilege, most specifically between white people and people of colour[25]. Whilst 'race' still appears to have currency in the USA literature we do not advocate its use.

The historical taboo surrounding research into race, the need for a greater understanding of social and cultural factors that shape and pattern health and disease, and to describe of the uptake of service provision and outcomes from interventions, created impetus for a new vocabulary and consequently, ethnicity is often now widely used. We see value in the definition of ethnicity as comprising two distinct dimensions[26]. First, it includes an attributional dimension that describes the unique sociocultural characteristics (e.g., culture, diet) of groups that include *"a shared culture and way of life, especially as reflected in language, folkways, religious and other institutional forms, material culture such as clothing and food, and cultural products such as music, literature, and art"* p.109[27]. The attributional dimension is useful for understanding personal identity and group sociocultural characteristics; however, alone it explains neither groups' social locations within society nor how societal forces can differentially influence the health of ethnically defined populations. It therefore needs to include a relational dimension that captures characteristics of the relationship between an ethnically defined group and the society in which it is situated. This dimension is particularly useful when research aims to understand how social stratification and social exposures (i.e., risk factors such as discrimination that derive from the social context) contribute to ethnic health inequities[26]. Targeting the relational dimension reduces the possibility of inappropriately attributing disparities to ethnic group characteristics instead of to the group's relationship to the broader society[26].

While ethnicity has no intrinsic biological meaning, this term has important, notwithstanding contested, social meanings. Neglecting to use ethnicity as a variable in palliative care research may disregard the reality of social stratification, injustices, and inequities with implications across the palliative care spectrum of interest. However, there is often highly variable use of terminology from one study to the next and it is this that concerns us. This comprises the integrity of the studies and their comparability. One problem is that the meaning of identity labels like ‘Asian’, ‘white’, ‘Caucasian’, and ‘Hispanic’ is taken for granted and rarely explained in palliative care research[28-35]. Another issue is that populations identified by current methods of measuring ethnicity are often too diverse to provide useful information[1]. At the crudest extreme, defining individuals as ‘non-white’[36-38] does not satisfactorily describe the rich cultural, social, and religious nuances that define ethnicity. Another single category of difference ‘Asian’, is similarly too broad a category and disguises important differences by country of origin, religion, language, diet, and other factors relevant to palliative, end-of-life and bereavement care. The same cautions apply to categories including those labelled as being ‘Indian’, ‘Chinese’, ‘Pakistani’, and ‘Afro-Caribbean’. Moreover, collective terms mask inequalities as they are experienced by different ethnic groups.

The current 18 United Kingdom Office of National Statistics categories and 11 categories in the USA[39] represent a pragmatic starting point[31, 40-43]. However, there is a tension between greater refinement and the need to interpret findings, particularly where sample sizes are small[44]. As a guiding principle, palliative care researchers must always be mindful of using the most appropriate ethnicity label and consider how conclusions may be flawed by inappropriate aggregation.

The United Nations Permanent Forum on Indigenous Issues (UNPFII) set out seven criteria for the identification of Indigenous peoples[45].

- self-identification as Indigenous peoples at the individual level and acceptance by the community as a member.
- historical continuity with pre-colonial or pre-settler societies.

- strong link to territories and surrounding natural resources.
- distinct social, economic, or political systems.
- distinct language, culture, and beliefs.
- people from non-dominant groups of society.
- resolve to maintain and reproduce their ancestral environments and systems as distinctive peoples and communities

There are an estimated 370 million Indigenous people living across 70 countries worldwide[46]. The term “Indigenous” has prevailed as a generic term for many years but some may prefer to be referred to as “First peoples” or people from “First nations”[47] Irrespective of this, these communities hold traditional values, visions, needs and priorities where ancestral land has fundamental importance for their collective physical and cultural survival and identity[47]. Among the indigenous peoples are those of the Americas (for example, the Lakota in the USA), Inuit and Aleutians of the circumpolar region, the Saami of northern Europe, Aborigines and Torres Strait Islanders of Australia and Māori of New Zealand.

Most recently and against a backdrop of key ethnocultural events[4-12], the debate about the nomenclature of defining differences concerning the most appropriate way to describe people of minority ethnic backgrounds and portray them in research has progressed[1] [44, 48, 49]. Word choice is critically important in research and continues to evolve; inclusive language supports diversity and conveys respect[1]. An important direction for researchers to follow is to provide a considered and transparent account of the concepts and categories they use. This builds on the guidance developed by the International Committee of Medical Journal Editors (ICMJE) recommending, that *“authors should define how they determined race or ethnicity* [and we believe other classifications we present] *and justify their relevance*”[50].

‘Black box epidemiology’ and its presence in palliative care research

Much research that has examined the relationship between ethnicity and health[51], can be described as "black box" epidemiology”. Skrabanek specifies that this type of research focuses on the relationship between exposures and outcomes but the causal mechanisms behind an association remain concealed [52]. Arguably some palliative care research could be viewed this way[31-33, 53] There is a moral imperative for researchers to endeavour to open, expose and understand the contents of the “black box”. First, researchers must also be mindful to indicate exactly why ethnicity is relevant for a particular study. Often this is not present - the inclusion of ethnicity has become a ‘knee-jerk’ reflex, accompanying many tables that examine demographic differences[54]. Whilst it might be appropriate to record self-assigned ethnicity and to analyse it, the reality that it was collected may not be sufficient reason to analyse outcomes associated with it.

Few studies have further examined the intersection between ethnicity and other important social determinants of health, such as socioeconomic position and age as well as contextual or cultural factors[55-58]. A recent systematic review, conducted before Covid-19, highlighted persistent structural and systemic inequalities among hospice care providers for some groups that included social factors, for example, ethnicity[59]. We require more studies that examine the underlying multifarious mechanisms and mediating pathways and the complex interaction between factors that lead to poor palliative care outcomes[60].

In addition to this, studies that have elucidated ethnic differences have not progressed research to examine if recommendations for clinical care or policy have been implemented and evaluated. We argue for a need to move from the repetitious demonstration of ethnicity variations that have already been demonstrated in palliative care research to advance research more strategically to deliver meaningful paths to patient, family and societal benefit.

The inclusion of minoritised communities in palliative care research

The inclusion of ethnically diverse, Indigenous, First nation and First people populations in palliative care studies is critical to ensure that improvements in health are relevant and effective. The exclusion of people from these groups from research perpetuates health inequities and may contravene human rights legislation that aims to prevent discrimination[61]. It is well recognised that in health research generally, in clinical trials[62]and palliative care research[28, 63] minoritised groups are chronically underrepresented. This fact was further highlighted during the Covid-19 pandemic[64-66]. Reasons for the exclusion of individuals from these groups may be due to ‘planned exclusion’, ‘inadvertent exclusion’, ‘non-participation,’ or a combination of these factors. Table 2 summarises the complex, multifarious explanations to account for this.

