The Terminally Ill Adults (End of Life) Bill 2024-2025

Written Evidence Submitted by The Association for Palliative Medicine's Race Equity Committee on 10.02.25

Introduction

The Association for Palliative Medicine's (APM) Race Equity Committee aims to help the APM and its members better understand how to enable greater equity for racially minoritised patients, carers, families and staff. This includes challenging racial prejudice and discrimination and supporting an inclusive and equitable environment for people and families facing death, dying and grief, professionals and stakeholders. The committee originally formed following the global COVID-19 pandemic and the events relating to George Floyd's murder, which starkly illuminated the far-reaching issues of structural discrimination and racial inequity within healthcare and wider society.

The committee comprises of:

- Chair Professor Qamar Abbas (Medical Director & Consultant in Palliative Medicine)
- Vice Chair Dr Bhajneek Grewal (Consultant in Palliative Medicine)
- Dr Jamilla Hussain (Consultant & Clinical Academic in Palliative Medicine)
- Dr Jasmine Lee (Consultant in Palliative Medicine)
- Dr Sunitha Daniel (Consultant in Palliative Medicine)
- Dr Karon Ornadel (Specialty Doctor in Palliative Medicine)
- Dr Amaal Weli (Resident Doctor)

This submission aims to provide insight into the racial disparities within the field of palliative care and the anticipated impact of these disparities on racially minoritised staff, patients, carers and families in relation to the proposed Terminally Ill Adults (End of Life) Bill. The evidence contained herein draws upon existing and collected data, including reflections and experiences of racialised staff working within palliative care.

A. Ethnicity in the Palliative Care medical workforce

A1. The Institute of Fiscal Studies produced a report in 2024 which looked at the ethnic makeup of consultants and other senior doctors across the NHS. 55.5% of consultants and other senior doctors were White. 30.1% of doctors were Asian/Asian British. 2.9% of doctors were Black/Black British. 2.5% were Mixed. 3.6% of doctors were from other ethnic groups. Data was unknown for 5.5%.

A2. In January 2025 the APM Race Equity Committee submitted a Freedom of Information request to the General Medical Council asking for available data on the ethnicity of doctors registered as working within Palliative Medicine. In 2024, 84.1% were White. 8.7% were Asian/Asian British, 2.8% were Mixed, 0.5% were Black/Black British and 0.5% were from other minoritised groups. Data was unknown for 3.3%. Palliative Medicine therefore has a much lower proportion of doctors from ethnic minority backgrounds, compared with the general medical workforce. Minoritised doctors are under-represented in the palliative care workforce.

B. Racial Inequity within Palliative Care

B1. In 2021 the British Medical Association undertook a survey on Racism in Medicine, in which 76% of responding doctors and medical students stated they had experienced racism in their workplace on at least one occasion in the past two years.

B2. Following on from this, the APM Race Equity Committee undertook a survey of those working within palliative care. The survey looked at the ethnic identity of the palliative care workforce, palliative care staff's personal experience of racism and the reporting and handling of racism within palliative care. The survey also gathered views on organisational structures within palliative care and views on equity of service provision and career opportunities. This survey was done without funding and was subject to a process of external peer review. The survey was distributed both within and out with the APM's membership group with wide engagement from national palliative care organisations.

B3. This survey had 1352 respondents comprising of 27.3% nurses, 24.4% doctors, and 15.5% support staff. 83.8% of respondents were White, 6.3% were Asian, 3.4% were Black and 3.2% were Mixed.

B4. 39% of all respondents had either directly experienced or witnessed discrimination related to race at their palliative care workplace. 63% of minority ethnic respondents had experienced or witnessed racism within their palliative care workplace. Racism is therefore prevalent in significant numbers within palliative care.

B5. To determine the current relevance of racism, respondents were asked about the timeline of these incidents. Out of 478 respondents who had experienced or witnessed racism, 77% said this had occurred within the last 2 years. This reinforces that racism is an active issue within palliative care.

B6. The survey revealed numerous examples of racist discrimination experienced by staff members at the hands of patients. "I don't want to be touched by them (Black/African nurse), they (Black/African) work at two speeds – slow and stop."

B7. 63.6% of those who experienced racism perpetrated by those at an executive level, were of non-white ethnicities. A respondent stated there was a "Assumption I did not speak English at home based on my name and skin colour (that was by the HR director!)" These responses highlight how structural discrimination is embedded from the highest level within palliative care organisations.

B8. 42.6% of respondents who had experienced or witnessed racial discrimination did not report any of these instances to their manager or organisation. The main reasons for not doing so were feeling uncomfortable about it, lacking confidence that action would be taken or thinking the instance was not serious enough to warrant reporting. This data highlights that palliative care staff feel disempowered to report racism.

