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Principles for developing, undertaking, and reporting research with minority ethnic populations in palliative and end of life care: a modified Delphi study

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Abstract:	Background Minority ethnic populations face persistent inequities in end-of-life care, yet research often fails to capture these disparities due to methodological limitations. Robust approaches are urgently needed to investigate and address these inequities. Aim To develop best practice principles for conducting qualitative and quantitative research on ethnicity in palliative and end of life care. Design We conducted a modified Delphi study online, comprising one qualitative round and two quantitative rounds. Round one collected open-ended responses to generate 97 statements. In rounds two and three,

participants rated these on a 5-point Likert scale; statements were retained if ≥75% rated them "very" or "extremely important." Consensus statements informed the development of guiding principles, which were further refined during a stakeholder workshop.

Setting/Participants
Participants were UK-based and included minority ethnic patients, carers, community representatives, researchers, health professionals, and palliative care specialists.

Results
Forty-five participants completed round one, 43 round two, and 45 round three. Of 97 statements, 78 (80%) reached consensus in round two, and all 78 (100%) in round three. Seventeen stakeholders attended the workshop, resulting in 13 consensus-based guiding principles.

Conclusions
This UK-based Delphi established 13 key principles to strengthen research involving minority ethnic populations in palliative and end-of-life care. Implementing these principles will help address inequities and improve the quality and impact of future studies, with validation needed in international contexts.

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Principles for developing, undertaking, and reporting research with minority ethnic populations in palliative and end of life care: a modified Delphi study

Short title: Best practices for research on ethnicity in palliative care

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Key words: minority ethnic, racism, Delphi, equity, inclusion, research, palliative care, principles

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Abstract

Background

Minority ethnic populations face persistent inequities in end-of-life care, yet research often fails to capture these disparities due to methodological limitations. Robust approaches are urgently needed to investigate and address these inequities.

Aim

To develop best practice principles for conducting qualitative and quantitative research on ethnicity in palliative and end of life care.

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What is already known about this topic?

- People from minority ethnic populations face significant inequities in palliative and end-of-life care, including disparities in poorly managed symptoms and a lower likelihood of dying in their preferred place.
- Existing studies often overlook or homogenise the experiences of minority ethnic patients.
- Data collection and analysis methods frequently lack the nuance needed to capture structural barriers and culturally specific needs and experiences, reinforcing systemic biases rather than challenging them.

What this paper adds?

- This modified Delphi survey is the first to establish guiding principles for conducting palliative care research that meaningfully includes patients and families from minority ethnic populations.
- By focusing on individual experiences and perspectives, this work lays the foundation for more equitable and culturally responsive research practices.

Implications for practice, theory, or policy

- To achieve equity, we must critically reassess and decolonise research agendas, ensuring that research questions are defined with, rather than about minority ethnic populations.
- This paper advocates for a fundamental shift in how data is collected, interpreted, and applied, ensuring methodological best practices in both qualitative and quantitative research related to ethnicity in palliative and end-of-life care.

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- By embedding inclusivity at every stage, we can drive meaningful policy and practice changes that improve outcomes for all.

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Introduction

People have migrated throughout history for multiple reasons, including escaping war, colonisation, famine, political torture, or for the prospect of economic and social advantage[1]. Globalisation has brought unprecedented numbers of people moving to high-income countries. As of 2020, Europe was the region with the largest number (87 million) of international migrants, followed by North America (59 million).[2] Many migrants who settled in earlier decades are now ageing and experiencing an increased burden of long-term and life-limiting conditions. The implications of this for palliative care are an increasing need for health and social care professionals, who currently occupy a limited range of ethnocultural backgrounds[3], to provide care for those whose backgrounds may differ from their own. Patients and their families may have to make challenging decisions and they may hold diverse understandings of illness, symptoms, grief, informal caregiving, and expectations of care from service providers[4].

Evidence increasingly demonstrates that those from minority ethnic populations encounter poor access to palliative care services and often receive suboptimal care[5-9] [10]. These care deficits are related to measures of a 'good death'[4, 11] and deficits in these areas can negatively affect grief outcomes[12, 13]. What is seen as a 'good death' can differ based on culture and religion; traditional notions of a 'good death' are rooted in White, Anglo-Christian sensibilities [14-16]. Recent world events, including the COVID-19 pandemic[17-21] have highlighted existing inequities in healthcare for minority ethnic populations, reiterated in the recent *Lancet Commission on the Value of Death*[4]. Despite proclamations to redress inequities, a recent editorial in *Palliative Medicine*[22] and a systematic review[23] stated improvements in delivering equitable end-of-life care will be stymied unless we research

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ethnic disparities and their intersection with other protected and social characteristics. This research also needs to be combined with developing and evaluating services to improve experiences and outcomes of care. Yet, without critical reflection on study methodologies and reporting practices, researchers may inadvertently undermine efforts to address injustices and perpetuate systemic racism[23].

We understand ethnicity as comprising both an *attributional dimension* (shared sociocultural characteristics such as language, religion, diet, or cultural practices) and a *relational dimension* (the position of an ethnically defined group within society and its exposure to structural factors such as discrimination)[24]. Research of the complex nexus between ethnicity and palliative care presents conceptual, methodological and ethical challenges. Whilst many of these challenges have been recognised, attempts to address them have largely been absent[23, 25, 26]. We therefore aimed to derive consensus - including patients, carers, and community representatives - on methodological principles and best practices for planning, conducting, and reporting palliative care research with minority ethnic populations to address disparities and promote equitable access.

In this study, we use "*minority ethnic*" to reflect the UK context [27]. We acknowledge that in other jurisdictions, different terminology is standard. For example, in the USA, populations are often described as "racially minoritised or marginalised" [28, 29]. In Canada, research commonly refers to "Indigenous peoples" (encompassing First Nations, Inuit, and Métis) [30]; in Australia, the term *First Nations* (or sometimes *Aboriginal and Torres Strait Islander*) is used [31]; and in New Zealand research is grounded in *Māori* perspectives (e.g. *kaupapa Māori*

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methodologies)[32] Validation would therefore be needed before applying findings from this study to other national or cultural contexts.

Methods

Study Design

We used a modified Delphi approach, a method used to systematically establish agreement on specific subject matter statements where there is scarce or equivocal evidence, while giving equal weight to all voices and allowing iteration and refinement between rounds[33]. This approach draws upon the collective judgment of experts on a particular topic and was chosen because there is little consensus concerning methodological principles to guide research involving minority ethnic populations in palliative and end-of-life care. The modified Delphi survey was developed across the following stages: 'mind-mapping' – experts identified key items; 'narrowing down' – refining identified items; 'ranking' – prioritising items to reach consensus; and refining research principles with stakeholders (Figure 1). The Delphi followed CREDES[34] guidelines, ensuring anonymity of participants for independent objectivity. Disagreements were resolved through discussions. To enhance rigour, an advisory panel of palliative care experts and a patient/community representative provided feedback on survey design, analysis, and reporting. To promote inclusivity, three minority ethnic members of Involve Hull Patient Public Involvement Experts (PPIE) reviewed wording for accessibility. The survey was piloted for face validity in two rounds, with researchers and clinicians separately suggesting minor revisions.

INSERT FIGURE 1 DELPHI SURVEY PROCESS HERE

Ethical Issues

The study received full ethical approval from Hull York Medical School, University of Hull, UK (Ref 22-23 34, 6 February 2023). Informed consent was obtained through participants' completion of each Delphi round survey and the stakeholder workshop demographics survey.

Population, Sample and Recruitment

Panel members were identified and recruited through purposive and snowball sampling in the United Kingdom (UK). For round one, panel members were selected based on team and advisory panel contacts, web searches, and Gutierrez's[35] criteria: expertise, valuable input, and commitment to the field. The panel included palliative care researchers, social scientists, health professionals serving minority ethnic populations and charity representatives (e.g., Marie Curie.). Invitations were also sent via two PPIE forums to 'experts by experience' (henceforth 'patient/family participants'), who were carers or patients affected by serious illness. JK and HE reviewed and finalised the list.

Personalised email invitations included study details and a survey link. To mitigate acceptability bias, we used snowball sampling where recipients were encouraged to share the invitation. The ideal Delphi panel size is debated, but Baker et al[36] recommend at least 20 participants for heterogeneous panels. As a token of appreciation, 'patient/family participants' received a £20 gift voucher.

In round two, we adjusted our recruitment strategy to include more patient/family participants, as their representation in round one was low. Additional recruitment was

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guided by the research team and supported by two PPIE forums. In round three, all previous participants were invited.

Data Collection and Analysis

Surveys were developed and administered via Qualtrics XM™ (an online secure platform administered through the University of York). A brief demographic survey collected contextual data. Round one remained open for four weeks, while rounds two and three ran for three and a half weeks. Weekly reminders were sent to maintain engagement. The Delphi rounds took place from October 2023 to April 2024, followed by an stakeholder workshop in June 2024.

For all rounds, data were downloaded from Qualtrics XM™ into SPSS (IBM SPSS Statistics for Windows, Version 29.0.1.0 Armonk, NY: IBM Corp). Descriptive statistics were used to report basic demographic information.

Round One

This qualitative, unstructured round[37] used 15 open-ended questions (Appendix A) to gather expert opinions on developing research questions, appropriate approaches, and reporting findings (the final questions invited feedback). The final question invited feedback. Questions were informed by a literature review[23]. A survey was sent to panel members, and findings shaped the structured second round.

Open-ended responses were compiled by question and analysed using a six-step thematic analysis[38]: (1) familiarisation with data, (2) generating initial codes, (3) searching for themes,

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(4) reviewing themes, (5) defining/naming themes, and (6) producing the report. Steps 1–4 were key in refining responses into statements for round two. HE conducted the initial analysis, with rigour assessed using Lincoln and Guba's criteria[39]: credibility (codes reviewed by HE and JK), transferability (detailed methods for replication), dependability (rich analytical descriptions), and confirmability (round one results informing subsequent stages). HE and JK independently drafted statements, revised by the advisory panel with input from a patient representative for clarity.

Round Two

An electronic survey presented statements from round one, categorised under the original 14 questions. Experts rated each on a five-point scale from 'not at all important' to 'extremely important'. Descriptive statistics (percentages, medians, and IQRs) were calculated in SPSS to assess agreement levels[34]. Statements were retained for round three if ≥75% of respondents rated them as 'very' or 'extremely' important.

Round Three

Statements lacking consensus in round two were removed; the remaining statements were again categorised under the original 14 questions and rated on the same scale. Consensus statements (≥75% agreement) were then categorised into overarching themes to develop methodological principles for palliative care research. To explore disciplinary perspectives, summary statistics compared responses across researchers, clinicians, and patient/family participants.