Table 2: Potential individual, professional, system and structural reasons for inequitable representation or reporting of minority ethnic groups in palliative care research

Reasons for underrepresentation and reporting	**Explanation**
Individual includes health and illness-related beliefs and worldview	• The wish to be involved in some studies may be governed by culturally patterned and channelled perceptions of illness. For example, fatalistic illness attributions associated with cancer[67] and multiple sclerosis[68] have been identified to be closely associated with faith-based beliefs. This may influence individuals' views of the relevance of study participation to them. • Decisions to participate in research are also largely guided by the individualistic western-centric conception of personal autonomy. This may not be a relevant and motivating factor for some individuals from ethnically diverse groups where more familial or communal approaches may also influence the decision-making to be (or not) involved in research studies.
Trust includes historical and current racial discrimination, prejudice and abuse	• There a well-known historic examples both in the USA (the Tuskegee syphilis study[69]) and the UK (Stop rickets campaign[70]) where health-related research was associated with ethical mistreatment and exploitation that erode the potential for trusting relationships with health professionals. Whilst these events have been shown to impact the willingness to participate in research[71] this may be amplified by previous negative health-related encounters among people from minority ethnic communities[72] • Moreover, interviews with British Social Asian cancer trial participants identified that some perceived that they were treated as 'outsiders' to society and therefore their willingness to contribute to knowledge was thwarted or discouraged.[73]
Structural barriers include issues around literacy, education, language,	• Evidence suggests that inadvertent exclusion from palliative care research may result from a combination of complex factors including patient literacy, community in-reach, dominant language ability and the additional costs of translation of key study materials into locally relevant languages to research teams and funders and the availability of researchers proficient in different languages.[74]

Study-related factors include data quality, site access, discrimination of recruiters, flexibility in study design, representation of study staff	• The reasons why people enrol in palliative care studies are multiple but include supporting medical research and altruism, among other factors[75 76]. Interpersonal relations with health professionals built on a foundation of trust have also been shown to be an important motivation for participation in clinical trials among patients with cancer. Whilst this has been demonstrated in a study of patients with myeloma, more common among the Black Caribbean community[77], this cannot be assumed across ethnic groups and may be negatively influenced by previous poor health encounters with health services. • Access to study sites is a general issue that may include factors directly or indirectly associated with ethnicity. People from minority ethnic groups are typically more likely to live in urban centres where issues of intersectionality, for example, material deprivation co-reside and social deprivation. Given demonstrable socio-economic disparities between ethnic groups, the underrepresentation of some ethnic groups in studies may result in part from racially determined socio-economic factors that amplify difference and inequity[31 55-57] Financial incentives may be required[78, 79] • The comprehensive collection of ethnicity data used for research purposes remains incomplete across the life course and is present at multiple points associated with end-of-life care from diagnosis[80], referral to services[11 81] and outcomes of care[82]. The European Commission recommends the monitoring of ethnic equality data across all EU member states. However, only three countries (Ireland, Finland, UK) have placed a legal duty of data collection on public bodies[83]. Moreover, unlike the USA[84], there is currently no explicit legal requirement to include ethnically diverse participants in publicly funded research intended to inform clinical decisions. In other countries, the benefits of wider inclusion are beginning to be extolled[85]. Palliative care often makes use of routine data to examine pertinent questions for example cause of death and place of death. However, currently, analysis of UK death registration certificates allows for the description of patterns within a whole population [86, 87] but does not include ethnicity. This is not the case in countries including the USA, Australia and Canada[88]. Instead, UK studies have relied on "country of birth" or "country of origin" as a proxy for

	ethnicity [31] which is open to criticism as it may only represent first-generation migrants. This invisibility – a potential manifestation of implicit racism - became visible during Covid-19 when disproportionate Covid-19 -related deaths were discovered among certain ethnic groups[89]. The UK government is now making the recording of ethnicity mandatory[90]. Another approach to further comprehending health variations across different ethnic groups is the use of hospital episode statistics (HES). However, whilst the completeness of HES has improved in recent years[91] [92], it still does not fully represent all patient episodes. • Explicit and implicit bias and prejudice may deter health care professionals from discussing research with patients from minority ethnic groups[93]. Some health professionals may incorrectly believe they know their patient's preferences[94]. Of concern, in the USA, research has identified that some health professionals possess implicit negative attitudes about African Americans that may lead them to believe they will be poor candidates for clinical trials[95]. For example, one study found that primary care physicians believed treatment compliance would be lower in patients from ethnically diverse communities than in white patients[96]. Consequently, fewer are invited compromising the ethical principle of justice. Yet studies from wider health services research have highlighted that people from minoritised communities are willing to participate in research if the study has direct relevance to them and their community and if they are approached with sensitivity and given clear explanations of what participation involves.[97] • Lack of cultural competency by researchers and referring health professionals has been identified as an important barrier to minority ethnic group participation in studies.[98] • Inadequate representation of researchers from minoritised communities in the development and conduct of palliative care-related studies. Diversity ensures that the research workforce and cultural literacy of a research team reflect changing population mixes and can meet the needs of all stakeholder communities.[15]

THE POTENTIAL TO CAUSE HARM

There are many historical examples of racist research[99-103]. Contemporary research on ethnicity in palliative care is guided by more robust ethical principles that prevent such overtly racist practices. However, we should always be mindful of potential unintended harms.

Victim blaming - There are numerous critics of ethnicity-based research who have concerns that research has the potential to be racist and is associated with victim-blaming. The belief that people from minoritised communities as being inherently unhealthy was once common. The Tuskegee study of untreated syphilis among African American sharecroppers in Macon County, Alabama, when interventions were present[104] and the 'Stop Rickets' health promotion campaign in the UK that incorrectly focused on individual dietary change rather than vitamin D fortification of food at a population level[105] are both cogent examples of this type of research. These explicit examples are worthy of mention for the following reason. First, with hindsight current critical, reflective appraisal of the methods and ethics underpinning research of this type could now be considered to be racist. The lasting messages from this work may perpetuate racial prejudice through the portrayal of people from minoritised ethnic groups as deficient, inferior and less deserving of services[106]. It chants to an assimilationist assumption about research and service provision. Second, we believe few people researching ethnicity and palliative care are deliberately racist and most hold benevolent and honourable views. Many, however, may inadvertently be working toward a racialised research agenda. This situation is uncomfortable to admit but demands our attention. Third, there may be some who would repudiate the value of ethnicity-based research, especially where it has historically been conflated with race due to its association with social Darwinism, European colonisation, slavery, segregation, apartheid in South Africa, the notorious philosophy of racial hygiene in German-occupied countries and more recent examples of genocide in Rwanda, Bosnia and

Herzegovina. This perspective is present in the legislature in Finland, Sweden, France, Austria and Germany[107]. However, this may inadvertently renounce important work that attempts to examine equity-based issues in access to palliative care. Last, whilst researchers cannot be held responsible for media reporting, they must, nevertheless, be cognizant of the potential impact of the way their research is reported by others and wider race relations. Researchers must depart from using phrases that include “ethnic minority”, “hard to reach”, “difficult to engage” and possibly even “marginalised”, associated with de-centering by a dominant, white, middle-class perspective [108]. None are neutral and all have the potential to be construed pejoratively and reinforce racist ideologies.