B9. Whilst the results of this survey do not directly related to assisted dying, the data highlight the racial discrimination faced by minoritised individuals in the palliative care workforce. The legalisation of assisted dying will impact this group of healthcare

professionals in specific ways (outlined below) which should be carefully considered by the Committee scrutinizing The Bill.

C. Views of minoritised palliative care staff on The Terminally Ill Adults (End of Life) Bill

C1. As part of the Race Equity Committee's workstream, meetings are held nationally for racialised staff working in palliative care to come together for peer support and education relating to racial discrimination. These meetings take the form of virtual 'ECHO networks', hosted by Hospice UK. In February 2025 the views of staff who identified as 'Black' or 'Brown' were gathered on the proposed Terminally Ill Adults (End of Life) Bill.

C2. The concerns of racialised staff centred around structural discrimination already present in healthcare and the amplification of this if assisted dying were to be introduced. Currently there are prevalent views within ethnic minority communities regarding the healthcare systems working against them. Staff expressed concern that the bill would be seen by ethnic minorities as another way for these systems to target them, particularly given the disparities seen during COVID-19.

C3. Mistrust in end-of-life care is a significant issue, with many communities already reluctant to engage in palliative care services due to the perception, for example, that hospices exist to kill people. Over the past decade, significant work has been done to widen access and build trust relating to palliative care for Asian and Black communities. Staff from these groups described fear that the introduction of assisted dying would undo this work, setting efforts back significantly and creating an even wider void between these communities and good access to high quality palliative care.

C4. There are complex, invisible layers of cultural and systemic issues at play in end-of-life care when looking after racialised communities. These issues are poorly understood generally by healthcare professionals. With poor understanding of cultural needs, comes poor access to culturally-informed palliative care.

C5. Racialised staff in palliative care face stigma within their own communities from being even remotely associated with assisted dying. Staff reflected on concerns from loved ones already encouraging them to leave the field of palliative care, for fear of social retribution if they remained aligned with a specialism which engages with state-sanctioned death.

C6. Black communities, often facing financial hardship, may see assisted dying as a favourable option not because of the desire to die but because of the lack of access to adequate care and support at the end of life.

C7. Whilst staff extended deep compassion for those individuals wanting control over their own death, generational trauma was recognised as contributing to the deep-rooted mistrust of structural healthcare systems both from communities and staff. There is a lack of control and agency within racialised communities when it comes to end-of-life care, and this contributes to issues of ongoing fear and mistrust.

C8. The role of family and loved ones was felt to play a significant role in decision-making in end-of-life care within racialised communities. Those writing legislation need to recognise this for the bill to be culturally relevant across society.

C9. Demand for assisted dying was felt to be low within racialised minority communities, with many staff voicing their perception that these community groups are generally against assisted dying.

D. Conclusions & Recommendations

D1. As a collective of healthcare professionals with an understanding of Palliative Care we are committed to challenging the prevalence of existing racial inequity in end-of-life care, healthcare and society. We hold concerns regarding the disproportionate impact that The Terminally Ill Adults (End of Life) Bill will have on the care of ethnic minority communities.

D2. **Recommendation:** The scrutinising Committee should consider these effects on patients, families, communities, particularly in relation to the precarious trust between these communities and healthcare professionals.

D3. Existing scientific data demonstrates that racism and structural discrimination is prevalent in healthcare. In addition, differentiation based on race has profound effects on patient outcomes, as demonstrated recently during the COVID-19 pandemic. The legalisation of assisted dying will result in differential effects on individuals with protected characteristics.

D4. **Recommendation:** The Bill should contain a clear directive for data to be collected prospectively on the impact of legalising assisted dying on ethnic minority staff and patients.

D5. Our ongoing work collaborating with racialised staff within palliative care highlights concerns that ethnic minorities are likely to face complex difficulties when engaging with assisted dying. This evidence has listed several factors including the relationship of ethnic minority communities with economic deprivation, historical context resulting in mistrust of healthcare and widespread racism in society.

D6. **Recommendation**: The scrutinising Committee should acknowledge the inevitable detrimental impact of the Bill on the experience of racialised staff within palliative care, and actively engage and work with this group of healthcare professionals with the goal of safeguarding them.

References

Institute for Fiscal Studies (London). Ethnic diversity of NHS doctors (2024). Available at: https://ifs.org.uk/publications/ethnic-diversity-nhs-doctors (Accessed: 9 February 2025).

BMA. Racism in Medicine (2022). Available at: https://www.bma.org.uk/media/5746/bma-racism-in-medicine-survey-report-15-june-2022.pdf (Accessed: 9 February 2025).

Race Equity Committee (Association for Palliative Medicine)

Gupta, G. 2023. Racial discrimination in Palliative Care settings – Race Equity Committee preliminary survey findings, Marie Curie Research Conference, 9 February 2023, online event.