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Development of Guidance Principles

The guidance was developed in the following manner. Included statements were listed within their separate questions. HE and JK independently read through the statements and grouped them into overarching themes which were evident *across* the entire dataset, accounting for any repetition or similarities to ensure the process was inclusive of all statements. Themes were identified, which were reviewed by the advisory panel; a draft guidance principle for each was developed and again reviewed by the advisory panel, who provided feedback. The guidance was subsequently amended.

Stakeholder Workshop

A stakeholder workshop was convened where the research team presented the guidance principles and encouraged feedback from invited stakeholders. This feedback was used to further refine the principles. The characteristics of the stakeholders present were collected via a survey on Qualtrics XM™ and completion of this survey implied consent to participate in the stakeholder workshop. The workshop comprised clinicians, researchers/academics, and patient, carer, and community representatives. To avoid confusion, we refer to this mixed group as 'stakeholders' throughout.

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Table 1 - Participant Characteristics

Variable	Round 1, n (%)	Round 2, n (%)	Round 3, n (%)	Stakeholder Workshop
Total Responses	45 (100)	43 (100)	45 (100)	17 (100)
Age				
Median (IQR)	45 (40-52)	52 (42-60)	51 (42-57.5)	55 (49.5-67)
Range (Min-Max)	47 (28-75)	53 (29-82)	60 (24-84)	53 (31-84)
Gender				
Female	39 (86.7)	34 (79.1)	34 (75.6)	12 (70.6)
Male	5 (11.1)	8 (18.6)	11 (24.4)	5 (29.4)
Prefer not to say	1 (2.2)	-	-	-
Non-binary	-	1 (2.3)	-	-
Self-assigned ethnic group				
Arab	1 (2.2)	-	-	-
African background	6 (13.3)	4 (9.3)	7 (15.6)	-
Bangladeshi	1 (2.2)	1 (2.3)	-	-
Caribbean	-	2 (4.7)	2 (4.4)	2 (11.8)
Chinese	1 (2.2)	1 (2.3)	1 (2.2)	1 (5.9)
English, Welsh, Scottish, Northern Irish or British	27 (60.0)	20 (46.5)	18 (40.0)	7 (41.2)
Irish	-	1 (2.3)	-	
Indian	3 (6.7)	4 (9.3)	6 (13.3)	2 (11.8)
Pakistani	2 (4.4)	3 (7.0)	3 (6.7)	2 (11.8)
Any other Asian background	-	-	1 (2.2)	1 (5.9)
Any other Black, Black British, Black Welsh, Black Scottish or Caribbean background	-	1 (2.3)	-	
Any other White background	3 (6.7)	3 (7.0)	7 (15.6)	2 (11.8)
Any other Mixed or multiple ethnic backgrounds	-	2 (4.7)	-	-
Any other ethnic group	1 (2.2)	1 (2.3)	-	-

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Role				
Clinician	13 (28.9)	11 (25.6)	7 (15.6)	3 (17.6)
Researcher/Academic	39 (86.7)	20 (46.5)	22 (48.9)	3 (17.6)
Patient, caregiver, or representative from a community or faith-based organisation	2 (4.4) **Ethnicity breakdown; n=2 (100):** African background – 1 (50.0) English, Welsh, Scottish, Northern Irish or British – 1 (50.0)	20 (46.5) **Ethnicity breakdown; n=20 (100):** African background – 1 (5.0) Bangladeshi – 1 (5.0) Caribbean - 2 (10.0) English, Welsh, Scottish, Northern Irish or British - 6 (30.0) Indian – 3 (15.0) Pakistani – 2 (10.0) Any other Black, Black British, Black Welsh, Black Scottish or Caribbean background – 1 (5.0) Any other Mixed or multiple ethnic backgrounds – 2 (10.0) Any other white background – 2 (10.0)	18 (40.0) **Ethnicity breakdown; n=18 (100):** African background – 2 (11.1) Caribbean – 2 (11.1) English, Welsh, Scottish, Northern Irish or British – 6 (33.3) Indian – 3 (16.7) Pakistani – 2 (11.1) Any other Asian background – 1 (5.6) Any other white background – 2 (11.1)	12 (70.6)
Number of individuals self-reporting as Clinicians *and* Academics	9 (20.0)	7 (16.3)	2 (4.4)	1 (5.9)
Number of individuals self-reporting as Clinicians, Academics, *and* Patient representatives	-	1 (2.3)	-	-

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Results

Round One

Forty-five individuals responded (13 clinicians, 39 researchers/academics, and two patient/family participants from a community or faith-based organisation). In this round, fifteen open-ended questions provided qualitative data, which were developed into 97 statements. **Error! Reference source not found.** provides a breakdown of the participant characteristics for all rounds (see Supplementary file for a more detailed breakdown of participant characteristics).

Round Two

Forty-three individuals participated (11 clinicians, 20 researchers/academics, and 12 patient/family members from community or faith-based organisations). Of 97 statements, 78 (≥75% agreement) progressed to round three (see Supplementary file). Statements with the lowest agreement (76.7%) included: different working approaches, use of self-identified demographic data, research time commitments, social support and service inequities, intersectionality, and ethics committee challenges. Statements with the highest agreement (95.3%) included evidence generation, awareness of discrimination/open-mindedness, and ethical issue management. Statements with <75% agreement were excluded from round three.

Round Three

Forty-five individuals responded (seven clinicians, 22 researchers/academics, and 18 patient/family participants from a community or faith-based organisation). All statements

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(78/78) reached consensus and were used to develop thirteen recommendations (principles) regarding methodological guidance (see Supplementary file).

Sub-analysis

In rounds two and three, we analysed score distribution across clinicians, researchers/academics, and patient/family participants. Overall, variation was minimal. In round two, Item 2.3 (monitoring ethnic diversity in research teams for cultural sensitivity) was rated 'very' or 'extremely important' more often by patients/caregivers (80%) than by clinicians (63.6%) or researchers (65%). Similarly, in round three, statement 4.1 (researchers should better understand ethnicity and cultures) received higher ratings from patient/caregiver and community members (88.9%) compared to clinicians (57.1%) or researchers (77.3%).

Stakeholder Workshop

Seventeen stakeholders attended the workshop (three clinicians, three researchers/academics, and 12 patient/family participants from a community or faith-based organisation, see Table 1**Error! Reference source not found.**). Feedback was given from stakeholders regarding the principles, and they were then refined by the research team.

Guidance Principles

The 13 guidance principles aim to progress standard practices when designing methodologies and conducting studies focused on ethnicity and palliative care. The principles are illustrated in **Error! Reference source not found.** and described in detail in Table 2.

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INSERT FIGURE 2 GUIDANCE PRINCIPLES INFOGRAPHIC HERE

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Table 2 - Guidance Principles for research with minority ethnic populations in palliative and end-of-life

Principles	Explanations
1. Equitable Palliative Care	• An equity-driven approach to assessing needs and delivering palliative care aims to promote fairness and improve the quality of life for all by addressing inequities (injustices) in services. This involves a focus on intersectionality (different factors such as gender, ethnicity, disability, socioeconomic position, employment etc, which overlap and accumulate to create discrimination) to understand different experiences and outcomes of care. It is essential to use clearly defined and acceptable terminology during research. • Community engagement should be used to ensure better access to services and address the needs of diverse groups. • There is a need for research to impact practice, policy, and academia.
2. PPIE	• Ethnically diverse patient and public involvement is essential, and it must be incorporated in a meaningful way throughout the research process. Consequently, adequate remuneration (financial) and sufficient resources (time, money, tools) should be costed into projects by researchers and supported by funding bodies.
3. Co-design and Co-production	• Research involving minority ethnic populations should prioritise co-design (an active collaboration between stakeholders to design ideas/contribute to part of a project), co-production (stakeholders actively involved throughout the entire project), and community engagement to ensure meaningful participation and appropriate dissemination through academic, community, and other channels. • Co-production with members of the public should be central to research teams, with adequate remuneration and supportive environments for contributors. • Funding bodies must allocate sufficient resources for PPIE compensation (researchers must consider what this is and factor this into research grants, including funding for pre-award work). • Training opportunities and mentoring schemes between universities and community organisations should be developed. • Inclusive dissemination strategies should involve stakeholders from minority ethnic populations. This includes co-authorship with non-academic community partners and disseminating findings through diverse channels such as community newsletters, social media, animations, and illustrations. • The research should translate into actionable recommendations that are owned by the community, with collaboration across multidisciplinary and diverse teams.
4. Acknowledgement of Lived Experience	• Research should consider how ethnicity intersects with other social factors including poverty, geography, gender, disability, employment, health, housing, and education. • Promote awareness of cultural and family differences to build respectful relationships with community members. • Research should be made more relevant and appropriate to those with lived experience and should consider the impact on families. Additionally, it is important to recognise differing views about death and dying and to consider health, disability, and cultural experiences, as well as interpretation and translation. Ultimately, the goal is to gain a better understanding of the

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	concerns, preferences, and needs of these communities, while also appreciating their culture and faith concerning death and dying.
5. Multidisciplinary and Diversity in Research Teams	• Research teams should strive to be diverse and multidisciplinary, including individuals with lived experience from the populations being studied and experts from various fields, including clinicians, academics, service leads, policymakers, and those with specific knowledge. This will allow a broad range of knowledge and diversity in the team which can improve recruitment and the quality of the research. • Utilising mixed methods approaches, cross-sector collaboration and co-production (considering the use of people from the communities being researched as community researchers), can better support diversity in research teams.
6. Empowerment and Access	• Understanding accessibility issues in palliative care services and research is crucial. To empower minority ethnic populations, it is essential to include them as either participants, PPIE members, lay researchers, or other research team members. • Increasing accessibility and understanding of palliative care research involves creating appropriate study materials in different languages and culturally suitable environments. Accessible and appropriate language should be considered in all study materials. • Diversifying research to include people from various backgrounds promotes inclusivity and understanding of needed changes. Enhancing inclusivity means considering barriers to recruitment and ensuring informed consent to avoid participant pressure. Providing translators, addressing health literacy in resources, minimising digital exclusion, and supporting family dynamics are necessary for effective participation. • Engagement with communities should address intersectionality and inequalities to improve access to services and promote fairness for all.
7. Cultural Safety	• Research teams should approach their work with an open mind, avoid making assumptions or generalisations, and be mindful of implicit and explicit bias, discrimination, and prejudice. • Teams need to be reflective of their level of cultural understanding (or lack thereof), and training and education needs. Additionally, there is a need for greater awareness of cultural and family differences to develop respectful relationships with community members and research participants. • Care, respect, and open-mindedness should be considered when reporting findings to ensure they are accessible to the communities they have drawn from. • There should be a focus on research in developing and providing effective culturally competent palliative and end-of-life care as well as person-centred care. • It is crucial to understand the palliative and end-of-life training and support needs of the workforce when caring for members of minority ethnic populations.
8. Funding of Studies/Financial Implications	• Recognition of the impact of socio-economic discrimination. To achieve this, PPIE representatives and co-production must be fully integrated into the research team, and funding bodies should allocate adequate resources (time, money, and tools) to compensate them appropriately. Furthermore, it is essential to provide suitable reimbursement and funding to enable research to proceed.