Comparing - Most research into ethnicity and palliative care that has taken place in the USA, the UK, Australia and New Zealand is based largely on the comparative architecture and present data that invariably use the “white” population, albeit unintentionally, as the standard[31, 32, 53, 82, 109-115]. This racial and ethnic nomenclature has the potential to lead to the phenomena of ethnocentricity or an inherent predisposition to view a single and often the majority culture as the standard against which others are or should be judged[116]. This has consequences for many aspects of palliative care research where ethnicity is a focus. Moreover, it has the potential to influence which research questions are considered important and legitimate, the methods employed to undertake research studies and the presentation and interpretation of findings. “Value-free”, impartial examination of important issues become compromised. This labelling and comparison, although it is changing in certain countries, conceal considerable variation between peoples who could be defined as white, conceals fascinating heterogeneity within cultures and inadvertently fosters the division of society by skin colour. This consequently may reinforce racial and ethnic stereotyping.

In comparative palliative care research, including a group from the majority population, and making use of terms such as ‘reference’, ‘control’, or ‘comparison’ population has distinct advantages compared to ‘white or ‘European’. Bhopal[117] and more recently guidance by Khunti[44] suggest this approach creates fewer expectations and prior assumptions. Nevertheless, all researchers must strive to provide more explicit detail on the populations studied, including their heterogeneity and origins. We acknowledge that this does not resolve all the dilemmas in how individuals perceive themselves in society. Moreover, it does not manage all the controversies regarding classification when collecting statistics. However, it does free researchers involved in palliative care studies from using imprecise and non-meaningful nomenclature.

Indifference to quality of palliative care service provision - The potential implications of comparative research, including the risk of ethnocentrism may lead to the misguided perception that the needs of people living with and dying from advanced diseases from ethnically diverse communities are inherently different from those of the majority population. Consequently, separate strategies may be required (but often do not materialise)[118, 119] or where national strategies are developed they provide only cursory mention of ethnically diverse groups[120]. The continued emphasis on descriptive ethnicity and race-directed palliative care studies has meant a focus on variation in diseases and service utilisation, as opposed to the quality and outcomes of services received. There is a huge hole in the record of research on the quality of care received by patients and their families from ethnically diverse groups[72, 121, 122].

DISCUSSION

Our concern to develop a new agenda for the research that accommodates minoritised communities was driven by a growing body of evidence that identifies that they are more at risk of experiencing poor outcomes at the end of life. How to effect change, however, will continue to be stymied if a radical change to how research takes place and is reported is not considered and does not expose manifestations of racism where they are present. Only with this will a path to patient and family benefit commence.

Recommendation 1 – Focus on equity. Research on ethnicity and health should explicitly be for the well-being of the populations being studied and equity should be the guiding ethical and moral principle. Ethnicity (and associated factors) has had renewed interest following the Covid-19 pandemic and the wish to level up services[57]. Evaluations of end-of-life care interventions rarely consider differential outcomes for groups according to their socio-economic position which may also include ethnicity. Few interventions have been developed to specifically reduce social inequality in care received towards the end of life[56]. However, there are important lessons from interventions outside palliative care, particularly those targeting older people to reduce social inequality[123] that share similar objectives to enhance quality of life. Palliative care researchers and funders of research have a moral imperative to invest in high-quality research that adopts a range of methodologies to identify and redress instances of inequity leading to improved outcomes of care.

Recommendation 2 – Reflect on and justify ethnicity classification. Higher priority should be paid to improving the methods for the classification of ethnicity and difference relevant to palliative care[124]. First, if the concept of ethnicity is used it should be viewed as being different from race and not as a synonym for it[21]. In the current absence of a consensus statement, developed using a Delphi approach, researchers must be explicit in stating their understanding of this concept, describe the characteristics of both the study and comparison populations, and provide and justify the ethnic coding. We argue that like other aspects of palliative care research, investigators should be cognisant to recognise the potential influence of their values, including the potential for ethnocentricity. We all are accompanied by implicit and explicit bias. This can inadvertently result in result in stereotyping or stigmatizing the populations we wish to research. Moreover, this has considerable potential to influence question formulation, study design and interpretation of findings. In addition, ethnicity's complex and dynamic nature should be respected[44]. This has ramifications for how the results of studies are interpreted and generalised; the context of and timing of research should present caution warnings.

Recommendation 3 – Explore and understand intersectionality. Examination of ethnic, Indigenous, First nation and First people inequalities and inequities must pay appropriate regard to the potential ways in which these variables intersect with other forms of social difference[56, 58]. While census categories collected by different countries are often invaluable for revealing disadvantages other complementary metrics are necessary to examine processes through which disadvantage is created, experienced and influences palliative care outcomes. Among others, they include gender, income, education, occupation, private medical insurance status, housing tenure, housing quality and area-based deprivation[56].

Recommendation 4- Optimise data quality. In addition, robust analysis of the intersection between ethnicity (which could include Indigenous, First people and First nation communities) and other socioeconomic variables can only take in the presence of complete data that reflects an individual's ethnicity[124]. Whilst this concern is well known[31, 88] the issue of missing ethnicity data became more evident during Covid-19 when it was realised this variable was not recorded on death certificates. This meant that disproportionate mortality rates among minority ethnic communities were not confirmed for non-hospital deaths. In line with several other countries, the UK is now making the recording of ethnicity on death certificates in England mandatory to mitigate their invisibility [125].

Moreover, data are not neutral entities. Statistics are ‘human artefacts’ and in colonizing nation-states these numbers applied to minoritised, Indigenous, First nation or First people have a ‘raced’ reality. Data are created and patterned by the assumptive determinations of researchers to collect items of information and not others, to interrogate some relationships over others, and to see truths in some and not others. The notion of indigenous data sovereignty is gaining attention and may pave a way for examining the currency of data collected and how it is spent [126]

Recommendation 5 –Decolonising research teams and methods. Patient and public involvement (PPI) in palliative care research are of value to palliative care studies[127, 128 129-131] and systematic reviews[132]. However, representation of individuals from minoritised communities in the PPI process is currently insufficient[133, 134]. This can result in a power imbalance, present in much health services research and may also be evident in palliative care[135 124]. In response, we must develop strategies that creatively reach out to communities we must better serve. Guidance on appropriate and acceptable models for involving members from ethnically diverse, Indigenous, First nation and First people communities across the entire research process [136] are available including those from the UK https://tinyurl.com/3tb8zejy[134], https://tinyurl.com/2p8j53tt[137], from Australia https://tinyurl.com/yuweu47k[138], Canada https://tinyurl.com/2tjkx89c[139] and South Africa https://tinyurl.com/mr2cjp8y[140]. PPI in all its forms should be actively endorsed, supported by palliative care researchers, commissioners of services, policymakers, and scientific journals and adequately resourced by study funders. However, this alone is insufficient if we are to effect change. We must also be open to critically decolonising research agendas, defining research questions, and critically examining what data is being collected, by what instrument and by whom. We must also work in concert with minoritised communities using participatory approaches to devise solutions that must then be evaluated.

Recommendation 6 –Research to reduce inequities. Social inequity present in wider society has been shown to persist in experiences and outcomes of care received by people towards the end of life. This must end. However, we must depart from merely describing the panorama. Instead, analysis and interpretation of ethnicity as an explanatory variable associated with social inequity must use relevant, valid and reliable theoretical models rather than simple descriptions of disparities. Moreover, we must attempt to examine how we can successfully follow through with the findings with the anti-racist actions outlined above and then rigorously evaluate their impact to identify best practices. Analysis of health inequality and inequity relevant to palliative care must consider the social context and processes in which 'differences that make a difference' influence health experiences and outcomes. Rigorously conducted qualitative studies or mixed methods studies, previously used in this area of palliative care inquiry may offer value by elucidating underlying processes[67, 112, 141-144].