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	• Address recruitment barriers by offering solutions such as financial support for participants with caring responsibilities, ensuring accessibility, suitable locations, and childcare facilities. Therefore, there is a requirement for longer and more sufficient funding commitment in this area. Funding bodies should be made more aware of the need for increased funding for public involvement and engagement.
9. Awareness of Discrimination	• When reporting or interpreting study findings, researchers should be aware of stereotyping and systemic or structural bias (practices or policies within institutions or organisations that create unfair treatment and result in some groups being disadvantaged). • Researchers should be aware of, understand, and avoid discriminatory practices. It is important to be mindful of both conscious and unconscious bias, discrimination, and prejudice. They must approach their work with open-mindedness, avoiding assumptions and generalisations. Researchers need to reflect on their own biases and be mindful not to identify minority ethnic groups as 'exotic'.
10. Methods Used	• There are a variety of research methods that provide detailed insight into the lived experiences of those from minority ethnic populations. Mixed methods approaches are encouraged using a combination of quantitative and qualitative methods, and in-depth qualitative approaches (e.g. participatory research, interviews, focus groups, ethnography) that provide detailed insight into the lived experiences of those from minority ethnic populations are most appropriate.
11. Consideration of Ethical/Practical Issues	• Participants in a study may face pressure to take part, emphasising the need for informed consent to protect participants and make sure they are treated fairly. • Care should be taken to manage ethical issues such as psychological impact (distress, fear, anxiety), respect, trust, and confidentiality to positively influence participants' experiences. • Addressing language barriers through translation and interpreter services, demonstrating cultural sensitivity, and accommodating cultural needs are essential. • For the participant, balancing research commitments with other obligations (such as family responsibilities or work) is crucial and must be respected. • Where required, research ethics committees must be challenged on approaches to maximise recruitment opportunities that previously would have prevented research from taking place. • Diversity on research ethics committees should be encouraged.
12. Relationship and Capability Building	• Researchers should be adequately resourced to engage in building strong, trusting relationships and partnerships with community members, and should be flexible and transparent in all activities. • To effectively engage with minority ethnic populations, it is crucial to actively listen to community organisations and identify how research can help to address their priorities and concerns. • It is imperative to embrace diverse ways of working and actively participate in community involvement initiatives and outreach, such co-production or co-research. Building long-lasting relationships with communities is important to work together with those most involved in research. This involves capacity and capability-building communities to undertake research alongside the research team.

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	• Demonstrating cultural sensitivity and awareness, and appropriately addressing cultural needs, are essential. • Understanding family involvement and confidentiality dynamics within families, as well as trust and power dynamics within communities, is vital. • Addressing any mistrust in the research process and questions asked is important. • Collaborating with non-academic, community-based or PPIE partners, disseminating findings outside normal academic channels, and translating research into actionable recommendations owned by the community are all critical. • Increasing engagement with communities, improving access to services, understanding intersectionality, and addressing inequalities are key objectives.
13. Data Used	• Transparency in how data is collected, used, and reported, clarifying definitions and terminology, and acknowledging data limitations is essential. • Research teams should also consider in advance, the impact of the data they collect and report on services, patients, and the public. • Studies collecting data should include detailed, and where possible, self-identified socio-demographic information (including ethnicity, language, religion, socioeconomic, and other protected characteristics), with a focus on intersectionality of characteristics. Health, disability, and cultural experiences must be considered. • Broad ethnic categories should be avoided, especially binary categories. • Reasons for collecting data should be provided to participants, so they are aware of why it is needed.

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Discussion

Ethnic inequities in palliative care persist, impacting patient and family experiences and outcomes[22, 23]. Ignoring these issues is ethically indefensible, reinforces disparities and undermines fairness and dignity[40]. Addressing these gaps requires critical reflection on research methods to develop solutions for patient benefit. This modified Delphi study, conducted through three surveys (one qualitative, two quantitative) and an stakeholder workshop, identified 13 guiding principles for researching ethnicity in palliative care. These principles address study design, funding, methods, team composition, and reporting. Despite differing perspectives, a consensus was reached, aligning with broader public health research on minority ethnic populations[41]. Our findings emphasise embedding equity and inclusivity in palliative care research[42] and advocate for systemic change through intersectional, equity-driven approaches[43]. Operationalisation of these principles in practice should consider, for instance, research funder criteria and university ethics/governance processes (discussed below).

The principles

A recurring theme in the development of these principles was the necessity of authentically embedding PPIE throughout the entire research process[44]. Whilst this has previously been described as an important ethical consideration[41], our principles focus on their presence as enhancing impact and relevance. This meaningful involvement of ethnically diverse PPIE representatives is not only a matter of inclusion but also a strategy to ensure that research is rooted in the lived experiences of those most affected by inequities[42], notably absent in previous studies[23]. This also involves recognising how ethnicity intersects with other social determinants, such as material deprivation, gender, and health[45]. Involving members of

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minority ethnic populations in decisions about the kind of data that should be collected could, for example, challenge researchers' ideas about the value or risk of collecting certain types of data and develop solutions where required. Irrespective of their task, PPIE necessitates adequate compensation. These efforts must also be supported by funding bodies to ensure the sustainability of this approach.

Researchers have faced criticism for 'parachute science'[46] — conducting studies among minority ethnic populations without adequate regard or respect for the time members of these communities share with researchers. Co-production, cross-sector collaboration, and community researcher involvement strengthen study design, recruitment, and dissemination. Research should be conducted *with*, not just *about*, diverse communities. Our principles advocate for capacity-building, extending engagement beyond research into community-owned recommendations. Co-authorship with non-academic partners and diverse dissemination - social media, community newsletters - maximise impact. Research outputs must be culturally appropriate, accessible, and financially supported.

Diverse, multidisciplinary teams enrich the research process. The composition of research teams was identified in this work as playing a pivotal role in achieving inclusive and impactful research. In the United States, the National Institutes of Health, which funds biomedical and health research, stipulates that researchers are required to replicate the ethnic composition of the population they seek to study[47]. Similarly, in the UK, the National Institute for Health Research are now making inclusion a key condition of funding, which extends from the aims of research, ensuring equitable participation in studies and the research teams themselves[48]. Our principles show consistency with this inclusion strategy.

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Research involving minority ethnic populations must also address barriers related to language, cultural appropriateness, and digital exclusion to foster greater inclusivity. The principles emphasise the need for tailored study materials, interpreter services, and consideration of family dynamics in research participation.

Cultural safety[49] is key to ethical research relevant to those from minority ethnic populations[50]. Unlike cultural competency, which prioritises learning customs[51], cultural safety encourages researchers to challenge power structures, decolonise methods, and reflect on barriers to participation. A key distinction is the concept of 'power'[52]. This principal rejects focusing solely on learning cultural customs and instead promotes awareness of systemic barriers, power dynamics, and reflective practice. It also calls for shifting away from stereotyping and 'exoticising' minority ethnic groups[23], advocating a strengths-based approach that respects and positively values diverse experiences.

Ethical rigour is paramount in palliative care research, particularly when working with those from minority ethnic or marginalised populations who may be intrinsically or situationally vulnerable[53, 54]. Previous palliative care research has highlighted the multi-dimensional vulnerabilities present when undertaking research among minority ethnic populations as 'caution areas', not to prevent research but to take heed when designing and undertaking safe research[55]. This specific principle emphasises the need for informed consent, transparency, and sensitivity to participants' cultural and emotional needs. Our principles also extend to research ethics committees, which should also critically reflect on how research is framed, not to 'gatekeep', but to ensure culturally sensitive oversight and inclusivity that maximises the ethical principle of justice. Adaptation of ethical guidelines to

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address structural and systemic barriers that may limit research participation warrants attention. This principle also advocates for the diversification of research ethics committees to include underrepresented groups to improve the scrutiny of the science[56]. Many UK research ethics committees still lack this representation[57].

The principle of equitable palliative care research underscores the importance of addressing systemic inequities that impact care access and outcomes[18]. Data is powerful. However, it must be complete, comprehensive, accurate, and address the research questions that matter most to the communities they are intended to serve[58, 59]. Panel members, therefore, emphasised the collection and use of data that is transparent and relevant to those from minority ethnic populations. Moreover, the principles acknowledge intersectionality. Researchers should be mindful to acknowledge how overlapping factors, such as ethnicity, gender, socioeconomic position, and disability, contribute to diverse experiences of palliative care[28, 45, 60-63].

Detailed socio-demographic data, including self-identified ethnicity and cultural characteristics, should therefore be collected to ensure nuanced analyses that reflect the heterogeneity within and across ethnic populations. This supports recent work highlighting the need to improve the quality of data reporting and equity in palliative and end-of-life care[26, 59]. However, this principle comes with precautions. Researchers often see the demographics section of questionnaires as the least threatening and easiest to design. Instead, these items may be perceived as highly sensitive and potentially upsetting, leading to incomplete data fields[64]. It has been suggested that locating demographic questions at the end of surveys minimises the threat to participants[65], together with clear information

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about why these details are required, what they will be used for, and how this personal information will be protected, are paramount to building trust[66].

Ultimately, palliative care researchers have an ethical duty to prioritise ethnicity where relevant[67]. This is more than guidance for those focused on ethnicity — it is a call to action for all researchers who may not typically consider ethnicity in their studies. All researchers must recognise the significance of incorporating ethnic considerations to ensure the inclusivity and relevance of their work.

This Delphi study builds directly on our earlier scoping review of research with minoritised communities in palliative care, which identified significant conceptual, methodological, and ethical shortcomings in the field [23]. Whereas the review highlighted problems and set out a methodological agenda, the Delphi translates these observations into concrete, consensus-based principles co-produced with patients, carers, community representatives, clinicians, and researchers. In hindsight, the continuity between the two stages could have been strengthened by involving stakeholders earlier in the review process to help prioritise issues for the Delphi. Nonetheless, the sequential design ensures that the Delphi addressed gaps identified in the review, maximising the usefulness of the process and the value of stakeholders' contribution.

Dissemination plans

We aim to disseminate our findings widely and to support their practical implementation. This includes integrating the principles into training resources for researchers and practitioners; engaging with research funders to encourage inclusion of these principles in

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grant requirements; working with universities and research governance bodies to embed them in ethics and approval processes; and liaising with journals to inform reviewer and editorial guidance. We will also share the principles with policy bodies and community organisations to ensure their relevance beyond academia and to promote their uptake in service development and evaluation.

Strengths of the study

Study strengths include its expert composition - researchers, clinicians, and patient, caregiver, and community representatives, notably from multiple minority ethnic populations. These representatives actively engaged throughout all Delphi rounds, addressing a key limitation of a previous framework development study where few participants identified as coming from a minority ethnic group[42]. We believe the relevance of the study to community and PPIE groups contributed to their responsiveness and collaboration. We also recognised the intersection of ethnicity with other social factors, for example, deprivation, and consequently ensured financial recognition for patient, caregiver, and community involvement at all stages.

Limitations of the study

This study has several limitations. First, this study used open-ended questions in round one, allowing participants to provide rich insights that informed subsequent rounds. However, using a Delphi survey for qualitative data raises concerns about bias, as validity depends on panel selection and question design[68]. Second, the definition of 'topic expert' is debated[36], and selection may affect study rigour. Like others[69, 70], we defined experts as 'informed individuals with subject-specific knowledge,' including researchers, clinicians, and

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patient/family representatives from minority ethnic backgrounds. Third, our Delphi panel was entirely UK-based, which may limit the transferability of findings to other national or cultural contexts. The principles should therefore be interpreted within a UK framework and validated in international settings before broader application. Fourth, patient and carer participation in round one was limited, which may have shaped the initial pool of statements that were generated and carried forward. This imbalance could have influenced the framing of early priorities in the Delphi process. To address this, recruitment strategies were adapted in round two to strengthen representation, and the contributions of patients and carers were considered equally in subsequent rounds and in the stakeholder workshop. Nevertheless, the relatively low number of patient/carer voices at the outset remains a limitation that may have influenced consensus outcomes. Despite targeted recruitment, White participants were over-represented across rounds (for example, 40% in round three), and minority ethnic representation was lower than anticipated. This imbalance may have influenced the nature of consensus achieved and limits the diversity of perspectives captured. While we sought to promote inclusivity throughout the study, the research team's ethnic composition and participant sample did not fully reflect the diversity of the populations we aimed to study, although seven members of the authorship team identify as being from minority ethnic backgrounds. This highlights the persistent challenges of achieving representational balance even within equity-focused research and reinforces the importance of the principles we advocate. Realising diversity in both research participation and team composition remains an ongoing process requiring sustained structural, institutional, and funding support.

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Fifth, the study relied on online participation and did not provide full translation of materials, which may have excluded some potential contributors. To mitigate these barriers, we conducted a PPIE review of the survey language and piloted rounds one and two for accessibility; however, these steps cannot fully overcome the structural challenges of ensuring equitable participation. Nevertheless, our approach represents an advance on recent efforts to foster equity, diversity, and inclusion in PPIE within palliative care research, where minority ethnic representation has often been limited[42, 71].

Last, we analysed panel members' views collectively and by group, identifying convergence and divergence. Consensus was reached on 78 out of 97 items, though some findings were more nuanced. While the Delphi-derived principles inform research, they do not address how guidance translates into improved palliative care policies for minority ethnic populations —an area for future exploration to enhance equity in end-of-life care.

Conclusion

There is continuing concern that palliative care is not equitably serving the interests of minority ethnic populations. However, research to resolve these inequities has been slow to advance, stymied by research approaches that have failed to question existing structural and systemic factors that govern how research questions have been conceived, the methods used, the composition of research teams, and how findings have been interpreted and reported, among other factors. To realise change, the principles derived from this Delphi exercise provide direction to inform decisions by those funding, undertaking, and publishing ethnicity-related studies in palliative and end-of-life care. This work also engages with debates in the USA[25, 58, 67, 72] and elsewhere[43, 73] regarding the application of palliative care-

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related research to better serve those from minority ethnic populations. There is scope to further develop these principles in collaboration with researchers, policymakers, practitioners, and community groups beyond the UK context, ensuring their global relevance and utility.

Authors' contributions

JK designed the study and, with support from EC, SB, JD, JH, GC, ZI, RK, ED, and FD obtained funding. HE-B and JK conducted the analyses. HE-B and JK drafted the manuscript. All authors (HE-B, JK, EC, SB, JD, JH, GC, ZI, RK, ED, FD) critically reviewed and revised the manuscript. All authors (HE-B, JK, EC, SB, JD, JH, GC, ZI, RK, ED, FD) have approved the final version and agree to be accountable for the work.

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Appendix A

Round 1 Open Ended Questions

Importance and purpose of research

Q1. "Ethnicity" can refer to the social and cultural characteristics of a group of people who share a similar culture and way of life. Examples of this might include country of origin, language, religion, clothing, food and drink, music, literature, and art. Understanding ethnicity can also include learning how different ethnic groups are described and located in a society.

Palliative care (defined by the World Health Organisation) is care that aims to improve the quality of life of people who are experiencing life-limiting illnesses, for example, cancer, dementia, heart failure, among other serious illnesses (and their families), and especially of those near the end of life. It helps to manage pain, discomfort, distress, and other concerns which may be physical, psychological, and spiritual.

What should be the **main purpose(s) of research** that focuses on ethnicity and palliative care? Please give reasons for your answer.

Q2. What do you think are the **main responsibilities of researchers** studying ethnicity and palliative care? For example, improve the end-of-life care for the populations being studied. Please give reasons for your answer.

Framing and focus of research

Q3. What kinds of **issues do you think are important** when palliative care research is focussed on people from minority ethnic communities? This could include participation of different groups.

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Q4. What **ideas or beliefs** do you think researchers should consider when conducting research in this field? For example, ethnicity may sometimes be associated with disadvantage or poor health. Please give reasons for your answer.

Q5. What do you think are the right **research approaches (ways of doing research)** when studying the relationship between ethnicity and palliative and end-of-life care? For example, surveys, interviews? Please give reasons for your answer.

Q6. What **ethical issues (right or wrong ways of doing things)** do you think might be present when studying ethnicity and palliative care? For example, ensuring confidentiality, managing distress. Please give reasons for your answer.

Members of the research team

Q7. Who do you think should be part of the **"research team"** when doing studies that focus on ethnicity and palliative and end-of-life care? Please give reasons for your answer.

Q8. How do you think research institutions (e.g., universities) can support **voluntary and community organisations** who represent minority ethnic communities when they **work together in research**? Please give reasons for your answer.

Q9. In what ways do you think we can **support the needs and preferences (e.g., knowledge, information, confidence, skills etc.)** of people from minority ethnic communities so they can be more involved in research? Please give reasons for your answer.

Collection of study data

Q10. In your own words, **what kind of information (or data) do you think is the most important to collect** when looking at the relationship between palliative care and people

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from minority ethnic communities? For example, demographic details, literacy, medical/health care needs, etc. Please give reasons for your answer.

Q11. Do you think there may be any **practical issues** when collecting data for research studies that look at the relationship between palliative care and people from minority ethnic communities? Please give reasons for your answer.

Analysis of study data

Q12. When analysing **data that might show us inequalities** related to ethnicity and palliative and end-of-life care, what **concerns** do you think researchers should think about? For example, housing circumstances, social needs, age etc. Please give reasons for your answer.

Reporting of research findings

Q13. When researchers are ready to **share their findings** from studies looking at the relationship between ethnicity and palliative care do you think there are any issues they should think about? For example, publishing articles in academic journals and speaking at conferences. Please give reasons for your answer.

Future directions and priorities for research

Q14. What do you think are the **main priorities and future directions** for research with minority ethnic communities when looking at palliative and end-of-life care issues? Please give reasons for your answer.

Any other comments or suggestions

Q15. Please use this space to make any **additional comments or suggestions** that you think are important, relating to minority ethnic communities and palliative and end-of-life care.

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For example, this could include your opinions on:

- important priorities for research,
- different ways of working,
- difficulties that stop research taking place,
- differences in care between different ethnic groups.

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Principles for developing, undertaking, and reporting research with minority ethnic populations in palliative and end of life care: a modified Delphi study

Short title: Best practices for research on ethnicity in palliative care

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Key words: minority ethnic, racism, Delphi, equity, inclusion, research, palliative care, principles

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Abstract

Background

Minority ethnic populations face persistent inequities in end-of-life care, yet research often fails to capture these disparities due to methodological limitations. Robust approaches are urgently needed to investigate and address these inequities.

Aim

To develop best practice principles for conducting qualitative and quantitative research on ethnicity in palliative and end of life care.

Design

We conducted a modified Delphi study online, comprising one qualitative round and two quantitative rounds. Round one collected open-ended responses to generate 97 statements. In rounds two and three, participants rated these on a 5-point Likert scale; statements were retained if ≥75% rated them “very” or “extremely important.” Consensus statements informed the development of guiding principles, which were further refined during a stakeholder workshop.

Setting/Participants

Participants were UK-based and included minority ethnic patients, carers, community representatives, researchers, health professionals, and palliative care specialists.

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Results

Forty-five participants completed round one, 43 round two, and 45 round three. Of 97 statements, 78 (80%) reached consensus in round two, and all 78 (100%) in round three. Seventeen stakeholders attended the workshop, resulting in 13 consensus-based guiding principles.

Conclusions

This UK-based Delphi established 13 key principles to strengthen research involving minority ethnic populations in palliative and end-of-life care. Implementing these principles will help address inequities and improve the quality and impact of future studies, with validation needed in international contexts.

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What is already known about this topic?

- People from minority ethnic populations face significant inequities in palliative and end-of-life care, including disparities in poorly managed symptoms and a lower likelihood of dying in their preferred place.
- Existing studies often overlook or homogenise the experiences of minority ethnic patients.
- Data collection and analysis methods frequently lack the nuance needed to capture structural barriers and culturally specific needs and experiences, reinforcing systemic biases rather than challenging them.

What this paper adds?

- This modified Delphi survey is the first to establish guiding principles for conducting palliative care research that meaningfully includes patients and families from minority ethnic populations.
- By focusing on individual experiences and perspectives, this work lays the foundation for more equitable and culturally responsive research practices.

Implications for practice, theory, or policy

- To achieve equity, we must critically reassess and decolonise research agendas, ensuring that research questions are defined with, rather than about minority ethnic populations.
- This paper advocates for a fundamental shift in how data is collected, interpreted, and applied, ensuring methodological best practices in both qualitative and quantitative research related to ethnicity in palliative and end-of-life care.

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- By embedding inclusivity at every stage, we can drive meaningful policy and practice changes that improve outcomes for all.