Limitations

As this is a critical debate paper we have identified and appraised literature relevant to the aims of the review. However, we did not undertake a comprehensive or systematic evidence review. Therefore, there is a possibility that some publications containing useful information may be absent. Nevertheless, we do draw on previous relevant systematic reviews where available and this manuscript was written in close collaboration with subject experts and expert methodologists to help ensure a suitable balance between evidence review and discussion.

Moreover, while we have attempted to provide global oversight of evidence spanning countries where the issues outlined in the review are currently germane, we accept that much of the evidence presented is from English-speaking countries. This may compromise the inferences that we drew from the evidence that influence the recommendations we suggest. Despite these limitations, we adhere closely to the quality checklist for maximising rigour in narrative review articles [19].

We acknowledge that recommendations to improve methods in palliative care research can be derived using a Delphi approach following well-established guidance [145]. We believe this should occur. However, in the process of appraising evidence, we have contrived primary recommendations to commence a new dialogue that redefines the architecture of palliative care research. Continued investment beyond this paper is vital.

CONCLUSION

The first step in addressing a problem is recognising there is one. For many from minoritised communities, the experience of abandonment at the end of life is an immutable truth. Scrutiny of evidence arrives at a verdict that racism is evident in palliative care research that has inadvertently been guided by in inherent, structural and systemic superiority of the majority. This has become normalised and obscured from our line of sight. To ignore commencing with this agenda of change perpetuates the whitewashing of this pervading issue. We are not naïve to believe the recommendations we propose are not associated with risk or that a paradigm shift is required to realise them. Equity checklists have been proposed for the submission of publications which we applaud[16]. However, without a root and branch solution, deeper within the research process, the consequences for the lived experiences and outcomes of care for patients and their families from minoritised communities are destined to remain in a state of paralysis[14]. We need to face our research shadow and this will require courage. We highlight how we can commence this journey many have the intention to make - to mitigate the effects of racial, social and intersectional injustice. Researchers may be required to engage in creative training solutions that demystify difference, safely build confidence in the retrenchment of anxieties when conducting research and foster previously untested collaborations and community links that build trust and empathy[14]. This will not be resource neutral. It may also disrupt existing power balances. Moreover, it requires leadership of academics from racial, ethnic and/or culturally dominant groups and organisations, including the European Association for Palliative Care (EAPC) and International Association for Hospice and Palliative Care (IAHPC) to effect changes from the front, allied to the lives of those we must change.

AUTHORSHIP

JK conceived the idea for this manuscript with important contributions from JMD, SB and JAH. JK drafted the manuscript article. All authors provided critical revisions of the manuscript for important intellectual content. All authors approved the version to be published. JK is the guarantor.

DECLARATION OF CONFLICTING INTERESTS

The author(s) declared no potential conflicts of interest concerning the research, authorship, and/or publication of this article.

ORCID ID

Jonathan Koffman	https://orcid.org/0000-0001-8513-5681
Sabrina Bajwah	https://orcid.org/0000-0001-5338-8107
Joanna M Davies	https://orcid.org/0000-0002-6375-0023
Jamilla Akhter Hussain	https://orcid.org/0000-0002-3644-6480

1. Pivodic L, Jennings N and Matthys M. The problems of using migration background as a conceptual framework in palliative care research. *Palliative Medicine* 2021; 35: 2028-2029. DOI: 10.1177/02692163211042766.
2. Department of Economic and Social Affairs Population Division. *World Population Prospects 2019 Highlights* New York: United Nations.
3. Shahid S, Taylor EV, Cheetham S, et al. Key features of palliative care service delivery to Indigenous peoples in Australia, New Zealand, Canada and the United States: a comprehensive review. *BMC Palliative Care* 2018; 17: 72. DOI: 10.1186/s12904-018-0325-1.
4. Sallnow L, Smith R, Ahmedzai SH, et al. Report of the Lancet Commission on the Value of Death: Bringing Death Back into Life. *The Lancet* 2022; 399: 837-884. DOI: 10.1016/S0140-6736(21)02314-X.
5. Horton R. Offline: A Caribbean consciousness. *The Lancet* 2018; 391: 1757. DOI: 10.1016/S0140-6736(18)31030-4.
6. Barber S. Death by racism. *The Lancet Infectious Diseases* 2020; 20: 903. DOI: 10.1016/S1473-3099(20)30567-3.
7. Yancy CW. Academic Medicine and Black Lives Matter: Time for Deep Listening. *Jama* 2020; 324: 435-436. 2020/08/05. DOI: 10.1001/jama.2020.12532.
8. Khunti K, Singh AK, Pareek M, et al. Is ethnicity linked to incidence or outcomes of covid-19? *BMJ* 2020; 369: m1548. DOI: 10.1136/bmj.m1548.
9. The Lancet. Medicine and medical science: Black lives must matter more. *The Lancet* 2020; 395: 1813. DOI: 10.1016/S0140-6736(20)31353-2.
10. Office of National Statistics. *Coronavirus (COVID-19) related deaths by ethnic group, England and Wales: 2 March 2020 to 15 May 2020.* 2020. London: Office of National Statistics.
11. Chidiac C, Feuer D, Flatley M, et al. The need for early referral to palliative care especially for Black, Asian and minority ethnic groups in a COVID-19 pandemic: Findings from a service evaluation. *Palliative Medicine* 2020; 34: 1241-1248.
12. Bajwah S, Koffman J, Hussain J, et al. Specialist palliative care services response to ethnic minority groups with COVID-19: equal but inequitable—an observational study. *BMJ Supportive &amp; Palliative Care* 2021: bmjspcare-2021-003083. DOI: 10.1136/bmjspcare-2021-003083.
13. Hospice UK. *Equality in hospice and end of life care: challenges and change.* 2021. London: Hospice UK.
14. Hussain JA, Koffman J and Bajwah S. Invited Editorial: Racism and palliative care. *Palliative Medicine* 2021; 35: 810-813. DOI: 10.1177/02692163211012887.