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Introduction

People have migrated throughout history for multiple reasons, including escaping war, colonisation, famine, political torture, or for the prospect of economic and social advantage[1]. Globalisation has brought unprecedented numbers of people moving to high-income countries. As of 2020, Europe was the region with the largest number (87 million) of international migrants, followed by North America (59 million).[2] Many migrants who settled in earlier decades are now ageing and experiencing an increased burden of long-term and life-limiting conditions. The implications of this for palliative care are an increasing need for health and social care professionals, who currently occupy a limited range of ethnocultural backgrounds[3], to provide care for those whose backgrounds may differ from their own. Patients and their families may have to make challenging decisions and they may hold diverse understandings of illness, symptoms, grief, informal caregiving, and expectations of care from service providers[4].

Evidence increasingly demonstrates that those from minority ethnic populations encounter poor access to palliative care services and often receive suboptimal care[5-9] [10]. These care deficits are related to measures of a 'good death'[4, 11] and deficits in these areas can negatively affect grief outcomes[12, 13]. What is seen as a 'good death' can differ based on culture and religion; traditional notions of a 'good death' are rooted in White, Anglo-Christian sensibilities [14-16]. Recent world events, including the COVID-19 pandemic[17-21] have highlighted existing inequities in healthcare for minority ethnic populations, reiterated in the recent *Lancet Commission on the Value of Death*[4]. Despite proclamations to redress inequities, a recent editorial in *Palliative Medicine*[22] and a systematic review[23] stated improvements in delivering equitable end-of-life care will be stymied unless we research

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ethnic disparities and their intersection with other protected and social characteristics. This research also needs to be combined with developing and evaluating services to improve experiences and outcomes of care. Yet, without critical reflection on study methodologies and reporting practices, researchers may inadvertently undermine efforts to address injustices and perpetuate systemic racism[23].

We understand ethnicity as comprising both an *attributional dimension* (shared sociocultural characteristics such as language, religion, diet, or cultural practices) and a *relational dimension* (the position of an ethnically defined group within society and its exposure to structural factors such as discrimination)[24]. Research of the complex nexus between ethnicity and palliative care presents conceptual, methodological and ethical challenges. Whilst many of these challenges have been recognised, attempts to address them have largely been absent[23, 25, 26]. We therefore aimed to derive consensus - including patients, carers, and community representatives - on methodological principles and best practices for planning, conducting, and reporting palliative care research with minority ethnic populations to address disparities and promote equitable access.

In this study, we use "*minority ethnic*" to reflect the UK context [27]. We acknowledge that in other jurisdictions, different terminology is standard. For example, in the USA, populations are often described as "racially minoritised or marginalised" [28, 29]. In Canada, research commonly refers to "Indigenous peoples" (encompassing First Nations, Inuit, and Métis) [30]; in Australia, the term *First Nations* (or sometimes *Aboriginal and Torres Strait Islander*) is used [31]; and in New Zealand research is grounded in *Māori* perspectives (e.g. *kaupapa Māori*

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methodologies)[32] Validation would therefore be needed before applying findings from this study to other national or cultural contexts.

Methods

Study Design

We used a modified Delphi approach, a method used to systematically establish agreement on specific subject matter statements where there is scarce or equivocal evidence, while giving equal weight to all voices and allowing iteration and refinement between rounds[33]. This approach draws upon the collective judgment of experts on a particular topic and was chosen because there is little consensus concerning methodological principles to guide research involving minority ethnic populations in palliative and end-of-life care. The modified Delphi survey was developed across the following stages: 'mind-mapping' – experts identified key items; 'narrowing down' – refining identified items; 'ranking' – prioritising items to reach consensus; and refining research principles with stakeholders (Figure 1). The Delphi followed CREDES[34] guidelines, ensuring anonymity of participants for independent objectivity. Disagreements were resolved through discussions. To enhance rigour, an advisory panel of palliative care experts and a patient/community representative provided feedback on survey design, analysis, and reporting. To promote inclusivity, three minority ethnic members of Involve Hull Patient Public Involvement Experts (PPIE) reviewed wording for accessibility. The survey was piloted for face validity in two rounds, with researchers and clinicians separately suggesting minor revisions.

INSERT FIGURE 1 DELPHI SURVEY PROCESS HERE

Ethical Issues

The study received full ethical approval from Hull York Medical School, University of Hull, UK (Ref 22-23 34, 6 February 2023). Informed consent was obtained through participants' completion of each Delphi round survey and the stakeholder workshop demographics survey.

Population, Sample and Recruitment

Panel members were identified and recruited through purposive and snowball sampling in the United Kingdom (UK). For round one, panel members were selected based on team and advisory panel contacts, web searches, and Gutierrez's[35] criteria: expertise, valuable input, and commitment to the field. The panel included palliative care researchers, social scientists, health professionals serving minority ethnic populations and charity representatives (e.g., Marie Curie.). Invitations were also sent via two PPIE forums to 'experts by experience' (henceforth 'patient/family participants'), who were carers or patients affected by serious illness. JK and HE reviewed and finalised the list.

Personalised email invitations included study details and a survey link. To mitigate acceptability bias, we used snowball sampling where recipients were encouraged to share the invitation. The ideal Delphi panel size is debated, but Baker et al[36] recommend at least 20 participants for heterogeneous panels. As a token of appreciation, 'patient/family participants' received a £20 gift voucher.

In round two, we adjusted our recruitment strategy to include more patient/family participants, as their representation in round one was low. Additional recruitment was

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guided by the research team and supported by two PPIE forums. In round three, all previous participants were invited.

Data Collection and Analysis

Surveys were developed and administered via Qualtrics XM™ (an online secure platform administered through the University of York). A brief demographic survey collected contextual data. Round one remained open for four weeks, while rounds two and three ran for three and a half weeks. Weekly reminders were sent to maintain engagement. The Delphi rounds took place from October 2023 to April 2024, followed by an stakeholder workshop in June 2024.

For all rounds, data were downloaded from Qualtrics XM™ into SPSS (IBM SPSS Statistics for Windows, Version 29.0.1.0 Armonk, NY: IBM Corp). Descriptive statistics were used to report basic demographic information.

Round One

This qualitative, unstructured round[37] used 15 open-ended questions (Appendix A) to gather expert opinions on developing research questions, appropriate approaches, and reporting findings (the final questions invited feedback). The final question invited feedback. Questions were informed by a literature review[23]. A survey was sent to panel members, and findings shaped the structured second round.

Open-ended responses were compiled by question and analysed using a six-step thematic analysis[38]: (1) familiarisation with data, (2) generating initial codes, (3) searching for themes,

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(4) reviewing themes, (5) defining/naming themes, and (6) producing the report. Steps 1–4 were key in refining responses into statements for round two. HE conducted the initial analysis, with rigour assessed using Lincoln and Guba's criteria[39]: credibility (codes reviewed by HE and JK), transferability (detailed methods for replication), dependability (rich analytical descriptions), and confirmability (round one results informing subsequent stages). HE and JK independently drafted statements, revised by the advisory panel with input from a patient representative for clarity.

Round Two

An electronic survey presented statements from round one, categorised under the original 14 questions. Experts rated each on a five-point scale from 'not at all important' to 'extremely important'. Descriptive statistics (percentages, medians, and IQRs) were calculated in SPSS to assess agreement levels[34]. Statements were retained for round three if ≥75% of respondents rated them as 'very' or 'extremely' important.

Round Three

Statements lacking consensus in round two were removed; the remaining statements were again categorised under the original 14 questions and rated on the same scale. Consensus statements (≥75% agreement) were then categorised into overarching themes to develop methodological principles for palliative care research. To explore disciplinary perspectives, summary statistics compared responses across researchers, clinicians, and patient/family participants.

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Development of Guidance Principles

The guidance was developed in the following manner. Included statements were listed within their separate questions. HE and JK independently read through the statements and grouped them into overarching themes which were evident *across* the entire dataset, accounting for any repetition or similarities to ensure the process was inclusive of all statements. Themes were identified, which were reviewed by the advisory panel; a draft guidance principle for each was developed and again reviewed by the advisory panel, who provided feedback. The guidance was subsequently amended.

Stakeholder Workshop

A stakeholder workshop was convened where the research team presented the guidance principles and encouraged feedback from invited stakeholders. This feedback was used to further refine the principles. The characteristics of the stakeholders present were collected via a survey on Qualtrics XM™ and completion of this survey implied consent to participate in the stakeholder workshop. The workshop comprised clinicians, researchers/academics, and patient, carer, and community representatives. To avoid confusion, we refer to this mixed group as 'stakeholders' throughout.

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Table 1 - Participant Characteristics

Variable	Round 1, n (%)	Round 2, n (%)	Round 3, n (%)	Stakeholder Workshop
Total Responses	45 (100)	43 (100)	45 (100)	17 (100)
Age				
Median (IQR)	45 (40-52)	52 (42-60)	51 (42-57.5)	55 (49.5-67)
Range (Min-Max)	47 (28-75)	53 (29-82)	60 (24-84)	53 (31-84)
Gender				
Female	39 (86.7)	34 (79.1)	34 (75.6)	12 (70.6)
Male	5 (11.1)	8 (18.6)	11 (24.4)	5 (29.4)
Prefer not to say	1 (2.2)	-	-	-
Non-binary	-	1 (2.3)	-	-
Self-assigned ethnic group				
Arab	1 (2.2)	-	-	-
African background	6 (13.3)	4 (9.3)	7 (15.6)	-
Bangladeshi	1 (2.2)	1 (2.3)	-	-
Caribbean	-	2 (4.7)	2 (4.4)	2 (11.8)
Chinese	1 (2.2)	1 (2.3)	1 (2.2)	1 (5.9)
English, Welsh, Scottish, Northern Irish or British	27 (60.0)	20 (46.5)	18 (40.0)	7 (41.2)
Irish	-	1 (2.3)	-	
Indian	3 (6.7)	4 (9.3)	6 (13.3)	2 (11.8)
Pakistani	2 (4.4)	3 (7.0)	3 (6.7)	2 (11.8)
Any other Asian background	-	-	1 (2.2)	1 (5.9)
Any other Black, Black British, Black Welsh, Black Scottish or Caribbean background	-	1 (2.3)	-	
Any other White background	3 (6.7)	3 (7.0)	7 (15.6)	2 (11.8)
Any other Mixed or multiple ethnic backgrounds	-	2 (4.7)	-	-
Any other ethnic group	1 (2.2)	1 (2.3)	-	-

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Role				
Clinician	13 (28.9)	11 (25.6)	7 (15.6)	3 (17.6)
Researcher/Academic	39 (86.7)	20 (46.5)	22 (48.9)	3 (17.6)
Patient, caregiver, or representative from a community or faith-based organisation	2 (4.4) **Ethnicity breakdown; n=2 (100):** African background – 1 (50.0) English, Welsh, Scottish, Northern Irish or British – 1 (50.0)	20 (46.5) **Ethnicity breakdown; n=20 (100):** African background – 1 (5.0) Bangladeshi – 1 (5.0) Caribbean - 2 (10.0) English, Welsh, Scottish, Northern Irish or British - 6 (30.0) Indian – 3 (15.0) Pakistani – 2 (10.0) Any other Black, Black British, Black Welsh, Black Scottish or Caribbean background – 1 (5.0) Any other Mixed or multiple ethnic backgrounds – 2 (10.0) Any other white background – 2 (10.0)	18 (40.0) **Ethnicity breakdown; n=18 (100):** African background – 2 (11.1) Caribbean – 2 (11.1) English, Welsh, Scottish, Northern Irish or British – 6 (33.3) Indian – 3 (16.7) Pakistani – 2 (11.1) Any other Asian background – 1 (5.6) Any other white background – 2 (11.1)	12 (70.6)
Number of individuals self-reporting as Clinicians *and* Academics	9 (20.0)	7 (16.3)	2 (4.4)	1 (5.9)
Number of individuals self-reporting as Clinicians, Academics, *and* Patient representatives	-	1 (2.3)	-	-

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Results

Round One

Forty-five individuals responded (13 clinicians, 39 researchers/academics, and two patient/family participants from a community or faith-based organisation). In this round, fifteen open-ended questions provided qualitative data, which were developed into 97 statements. **Error! Reference source not found.** provides a breakdown of the participant characteristics for all rounds (see Supplementary file for a more detailed breakdown of participant characteristics).

Round Two

Forty-three individuals participated (11 clinicians, 20 researchers/academics, and 12 patient/family members from community or faith-based organisations). Of 97 statements, 78 (≥75% agreement) progressed to round three (see Supplementary file). Statements with the lowest agreement (76.7%) included: different working approaches, use of self-identified demographic data, research time commitments, social support and service inequities, intersectionality, and ethics committee challenges. Statements with the highest agreement (95.3%) included evidence generation, awareness of discrimination/open-mindedness, and ethical issue management. Statements with <75% agreement were excluded from round three.

Round Three

Forty-five individuals responded (seven clinicians, 22 researchers/academics, and 18 patient/family participants from a community or faith-based organisation). All statements

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(78/78) reached consensus and were used to develop thirteen recommendations (principles) regarding methodological guidance (see Supplementary file).

Sub-analysis

In rounds two and three, we analysed score distribution across clinicians, researchers/academics, and patient/family participants. Overall, variation was minimal. In round two, Item 2.3 (monitoring ethnic diversity in research teams for cultural sensitivity) was rated 'very' or 'extremely important' more often by patients/caregivers (80%) than by clinicians (63.6%) or researchers (65%). Similarly, in round three, statement 4.1 (researchers should better understand ethnicity and cultures) received higher ratings from patient/caregiver and community members (88.9%) compared to clinicians (57.1%) or researchers (77.3%).

Stakeholder Workshop

Seventeen stakeholders attended the workshop (three clinicians, three researchers/academics, and 12 patient/family participants from a community or faith-based organisation, see Table 1**Error! Reference source not found.**). Feedback was given from stakeholders regarding the principles, and they were then refined by the research team.

Guidance Principles

The 13 guidance principles aim to progress standard practices when designing methodologies and conducting studies focused on ethnicity and palliative care. The principles are illustrated in **Error! Reference source not found.** and described in detail in Table 2.

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INSERT FIGURE 2 GUIDANCE PRINCIPLES INFOGRAPHIC HERE

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Table 2 - Guidance Principles for research with minority ethnic populations in palliative and end-of-life

Principles	Explanations
1. Equitable Palliative Care	• An equity-driven approach to assessing needs and delivering palliative care aims to promote fairness and improve the quality of life for all by addressing inequities (injustices) in services. This involves a focus on intersectionality (different factors such as gender, ethnicity, disability, socioeconomic position, employment etc, which overlap and accumulate to create discrimination) to understand different experiences and outcomes of care. It is essential to use clearly defined and acceptable terminology during research. • Community engagement should be used to ensure better access to services and address the needs of diverse groups. • There is a need for research to impact practice, policy, and academia.
2. PPIE	• Ethnically diverse patient and public involvement is essential, and it must be incorporated in a meaningful way throughout the research process. Consequently, adequate remuneration (financial) and sufficient resources (time, money, tools) should be costed into projects by researchers and supported by funding bodies.
3. Co-design and Co-production	• Research involving minority ethnic populations should prioritise co-design (an active collaboration between stakeholders to design ideas/contribute to part of a project), co-production (stakeholders actively involved throughout the entire project), and community engagement to ensure meaningful participation and appropriate dissemination through academic, community, and other channels. • Co-production with members of the public should be central to research teams, with adequate remuneration and supportive environments for contributors. • Funding bodies must allocate sufficient resources for PPIE compensation (researchers must consider what this is and factor this into research grants, including funding for pre-award work). • Training opportunities and mentoring schemes between universities and community organisations should be developed. • Inclusive dissemination strategies should involve stakeholders from minority ethnic populations. This includes co-authorship with non-academic community partners and disseminating findings through diverse channels such as community newsletters, social media, animations, and illustrations. • The research should translate into actionable recommendations that are owned by the community, with collaboration across multidisciplinary and diverse teams.
4. Acknowledgement of Lived Experience	• Research should consider how ethnicity intersects with other social factors including poverty, geography, gender, disability, employment, health, housing, and education. • Promote awareness of cultural and family differences to build respectful relationships with community members. • Research should be made more relevant and appropriate to those with lived experience and should consider the impact on families. Additionally, it is important to recognise differing views about death and dying and to consider health, disability, and cultural experiences, as well as interpretation and translation. Ultimately, the goal is to gain a better understanding of the

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	concerns, preferences, and needs of these communities, while also appreciating their culture and faith concerning death and dying.
5. Multidisciplinary and Diversity in Research Teams	• Research teams should strive to be diverse and multidisciplinary, including individuals with lived experience from the populations being studied and experts from various fields, including clinicians, academics, service leads, policymakers, and those with specific knowledge. This will allow a broad range of knowledge and diversity in the team which can improve recruitment and the quality of the research. • Utilising mixed methods approaches, cross-sector collaboration and co-production (considering the use of people from the communities being researched as community researchers), can better support diversity in research teams.
6. Empowerment and Access	• Understanding accessibility issues in palliative care services and research is crucial. To empower minority ethnic populations, it is essential to include them as either participants, PPIE members, lay researchers, or other research team members. • Increasing accessibility and understanding of palliative care research involves creating appropriate study materials in different languages and culturally suitable environments. Accessible and appropriate language should be considered in all study materials. • Diversifying research to include people from various backgrounds promotes inclusivity and understanding of needed changes. Enhancing inclusivity means considering barriers to recruitment and ensuring informed consent to avoid participant pressure. Providing translators, addressing health literacy in resources, minimising digital exclusion, and supporting family dynamics are necessary for effective participation. • Engagement with communities should address intersectionality and inequalities to improve access to services and promote fairness for all.
7. Cultural Safety	• Research teams should approach their work with an open mind, avoid making assumptions or generalisations, and be mindful of implicit and explicit bias, discrimination, and prejudice. • Teams need to be reflective of their level of cultural understanding (or lack thereof), and training and education needs. Additionally, there is a need for greater awareness of cultural and family differences to develop respectful relationships with community members and research participants. • Care, respect, and open-mindedness should be considered when reporting findings to ensure they are accessible to the communities they have drawn from. • There should be a focus on research in developing and providing effective culturally competent palliative and end-of-life care as well as person-centred care. • It is crucial to understand the palliative and end-of-life training and support needs of the workforce when caring for members of minority ethnic populations.
8. Funding of Studies/Financial Implications	• Recognition of the impact of socio-economic discrimination. To achieve this, PPIE representatives and co-production must be fully integrated into the research team, and funding bodies should allocate adequate resources (time, money, and tools) to compensate them appropriately. Furthermore, it is essential to provide suitable reimbursement and funding to enable research to proceed.

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	• Address recruitment barriers by offering solutions such as financial support for participants with caring responsibilities, ensuring accessibility, suitable locations, and childcare facilities. Therefore, there is a requirement for longer and more sufficient funding commitment in this area. Funding bodies should be made more aware of the need for increased funding for public involvement and engagement.
9. Awareness of Discrimination	• When reporting or interpreting study findings, researchers should be aware of stereotyping and systemic or structural bias (practices or policies within institutions or organisations that create unfair treatment and result in some groups being disadvantaged). • Researchers should be aware of, understand, and avoid discriminatory practices. It is important to be mindful of both conscious and unconscious bias, discrimination, and prejudice. They must approach their work with open-mindedness, avoiding assumptions and generalisations. Researchers need to reflect on their own biases and be mindful not to identify minority ethnic groups as 'exotic'.
10. Methods Used	• There are a variety of research methods that provide detailed insight into the lived experiences of those from minority ethnic populations. Mixed methods approaches are encouraged using a combination of quantitative and qualitative methods, and in-depth qualitative approaches (e.g. participatory research, interviews, focus groups, ethnography) that provide detailed insight into the lived experiences of those from minority ethnic populations are most appropriate.
11. Consideration of Ethical/Practical Issues	• Participants in a study may face pressure to take part, emphasising the need for informed consent to protect participants and make sure they are treated fairly. • Care should be taken to manage ethical issues such as psychological impact (distress, fear, anxiety), respect, trust, and confidentiality to positively influence participants' experiences. • Addressing language barriers through translation and interpreter services, demonstrating cultural sensitivity, and accommodating cultural needs are essential. • For the participant, balancing research commitments with other obligations (such as family responsibilities or work) is crucial and must be respected. • Where required, research ethics committees must be challenged on approaches to maximise recruitment opportunities that previously would have prevented research from taking place. • Diversity on research ethics committees should be encouraged.
12. Relationship and Capability Building	• Researchers should be adequately resourced to engage in building strong, trusting relationships and partnerships with community members, and should be flexible and transparent in all activities. • To effectively engage with minority ethnic populations, it is crucial to actively listen to community organisations and identify how research can help to address their priorities and concerns. • It is imperative to embrace diverse ways of working and actively participate in community involvement initiatives and outreach, such co-production or co-research. Building long-lasting relationships with communities is important to work together with those most involved in research. This involves capacity and capability-building communities to undertake research alongside the research team.