15. Powell RA, Njoku C, Elangovan R, et al. Tackling racism in UK health research. *BMJ* 2022; 376: e065574. DOI: 10.1136/bmj-2021-065574.
16. Sanders JJ, Gray TF, Sihlongonyane B, et al. A Framework for Anti-Racist Publication in Palliative Care: Structures, Processes, and Outcomes. *Journal of Pain and Symptom Management* 2022; 63: e337-e343. DOI: https://doi.org/10.1016/j.jpainsymman.2021.10.001.
17. Rowley J, Richards N, Carduff E, et al. The impact of poverty and deprivation at the end of life: a critical review. *Palliative Care and Social Practice* 2021; 15: 26323524211033873. DOI: 10.1177/26323524211033873.
18. Coughlan M and Cronin P. *Doing a Literature Review in Nursing, Health and Social Care*. Second ed. London: Sage Publishing, 2017, p.8.
19. Baethge C, Goldbeck-Wood S and Mertens S. SANRA—a scale for the quality assessment of narrative review articles. *Research Integrity and Peer Review* 2019; 4: 5. DOI: 10.1186/s41073-019-0064-8.
20. Koffman J. The language of diversity: controversies relevant to palliative care research. *European Journal of Palliative Care* 2006; 11: 18-121.
21. Clarke D, Gombert-Waldron K, Honey S, et al. Co-designing organisational improvements and interventions to increase inpatient activity in four stroke units in England: a mixed-methods process evaluation using normalisation process theory. *BMJ Open* 2021; 11: e042723. DOI: 10.1136/bmjopen-2020-042723.
22. Lee C. “Race” and “ethnicity” in biomedical research: How do scientists construct and explain differences in health? *Social Science & Medicine* 2009; 68: 1183-1190. DOI: https://doi.org/10.1016/j.socscimed.2008.12.036.
23. Spiers GF, Liddle JE, Stow D, et al. Measuring older people’s socioeconomic position: a scoping review of studies of self-rated health, health service and social care use. *Journal of Epidemiology and Community Health* 2022: jech-2021-218265. DOI: 10.1136/jech-2021-218265.
24. Crawley L. Racial, cultural, and ethnic factors influencing end-of-life care. *Jounal of Palliative Medicine* 2005; 8: S58-S69.
25. Markus HR. Pride, prejudice, and ambivalence: toward a unified theory of race and ethnicity. *American Psychologist* 2008; 63: 651.
26. Ford CL and Harawa NT. A new conceptualization of ethnicity for social epidemiologic and health equity research. *Soc Sci Med* 2010; 71: 251-258. 2010/05/22. DOI: 10.1016/j.socscimed.2010.04.008.
27. Johnson AG. *The Blackwell Dictionary of Sociology: A User's Guide to Sociological Language*. Malden, MA: Blackwell Publishers, 2000.
28. Pirl WF, Saez-Flores E, Schlumbrecht M, et al. Race and Ethnicity in the Evidence for Integrating Palliative Care Into Oncology. *Journal of Oncology Practice* 2018; 14: e346-e356. DOI: 10.1200/JOP.17.00016.
29. Orlovic M, Smith K and Mossialos E. Racial and ethnic differences in end-of-life care in the United States: Evidence from the Health and Retirement Study (HRS). *SSM Popul Health* 2018; 7: 100331-100331. DOI: 10.1016/j.ssmph.2018.100331.
30. Estrada LV, Harrison JM, Dick AW, et al. Examining Regional Differences in Nursing Home Palliative Care for Black and Hispanic Residents. *Journal of Palliative Medicine* 2022. DOI: 10.1089/jpm.2021.0416.
31. Koffman J, Ho YK, Davies J, et al. Does Ethnicity Affect Where People with Cancer Die? A Population-Based 10 Year Study. *PLOS ONE* 2014; 9: e95052. DOI: 10.1371/journal.pone.0095052.
32. Koffman J, Burke G, Dias A, et al. Demographic factors and awareness of palliative care and related services. *Palliative Medicine* 2007; 21: 145-153.

33. Davison SN, Jhangri GS and Koffman J. Knowledge of and attitudes towards palliative care and hospice services among patients with advanced chronic kidney disease. *BMJ Supportive &amp; Palliative Care* 2016; 6: 66. DOI: 10.1136/bmjspcare-2013-000610.

34. Wen Y, Jiang C, Koncicki HM, et al. Trends and Racial Disparities of Palliative Care Use among Hospitalized Patients with ESKD on Dialysis. *Journal of the American Society of Nephrology* 2019; 30: 1687. DOI: 10.1681/ASN.2018121256.

35. Taber JM, Ellis EM, Reblin M, et al. Knowledge of and beliefs about palliative care in a nationally-representative U.S. sample. *PLOS ONE* 2019; 14: e0219074. DOI: 10.1371/journal.pone.0219074.

36. Gazaway S, Stewart M and Schumacher A. Integrating Palliative Care into the Chronic Illness Continuum: a Conceptual Model for Minority Populations. *Journal of Racial and Ethnic Health Disparities* 2019; 6: 1078-1086. DOI: 10.1007/s40615-019-00610-y.

37. Ingersoll LT, Alexander SC, Priest J, et al. Racial/ethnic differences in prognosis communication during initial inpatient palliative care consultations among people with advanced cancer. *Patient Education and Counseling* 2019; 102: 1098-1103. DOI: https://doi.org/10.1016/j.pec.2019.01.002.

38. Trivedi N, Peterson EB, Ellis EM, et al. Awareness of Palliative Care among a Nationally Representative Sample of U.S. Adults. *Journal of Palliative Medicine* 2019; 22: 1578-1582. DOI: 10.1089/jpm.2018.0656.

39. United States Census Bureau. Research to Improve Data on Race and Ethnicity, https://www.census.gov/about/our-research/race-ethnicity.html (2022, accessed 22.03.2022).

40. Coupland VH, Madden P, Jack RH, et al. Does place of death from cancer vary between ethnic groups in South East England? *Palliative Medicine* 2011; 25: 314-322.

41. Kirtane K, Downey L, Lee SJ, et al. Intensity of End-of-Life Care for Patients with Hematologic Malignancies and the Role of Race/Ethnicity. *Journal of Palliative Medicine* 2018; 21: 1466-1471. DOI: 10.1089/jpm.2018.0152.

42. Johnson T, Walton S, Levine S, et al. Racial and ethnic disparity in palliative care and hospice use. *Am J Manag Care* 2020; 26: e36-e40.

43. Cole AP, Nguyen D-D, Meirkhanov A, et al. Association of Care at Minority-Serving vs Non–Minority-Serving Hospitals With Use of Palliative Care Among Racial/Ethnic Minorities With Metastatic Cancer in the United States. *JAMA Network Open* 2019; 2: e187633-e187633. DOI: 10.1001/jamanetworkopen.2018.7633.

44. Khunti K. Editorials - The language of ethnicity. *British Medical Journal* 2020; 371. DOI: doi: https://doi.org/10.1136/bmj.m4493

45. United Nations. *United Nations Permanent Forum on Indigenous Peoples, Factsheet. Who are indigenous peoples?* 2007. United Nations.

46. United Nations. State of the World's Indigenous Peoples. New York: United Nations, 2010.

47. United Nations. The Concept of Indigenous Peoples. New York 2004, p. 4.

48. Flanagin A, Frey T, Christiansen SL, et al. The Reporting of Race and Ethnicity in Medical and Science Journals: Comments Invited. *JAMA* 2021; 325: 1049-1052. DOI: 10.1001/jama.2021.2104.

49. Ioannidis JPA, Powe NR and Yancy C. Recalibrating the Use of Race in Medical Research. *JAMA* 2021; 325: 623-624. DOI: 10.1001/jama.2021.0003.

50. Iverson C, Chritiansen S, Flanagin A, et al. *Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals*. December 2021 2021. International Committee of Medical Journal Editors.

51. Bhopal R. Is research into ethnicity and health racist, unsound, or important science? *British Medical Journal* 1997; 314: 1751-1756.

52. Skrabanek P. The emptiness of the black box. *Epidemiology* 1994; 5: 553-555. 1994/09/01.
53. Koffman J, Donaldson N, Hotopf M, et al. Does ethnicity matter? Bereavement outcomes in two ethnic groups living in the United Kingdom. *Palliat Support Care* 2005; 3: 183-190. 2006/04/06. DOI: 10.1017/s1478951505050303.
54. Rivara F and Finberg L. Use of the terms race and ethnicity. *Arch Pediatr Adolesc Med* 2001; 155: 119. 2001/02/15. DOI: 10.1001/archpedi.155.2.119.
55. Davies JM, Gao W, Sleeman KE, et al. Using routine data to improve palliative and end of life care. *BMJ Supportive & Palliative Care* 2016; 6: 257. DOI: 10.1136/bmjspcare-2015-000994.
56. Davies JM, Sleeman KE, Leniz J, et al. Socioeconomic position and use of healthcare in the last year of life: A systematic review and meta-analysis. *PLOS Medicine* 2019; 16: e1002782. DOI: 10.1371/journal.pmed.1002782.
57. Marmot M, Allen J, Boyce T, et al. *Health Equity in England: The Mramot Review 10 Years On*. 2020. London: Institute of Health Equity.
58. Marmot M, Allen J, Goldblatt P, et al. *Build Back Fairer: The COVID-19 Marmot Review. The Pandemic, Socioeconomic and Health Inequalities in England*. 2020. London: Institute of Health Equity.
59. Tobin RS, Samsky MD, Kuchibhatla M, et al. Race Differences in Quality of Life following a Palliative Care Intervention in Patients with Advanced Heart Failure: Insights from the Palliative Care in Heart Failure Trial. *Journal of Palliative Medicine* 2021; 25: 296-300. DOI: 10.1089/jpm.2021.0220.
60. Davies JM, Maddocks M, Chua K-C, et al. Socioeconomic position and use of hospital-based care towards the end of life: a mediation analysis using the English Longitudinal Study of Ageing. *The Lancet Public Health* 2021; 6: e155-e163. DOI: 10.1016/S2468-2667(20)30292-9.
61. Legislation.gov.uk. Equality Act, https://www.legislation.gov.uk/ukpga/2010/15/contents (2010).
62. Loree JM, Anand S, Dasari A, et al. Disparity of Race Reporting and Representation in Clinical Trials Leading to Cancer Drug Approvals From 2008 to 2018. *JAMA Oncol* 2019; 5: e191870. 2019/08/16. DOI: 10.1001/jamaoncol.2019.1870.
63. Torensma M, Onwuteaka-Philipsen BD, Strackee KL, et al. How to help researchers in palliative care improve responsiveness to migrants and other underrepresented populations: developing and testing a self-assessment instrument. *BMC Palliative Care* 2019; 18: 83. DOI: 10.1186/s12904-019-0470-1.
64. Pareek M, Bangash MN, Pareek N, et al. Ethnicity and COVID-19: an urgent public health research priority. *Lancet (London, England)* 2020; 395: 1421-1422. 2020/04/21. DOI: 10.1016/S0140-6736(20)30922-3.
65. Etti M, Fofie H, Razai M, et al. Ethnic minority and migrant underrepresentation in Covid-19 research: Causes and solutions. *eClinicalMedicine* 2021; 36. DOI: 10.1016/j.eclinm.2021.100903.
66. Sethi S, Kumar A, Mandal A, et al. The UPTAKE study: implications for the future of COVID-19 vaccination trial recruitment in UK and beyond. *Trials* 2021; 22: 296. DOI: 10.1186/s13063-021-05250-4.
67. Koffman J, Morgan M, Edmonds P, et al. “I know he controls cancer”: The meanings of religion among Black Caribbean and White British patients with advanced cancer. *Social Science & Medicine* 2008; 67: 780-789. DOI: https://doi.org/10.1016/j.socscimed.2008.05.004.
68. Koffman J, Goddard C, Gao W, et al. Exploring meanings of illness causation among those severely affected by multiple sclerosis: a comparative qualitative study of Black

Caribbean and White British people. *BMC Palliative Care* 2015; 14: 13. DOI: 10.1186/s12904-015-0017-z.

69. Zeiger R and Frydman G. Chapter 17 - Patient-Centered Approaches to Improving Clinical Trials for Cancer. In: Hesse BW, Ahern DK and Beckjord E (eds) *Oncology Informatics*. Boston: Academic Press, 2016, pp.331-341.

70. Dunnigan MG, Glekin BM, Henderson JB, et al. Prevention of rickets in Asian children: assessment of the Glasgow campaign. *British Medical Journal (Clinical research ed)* 1985; 291: 239. DOI: 10.1136/bmj.291.6490.239.

71. Katz RV, Kegeles SS, Kressin NR, et al. The Tuskegee Legacy Project: willingness of minorities to participate in biomedical research. *J Health Care Poor Underserved* 2006; 17: 698-715. DOI: 10.1353/hpu.2006.0126.

72. Koffman J and Higginson IJ. Accounts of carers' satisfaction with health care at the end of life: a comparison of first generation black Caribbeans and white patients with advanced disease. *Palliative Medicine* 2001; 15: 337-345.

73. Hussain-Gambles M, Atkin K and Leese B. Why ethnic minority groups are under-represented in clinical trials: a review of the literature. *Health Soc Care Community* 2004; 12: 382-388. 2004/09/18. DOI: 10.1111/j.1365-2524.2004.00507.x.

74. Duncan M, Korszun A, White P, et al. Qualitative analysis of feasibility of recruitment and retention in a planned randomised controlled trial of a psychosocial cancer intervention within the NHS. *Trials* 2018; 19: 327. DOI: 10.1186/s13063-018-2728-y.

75. Gysels M, Evans CJ, Lewis P, et al. MORECare research methods guidance development: Recommendations for ethical issues in palliative and end-of-life care research. *Palliative Medicine* 2013; 27: 908-917. DOI: 10.1177/0269216313488018.

76. Gysels M, Shipman C and Higginson IJ. Is the qualitative research interview an acceptable medium for research with palliative care patients and carers? *BMC Medical Ethics* 2008; 9: 7. DOI: 10.1186/1472-6939-9-7.

77. Skyers S, Kerr C and Johnson P. *Count Me In! Informing the future of personalised medicine from bench to bedside*. 2017.

78. Bamidele OO, E. McGarvey H, Lagan BM, et al. “Hard to reach, but not out of reach”: Barriers and facilitators to recruiting Black African and Black Caribbean men with prostate cancer and their partners into qualitative research. *European Journal of Cancer Care* 2019; 28: e12977. https://doi.org/10.1111/ecc.12977. DOI: https://doi.org/10.1111/ecc.12977.

79. Manríquez Roa T and Biller-Andorno N. Financial incentives for participants in health research: when are they ethical? *Swiss Med Wkly* 2022; 152: w30166. 2022/03/23. DOI: 10.4414/smw.2022.w30166.

80. Johnson KS. Racial and ethnic disparities in palliative care. *J Palliat Med* 2013; 16: 1329-1334. 2013/10/01. DOI: 10.1089/jpm.2013.9468.

81. Isenberg SR, Bonares M, Kurahashi AM, et al. Race and birth country are associated with discharge location from hospital: A retrospective cohort study of demographic differences for patients receiving inpatient palliative care. *eClinicalMedicine* 2022; 45. DOI: 10.1016/j.eclinm.2022.101303.

82. Sharma RK, Freedman VA, Mor V, et al. Association of Racial Differences With End-of-Life Care Quality in the United States. *JAMA Internal Medicine* 2017; 177: 1858-1860. DOI: 10.1001/jamainternmed.2017.4793.