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	• Demonstrating cultural sensitivity and awareness, and appropriately addressing cultural needs, are essential. • Understanding family involvement and confidentiality dynamics within families, as well as trust and power dynamics within communities, is vital. • Addressing any mistrust in the research process and questions asked is important. • Collaborating with non-academic, community-based or PPIE partners, disseminating findings outside normal academic channels, and translating research into actionable recommendations owned by the community are all critical. • Increasing engagement with communities, improving access to services, understanding intersectionality, and addressing inequalities are key objectives.
13. Data Used	• Transparency in how data is collected, used, and reported, clarifying definitions and terminology, and acknowledging data limitations is essential. • Research teams should also consider in advance, the impact of the data they collect and report on services, patients, and the public. • Studies collecting data should include detailed, and where possible, self-identified socio-demographic information (including ethnicity, language, religion, socioeconomic, and other protected characteristics), with a focus on intersectionality of characteristics. Health, disability, and cultural experiences must be considered. • Broad ethnic categories should be avoided, especially binary categories. • Reasons for collecting data should be provided to participants, so they are aware of why it is needed.

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Discussion

Ethnic inequities in palliative care persist, impacting patient and family experiences and outcomes[22, 23]. Ignoring these issues is ethically indefensible, reinforces disparities and undermines fairness and dignity[40]. Addressing these gaps requires critical reflection on research methods to develop solutions for patient benefit. This modified Delphi study, conducted through three surveys (one qualitative, two quantitative) and an stakeholder workshop, identified 13 guiding principles for researching ethnicity in palliative care. These principles address study design, funding, methods, team composition, and reporting. Despite differing perspectives, a consensus was reached, aligning with broader public health research on minority ethnic populations[41]. Our findings emphasise embedding equity and inclusivity in palliative care research[42] and advocate for systemic change through intersectional, equity-driven approaches[43]. Operationalisation of these principles in practice should consider, for instance, research funder criteria and university ethics/governance processes (discussed below).

The principles

A recurring theme in the development of these principles was the necessity of authentically embedding PPIE throughout the entire research process[44]. Whilst this has previously been described as an important ethical consideration[41], our principles focus on their presence as enhancing impact and relevance. This meaningful involvement of ethnically diverse PPIE representatives is not only a matter of inclusion but also a strategy to ensure that research is rooted in the lived experiences of those most affected by inequities[42], notably absent in previous studies[23]. This also involves recognising how ethnicity intersects with other social determinants, such as material deprivation, gender, and health[45]. Involving members of

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minority ethnic populations in decisions about the kind of data that should be collected could, for example, challenge researchers' ideas about the value or risk of collecting certain types of data and develop solutions where required. Irrespective of their task, PPIE necessitates adequate compensation. These efforts must also be supported by funding bodies to ensure the sustainability of this approach.

Researchers have faced criticism for 'parachute science'[46] — conducting studies among minority ethnic populations without adequate regard or respect for the time members of these communities share with researchers. Co-production, cross-sector collaboration, and community researcher involvement strengthen study design, recruitment, and dissemination. Research should be conducted *with*, not just *about*, diverse communities. Our principles advocate for capacity-building, extending engagement beyond research into community-owned recommendations. Co-authorship with non-academic partners and diverse dissemination - social media, community newsletters - maximise impact. Research outputs must be culturally appropriate, accessible, and financially supported.

Diverse, multidisciplinary teams enrich the research process. The composition of research teams was identified in this work as playing a pivotal role in achieving inclusive and impactful research. In the United States, the National Institutes of Health, which funds biomedical and health research, stipulates that researchers are required to replicate the ethnic composition of the population they seek to study[47]. Similarly, in the UK, the National Institute for Health Research are now making inclusion a key condition of funding, which extends from the aims of research, ensuring equitable participation in studies and the research teams themselves[48]. Our principles show consistency with this inclusion strategy.

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Research involving minority ethnic populations must also address barriers related to language, cultural appropriateness, and digital exclusion to foster greater inclusivity. The principles emphasise the need for tailored study materials, interpreter services, and consideration of family dynamics in research participation.

Cultural safety[49] is key to ethical research relevant to those from minority ethnic populations[50]. Unlike cultural competency, which prioritises learning customs[51], cultural safety encourages researchers to challenge power structures, decolonise methods, and reflect on barriers to participation. A key distinction is the concept of 'power'[52]. This principal rejects focusing solely on learning cultural customs and instead promotes awareness of systemic barriers, power dynamics, and reflective practice. It also calls for shifting away from stereotyping and 'exoticising' minority ethnic groups[23], advocating a strengths-based approach that respects and positively values diverse experiences.

Ethical rigour is paramount in palliative care research, particularly when working with those from minority ethnic or marginalised populations who may be intrinsically or situationally vulnerable[53, 54]. Previous palliative care research has highlighted the multi-dimensional vulnerabilities present when undertaking research among minority ethnic populations as 'caution areas', not to prevent research but to take heed when designing and undertaking safe research[55]. This specific principle emphasises the need for informed consent, transparency, and sensitivity to participants' cultural and emotional needs. Our principles also extend to research ethics committees, which should also critically reflect on how research is framed, not to 'gatekeep', but to ensure culturally sensitive oversight and inclusivity that maximises the ethical principle of justice. Adaptation of ethical guidelines to

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address structural and systemic barriers that may limit research participation warrants attention. This principle also advocates for the diversification of research ethics committees to include underrepresented groups to improve the scrutiny of the science[56]. Many UK research ethics committees still lack this representation[57].

The principle of equitable palliative care research underscores the importance of addressing systemic inequities that impact care access and outcomes[18]. Data is powerful. However, it must be complete, comprehensive, accurate, and address the research questions that matter most to the communities they are intended to serve[58, 59]. Panel members, therefore, emphasised the collection and use of data that is transparent and relevant to those from minority ethnic populations. Moreover, the principles acknowledge intersectionality. Researchers should be mindful to acknowledge how overlapping factors, such as ethnicity, gender, socioeconomic position, and disability, contribute to diverse experiences of palliative care[28, 45, 60-63].

Detailed socio-demographic data, including self-identified ethnicity and cultural characteristics, should therefore be collected to ensure nuanced analyses that reflect the heterogeneity within and across ethnic populations. This supports recent work highlighting the need to improve the quality of data reporting and equity in palliative and end-of-life care[26, 59]. However, this principle comes with precautions. Researchers often see the demographics section of questionnaires as the least threatening and easiest to design. Instead, these items may be perceived as highly sensitive and potentially upsetting, leading to incomplete data fields[64]. It has been suggested that locating demographic questions at the end of surveys minimises the threat to participants[65], together with clear information

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about why these details are required, what they will be used for, and how this personal information will be protected, are paramount to building trust[66].

Ultimately, palliative care researchers have an ethical duty to prioritise ethnicity where relevant[67]. This is more than guidance for those focused on ethnicity — it is a call to action for all researchers who may not typically consider ethnicity in their studies. All researchers must recognise the significance of incorporating ethnic considerations to ensure the inclusivity and relevance of their work.

This Delphi study builds directly on our earlier scoping review of research with minoritised communities in palliative care, which identified significant conceptual, methodological, and ethical shortcomings in the field [23]. Whereas the review highlighted problems and set out a methodological agenda, the Delphi translates these observations into concrete, consensus-based principles co-produced with patients, carers, community representatives, clinicians, and researchers. In hindsight, the continuity between the two stages could have been strengthened by involving stakeholders earlier in the review process to help prioritise issues for the Delphi. Nonetheless, the sequential design ensures that the Delphi addressed gaps identified in the review, maximising the usefulness of the process and the value of stakeholders' contribution.

Dissemination plans

We aim to disseminate our findings widely and to support their practical implementation. This includes integrating the principles into training resources for researchers and practitioners; engaging with research funders to encourage inclusion of these principles in

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grant requirements; working with universities and research governance bodies to embed them in ethics and approval processes; and liaising with journals to inform reviewer and editorial guidance. We will also share the principles with policy bodies and community organisations to ensure their relevance beyond academia and to promote their uptake in service development and evaluation.

Strengths of the study

Study strengths include its expert composition - researchers, clinicians, and patient, caregiver, and community representatives, notably from multiple minority ethnic populations. These representatives actively engaged throughout all Delphi rounds, addressing a key limitation of a previous framework development study where few participants identified as coming from a minority ethnic group[42]. We believe the relevance of the study to community and PPIE groups contributed to their responsiveness and collaboration. We also recognised the intersection of ethnicity with other social factors, for example, deprivation, and consequently ensured financial recognition for patient, caregiver, and community involvement at all stages.

Limitations of the study

This study has several limitations. First, this study used open-ended questions in round one, allowing participants to provide rich insights that informed subsequent rounds. However, using a Delphi survey for qualitative data raises concerns about bias, as validity depends on panel selection and question design[68]. Second, the definition of 'topic expert' is debated[36], and selection may affect study rigour. Like others[69, 70], we defined experts as 'informed individuals with subject-specific knowledge,' including researchers, clinicians, and

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patient/family representatives from minority ethnic backgrounds. Third, our Delphi panel was entirely UK-based, which may limit the transferability of findings to other national or cultural contexts. The principles should therefore be interpreted within a UK framework and validated in international settings before broader application. Fourth, patient and carer participation in round one was limited, which may have shaped the initial pool of statements that were generated and carried forward. This imbalance could have influenced the framing of early priorities in the Delphi process. To address this, recruitment strategies were adapted in round two to strengthen representation, and the contributions of patients and carers were considered equally in subsequent rounds and in the stakeholder workshop. Nevertheless, the relatively low number of patient/carer voices at the outset remains a limitation that may have influenced consensus outcomes. Despite targeted recruitment, White participants were over-represented across rounds (for example, 40% in round three), and minority ethnic representation was lower than anticipated. This imbalance may have influenced the nature of consensus achieved and limits the diversity of perspectives captured. While we sought to promote inclusivity throughout the study, the research team's ethnic composition and participant sample did not fully reflect the diversity of the populations we aimed to study, although seven members of the authorship team identify as being from minority ethnic backgrounds. This highlights the persistent challenges of achieving representational balance even within equity-focused research and reinforces the importance of the principles we advocate. Realising diversity in both research participation and team composition remains an ongoing process requiring sustained structural, institutional, and funding support.

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Fifth, the study relied on online participation and did not provide full translation of materials, which may have excluded some potential contributors. To mitigate these barriers, we conducted a PPIE review of the survey language and piloted rounds one and two for accessibility; however, these steps cannot fully overcome the structural challenges of ensuring equitable participation. Nevertheless, our approach represents an advance on recent efforts to foster equity, diversity, and inclusion in PPIE within palliative care research, where minority ethnic representation has often been limited[42, 71].