83. European C, Directorate-General for J, Consumers, et al. *Analysis and comparative review of equality data collection practices in the European Union : data collection in the field of ethnicity*. Publications Office, 2020.

84. National Institute for Health. *NIH Policy and Guidelines on The Inclusion of Women and Minorities as Subjects in Clinical Research*. 2001.

85. Redwood S and Gill PS. Under-representation of minority ethnic groups in research--call for action. *Br J Gen Pract* 2013; 63: 342-343. 2013/07/10. DOI: 10.3399/bjgp13X668456.
86. Sleeman K, Ho Y, Verne J, et al. Place of death, and its relation with underlying cause of death, in Parkinson's disease, motor neurone disease, and multiple sclerosis in England 1993-2010 : A population-based study. *Palliative Medicine* 2013; 27: 840-846. DOI: 10.1177/0269216313490436.
87. Wei G, Ho YK, Verne J, et al. Changing patterns in place of cancer death in England: a population-based study. *PLOS MEDICINE* 2013; 10.
88. Aspinall PJ, Jacobsen B and Polato GM. *Missing record: The case for recording ethnicity at birth and death registration*. 2003. London: London Health Observatory.
89. Murugesu J. Our death certificates don’t record ethnicity. During Covid, this gap became deadly. *Prospect*. 2020.
90. Race Disparity Unit. *Quarterly report on progress to address COVID-19 health inequalities*. 2020. London: Cabinet Office, Gov.UK.
91. Mathur R, Bhaskaran K, Chaturvedi N, et al. Completeness and usability of ethnicity data in UK-based primary care and hospital databases. *Journal of Public Health* 2014; 36: 684-692. DOI: 10.1093/pubmed/fdt116.
92. Jain A, van Hoek AJ, Walker JL, et al. Identifying social factors amongst older individuals in linked electronic health records: An assessment in a population based study. *PloS one* 2017; 12: e0189038-e0189038. DOI: 10.1371/journal.pone.0189038.
93. Hamel LM, Penner LA, Albrecht TL, et al. Barriers to Clinical Trial Enrollment in Racial and Ethnic Minority Patients With Cancer. *Cancer Control* 2016; 23: 327-337. DOI: 10.1177/107327481602300404.
94. Wendler D, Kington R, Madans J, et al. Are Racial and Ethnic Minorities Less Willing to Participate in Health Research? *PLOS Medicine* 2005; 3: e19. DOI: 10.1371/journal.pmed.0030019.
95. Moskowitz GB, Stone J and Childs A. Implicit stereotyping and medical decisions: unconscious stereotype activation in practitioners' thoughts about African Americans. *Am J Public Health* 2012; 102: 996-1001. 2012/03/17. DOI: 10.2105/ajph.2011.300591.
96. Sabin JA, Rivara FP and Greenwald AG. Physician implicit attitudes and stereotypes about race and quality of medical care. *Med Care* 2008; 46: 678-685. 2008/06/27. DOI: 10.1097/MLR.0b013e3181653d58.
97. Scarinci IC, Hansen B, Green BL, et al. Willingness to participate in various nontherapeutic cancer research activities among urban and rural African American and Latinx healthy volunteers. *Cancer Causes & Control* 2022. DOI: 10.1007/s10552-022-01576-9.
98. Clark LT, Watkins L, Piña IL, et al. Increasing Diversity in Clinical Trials: Overcoming Critical Barriers. *Current Problems in Cardiology* 2019; 44: 148-172. DOI: https://doi.org/10.1016/j.cpcardiol.2018.11.002.
99. Gould SJ. *The Mismeasure of Man*. New York: W. W. Norton & Company, 1996.
100. Graves JL. *The Emperor's New Clothes*. New Jersey, USA: Rutgers University Press, 2001.
101. Shamoo AE and Tauer CA. Ethically Questionable Research with Children: The Fenfluramine Study. *Accountability in Research* 2002; 9: 143-166. DOI: 10.1080/08989620214685.
102. Gilpin NW and Taffe MA. Toward an Anti-Racist Approach to Biomedical and Neuroscience Research. *The Journal of Neuroscience* 2021; 41: 8669. DOI: 10.1523/JNEUROSCI.1319-21.2021.

103. Warner J. Psychiatry Confronts Its Racist Past, and Tries to Make Amends. *The New York Times*, 30.04.2021 2021, p.6.
104. Crawley LM. African-American participation in clinical trials: situating trust and trustworthiness. *Journal of the National Medical Association* 2001; 93: 14S-17S.
105. Bivins R. Ideology and disease identity: the politics of rickets, 1929–1982. *Medical Humanities* 2014; 40: 3. DOI: 10.1136/medhum-2013-010400.
106. Adams S. Ethnic minorities now make up a higher proportion of Covid deaths than ever before, as experts warn jab hesitancy is starting to have a tragic impact. *Daily Mail*, 8 August 2021 2021.
107. Lappin R. Should CERED repudiate the notion of race? *Journal of Social Justice* 2017; 2 8 3 9 3 – 3 9 8. DOI: DOI: 10.1080/10402659.2016.1237077.
108. Selvarajah S, Deivanayagam TA, Lasco G, et al. Categorisation and Minoritisation. *BMJ Glob Health* 2020; 5 2021/01/01. DOI: 10.1136/bmjgh-2020-004508.
109. Perry LM, Walsh LE, Horswell R, et al. Racial Disparities in End-of-Life Care Between Black and White Adults With Metastatic Cancer. *Journal of Pain and Symptom Management* 2021; 61: 342-349.e341. DOI: https://doi.org/10.1016/j.jpainsymman.2020.09.017.
110. Loggers ET, Maciejewski PK, Paulk E, et al. Racial differences in predictors of intensive end-of-life care in patients with advanced cancer. *J Clin Oncol* 2009; 27: 5559-5564. 2009/10/05. DOI: 10.1200/JCO.2009.22.4733.
111. Ornstein KA, Roth DL, Huang J, et al. Evaluation of Racial Disparities in Hospice Use and End-of-Life Treatment Intensity in the REGARDS Cohort. *JAMA Network Open* 2020; 3: e2014639-e2014639. DOI: 10.1001/jamanetworkopen.2020.14639.
112. Koffman J, Gao W, Goddard C, et al. Progression, Symptoms and Psychosocial Concerns among Those Severely Affected by Multiple Sclerosis: A Mixed-Methods Cross-Sectional Study of Black Caribbean and White British People. *PLOS ONE* 2013; 8: e75431. DOI: 10.1371/journal.pone.0075431.
113. Bazargan M, Cobb S and Assari S. Completion of advance directives among African Americans and Whites adults. *Patient Education and Counseling* 2021; 104: 2763-2771. DOI: https://doi.org/10.1016/j.pec.2021.03.031.
114. Burgio KL, Williams BR, Dionne-Odom JN, et al. Racial Differences in Processes of Care at End of Life in VA Medical Centers: Planned Secondary Analysis of Data from the BEACON Trial. *Journal of Palliative Medicine* 2016; 19: 157-163. DOI: 10.1089/jpm.2015.0311.
115. Gurney JK, Stanley J, Koea J, et al. Where Are We Dying? Ethnic Differences in Place of Death Among New Zealanders Dying of Cancer. *JCO Global Oncology* 2022: e2200024. DOI: 10.1200/GO.22.00024.
116. Quest TE, Periyakoil VS, Quill TE, et al. Racial Equity in Palliative Care. *Journal of Pain and Symptom Management* 2021; 61: 435-437. DOI: 10.1016/j.jpainsymman.2020.12.005.
117. Bhopal R and Donaldson L. White, European, Western, Caucasian, or what? Inappropriate labeling in research on race, ethnicity, and health. *Am J Public Health* 1998; 88: 1303-1307. DOI: 10.2105/ajph.88.9.1303.
118. Calanzani N, Koffman J and Higginson I, J. . *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*. 2013. London: Marie Curie Cancer Care.
119. Care Quality Commission. *People from Black and minority ethnic communities: a different ending - addressing inequalities in end of life care*. May 2016 2016. Newcastle upon Tyne: Care Quality Commission

120. National Palliative and End of Life Care Partnership. *Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026*. May 2021 2021.
121. Boateng A and Aslakson RA. Navigating the Complex Ecosystem of Race, Ethnicity, Structural Racism, Socioeconomic Factors, Medical Care Delivery, and End-of-Life Care—Casting Away the Compass to Make a Map. *JAMA Network Open* 2021; 4: e2126348-e2126348. DOI: 10.1001/jamanetworkopen.2021.26348.
122. Algu K. Denied the right to comfort: Racial inequities in palliative care provision. *eClinicalMedicine* 2021; 34. DOI: 10.1016/j.eclinm.2021.100833.
123. Bambra C, Gibson M, Sowden A, et al. Tackling the wider social determinants of health and health inequalities: evidence from systematic reviews. *J Epidemiol Community Health* 2010; 64: 284-291. 2009/08/21. DOI: 10.1136/jech.2008.082743.
124. Clarke G, Hussain JA, Allsop MJ, et al. Ethnicity and palliative care: we need better data – five key considerations. *BMJ Supportive &amp; Palliative Care* 2022: bmjspcare-2022-003565. DOI: 10.1136/bmjspcare-2022-003565.
125. House of Commons Women and Equalities Committee. *Unequal impact? Coronavirus and BAME people*. 2020. London: House of Commons.
126. Walter M and Russo Carroll S. Indigenous data sovereignty, governance and the link to Indigenous policy. In: Walter M, Kukutai T, Russo Carroll S, et al. (eds) *Indigenous Data Sovereignty and Policy*. London: Routledge, 2020, pp.244.
127. Daveson BA, de Wolf-Linder S, Witt J, et al. Results of a transparent expert consultation on patient and public involvement in palliative care research. *Palliative Medicine* 2015; 29: 939-949. DOI: 10.1177/0269216315584875.
128. Brighton LJ, Pask S, Benalia H, et al. Taking patient and public involvement online: qualitative evaluation of an online forum for palliative care and rehabilitation research. *Res Involv Engagem* 2018; 4: 14. 2018/05/11. DOI: 10.1186/s40900-018-0097-z.
129. Johnson H, Davies JM, Leniz J, et al. Opportunities for public involvement in big data research in palliative and end-of-life care. *Palliative Medicine* 2021; 35: 1724-1726. DOI: 10.1177/02692163211002101.
130. Johnson H, Ogden M, Brighton LJ, et al. Patient and public involvement in palliative care research: What works, and why? A qualitative evaluation. *Palliat Med* 2021; 35: 151-160. 2020/09/12. DOI: 10.1177/0269216320956819.
131. Chambers E, Gardiner C, Thompson J, et al. Patient and carer involvement in palliative care research: An integrative qualitative evidence synthesis review. *Palliative Medicine* 2019; 33: 969-984. DOI: 10.1177/0269216319858247.
132. Clarke G, Chapman E, Crooks J, et al. Does ethnicity affect pain management for people with advanced disease? A mixed methods cross-national systematic review of 'very high' Human Development Index English-speaking countries. *BMC Palliative Care* 2022; 21: 46. DOI: 10.1186/s12904-022-00923-6.
133. Dawson S, Campbell SM, Giles SJ, et al. Black and minority ethnic group involvement in health and social care research: A systematic review. *Health Expectations* 2018; 21: 3-22. https://doi.org/10.1111/hex.12597. DOI: https://doi.org/10.1111/hex.12597.
134. Ekezie W, Routen A, Denegri S, et al. Patient and public involvement for ethnic minority research: an urgent need for improvement. *Journal of the Royal Society of Medicine* 2021; 114: 347-350. DOI: 10.1177/0141076821994274.
135. Gunaratnam Y. *Researching 'Race' and Ethnicity Methods, Knowledge and Power*. Sage Publications Ltd 2003.
136. Keane M, Khupe C and Seehawer M. Decolonising methodology: who benefits from indigenous knowledge research? *Educational Research for Social Change* 2017; 6: 12-24.

137. Farooqi A, Raghavan R, Wilson A, et al. *Increasing participation of Black Asian and Minority Ethnic (BAME) groups in health and social care research*. 2018. Leicester: Applied Research Collaboration East Midlands.

138. Harrison R, Walton M, Manias E, et al. Codesigning consumer engagement strategies with ethnic minority consumers in Australian cancer services: the CanEngage Project protocol. *BMJ Open* 2021; 11: e048389. 2021/08/04. DOI: 10.1136/bmjopen-2020-048389.

139. Kelley ML, Prince H, Nadin S, et al. Developing palliative care programs in Indigenous communities using participatory action research: a Canadian application of the public health approach to palliative care. *Annals of palliative medicine* 2018; 7: S52-S72. DOI: 10.21037/apm.2018.03.06.

140. Keikelame MJ and Swartz L. Decolonising research methodologies: lessons from a qualitative research project, Cape Town, South Africa. *Glob Health Action* 2019; 12: 1561175. 2019/01/22. DOI: 10.1080/16549716.2018.1561175.

141. Green A, Jerzmanowska N, Green M, et al. 'Death is difficult in any language': A qualitative study of palliative care professionals' experiences when providing end-of-life care to patients from culturally and linguistically diverse backgrounds. *Palliative Medicine* 2018; 32: 1419-1427. DOI: 10.1177/0269216318776850.

142. Islam Z, Taylor L and Faull C. Thinking ahead in advanced illness: Exploring clinicians' perspectives on discussing resuscitation with patients and families from ethnic minority communities. *Future Healthc J* 2021; 8: e619-e624. DOI: 10.7861/fhj.2021-0012.

143. Chen AT, Tsui S and Sharma RK. Characterizing uncertainty in goals-of-care discussions among black and white patients: a qualitative study. *BMC Palliative Care* 2022; 21: 24. DOI: 10.1186/s12904-022-00912-9.

144. Hughes MC, Vernon E, Kowalczyk M, et al. US hospices' approach to racial/ethnic minority inclusion: a qualitative study. *BMJ Supportive &amp; Palliative Care* 2021: bmjspcare-2020-002680. DOI: 10.1136/bmjspcare-2020-002680.

145. Jünger S, Payne SA, Brine J, et al. Guidance on Conducting and REporting DElphi Studies (CREDES) in palliative care: Recommendations based on a methodological systematic review. *Palliat Med* 2017; 31: 684-706. 2017/02/14. DOI: 10.1177/0269216317690685.