Last, we analysed panel members' views collectively and by group, identifying convergence and divergence. Consensus was reached on 78 out of 97 items, though some findings were more nuanced. While the Delphi-derived principles inform research, they do not address how guidance translates into improved palliative care policies for minority ethnic populations —an area for future exploration to enhance equity in end-of-life care.

Conclusion

There is continuing concern that palliative care is not equitably serving the interests of minority ethnic populations. However, research to resolve these inequities has been slow to advance, stymied by research approaches that have failed to question existing structural and systemic factors that govern how research questions have been conceived, the methods used, the composition of research teams, and how findings have been interpreted and reported, among other factors. To realise change, the principles derived from this Delphi exercise provide direction to inform decisions by those funding, undertaking, and publishing ethnicity-related studies in palliative and end-of-life care. This work also engages with debates in the USA[25, 58, 67, 72] and elsewhere[43, 73] regarding the application of palliative care-

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related research to better serve those from minority ethnic populations. There is scope to further develop these principles in collaboration with researchers, policymakers, practitioners, and community groups beyond the UK context, ensuring their global relevance and utility.

Authors' contributions

JK designed the study and, with support from EC, SB, JD, JH, GC, ZI, RK, ED, and FD obtained funding. HE-B and JK conducted the analyses. HE-B and JK drafted the manuscript. All authors (HE-B, JK, EC, SB, JD, JH, GC, ZI, RK, ED, FD) critically reviewed and revised the manuscript. All authors (HE-B, JK, EC, SB, JD, JH, GC, ZI, RK, ED, FD) have approved the final version and agree to be accountable for the work.

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Appendix A

Round 1 Open Ended Questions

Importance and purpose of research

Q1. "Ethnicity" can refer to the social and cultural characteristics of a group of people who share a similar culture and way of life. Examples of this might include country of origin, language, religion, clothing, food and drink, music, literature, and art. Understanding ethnicity can also include learning how different ethnic groups are described and located in a society.

Palliative care (defined by the World Health Organisation) is care that aims to improve the quality of life of people who are experiencing life-limiting illnesses, for example, cancer, dementia, heart failure, among other serious illnesses (and their families), and especially of those near the end of life. It helps to manage pain, discomfort, distress, and other concerns which may be physical, psychological, and spiritual.

What should be the **main purpose(s) of research** that focuses on ethnicity and palliative care? Please give reasons for your answer.

Q2. What do you think are the **main responsibilities of researchers** studying ethnicity and palliative care? For example, improve the end-of-life care for the populations being studied. Please give reasons for your answer.

Framing and focus of research

Q3. What kinds of **issues do you think are important** when palliative care research is focussed on people from minority ethnic communities? This could include participation of different groups.

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Q4. What **ideas or beliefs** do you think researchers should consider when conducting research in this field? For example, ethnicity may sometimes be associated with disadvantage or poor health. Please give reasons for your answer.

Q5. What do you think are the right **research approaches (ways of doing research)** when studying the relationship between ethnicity and palliative and end-of-life care? For example, surveys, interviews? Please give reasons for your answer.

Q6. What **ethical issues (right or wrong ways of doing things)** do you think might be present when studying ethnicity and palliative care? For example, ensuring confidentiality, managing distress. Please give reasons for your answer.

Members of the research team

Q7. Who do you think should be part of the **"research team"** when doing studies that focus on ethnicity and palliative and end-of-life care? Please give reasons for your answer.

Q8. How do you think research institutions (e.g., universities) can support **voluntary and community organisations** who represent minority ethnic communities when they **work together in research**? Please give reasons for your answer.

Q9. In what ways do you think we can **support the needs and preferences (e.g., knowledge, information, confidence, skills etc.)** of people from minority ethnic communities so they can be more involved in research? Please give reasons for your answer.

Collection of study data

Q10. In your own words, **what kind of information (or data) do you think is the most important to collect** when looking at the relationship between palliative care and people

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from minority ethnic communities? For example, demographic details, literacy, medical/health care needs, etc. Please give reasons for your answer.

Q11. Do you think there may be any **practical issues** when collecting data for research studies that look at the relationship between palliative care and people from minority ethnic communities? Please give reasons for your answer.

Analysis of study data

Q12. When analysing **data that might show us inequalities** related to ethnicity and palliative and end-of-life care, what **concerns** do you think researchers should think about? For example, housing circumstances, social needs, age etc. Please give reasons for your answer.

Reporting of research findings

Q13. When researchers are ready to **share their findings** from studies looking at the relationship between ethnicity and palliative care do you think there are any issues they should think about? For example, publishing articles in academic journals and speaking at conferences. Please give reasons for your answer.

Future directions and priorities for research

Q14. What do you think are the **main priorities and future directions** for research with minority ethnic communities when looking at palliative and end-of-life care issues? Please give reasons for your answer.

Any other comments or suggestions

Q15. Please use this space to make any **additional comments or suggestions** that you think are important, relating to minority ethnic communities and palliative and end-of-life care.

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For example, this could include your opinions on:

- important priorities for research,
- different ways of working,
- difficulties that stop research taking place,
- differences in care between different ethnic groups.

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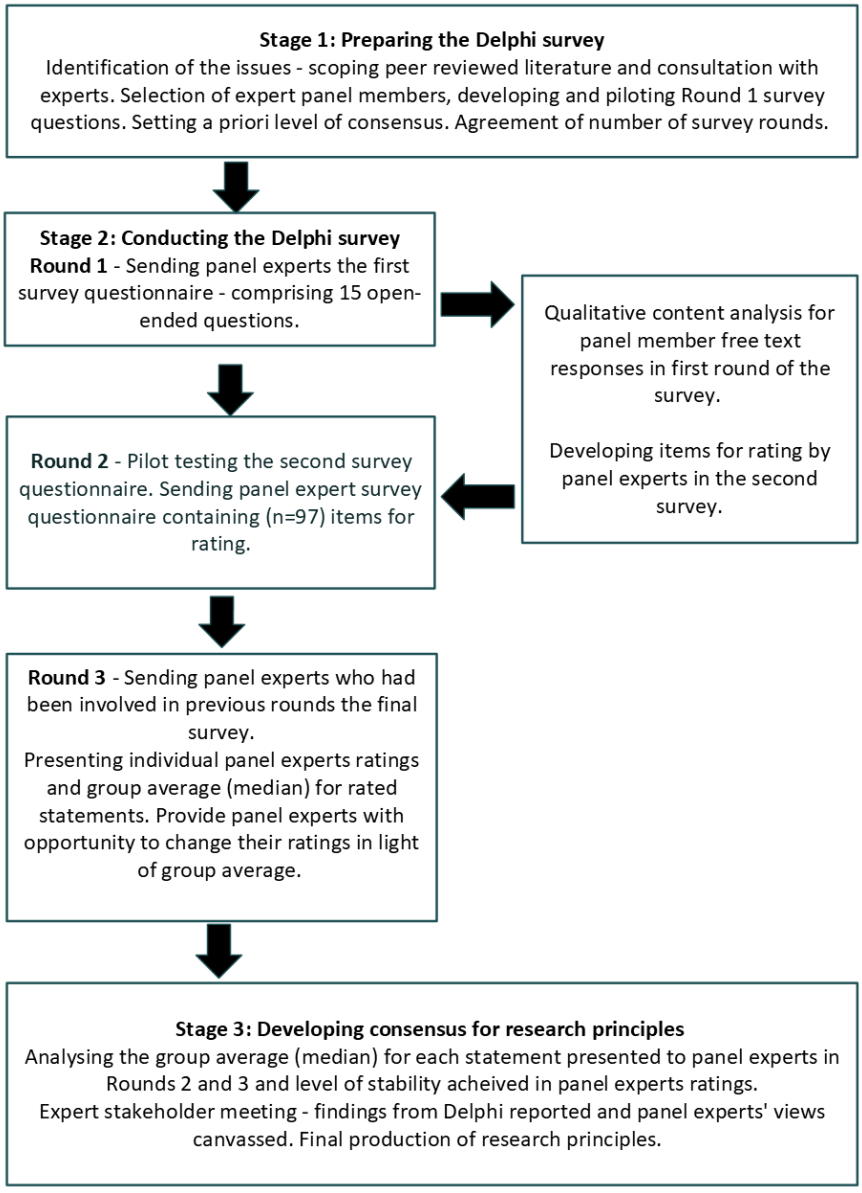


Figure 1: Delphi process flow diagram

161x221mm (144 x 144 DPI)

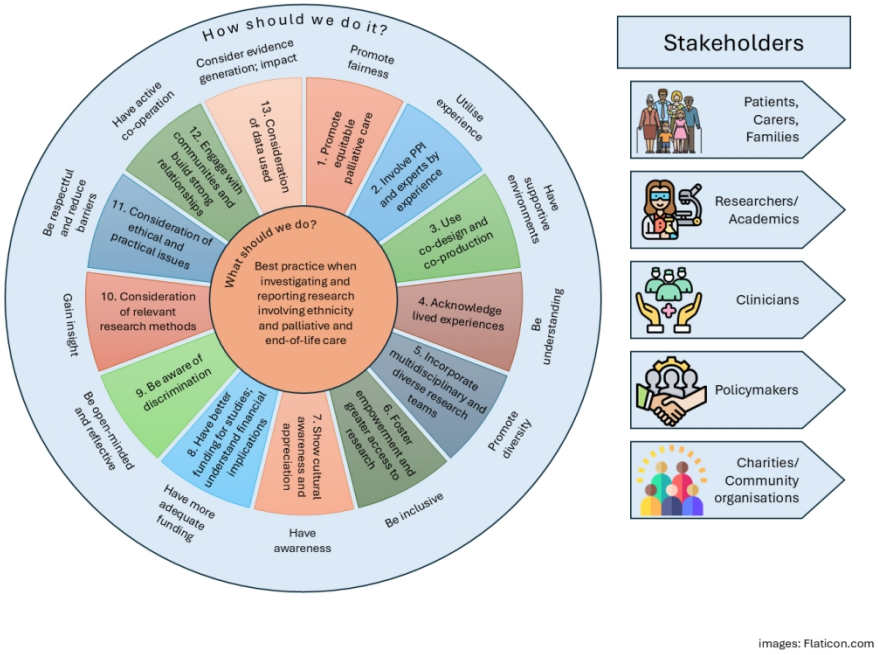


Figure 2: Delphi principles relevant to undertaking research with minority ethnic populations

400x300mm (96 x 96 DPI)

Supplementary File

Table 1 – Extended Participant Characteristics

Variable	Round 1, n (%)	Round 2, n (%)	Round 3, n (%)	Expert Workshop
Total Responses	45 (100)	43 (100)	45 (100)	17 (100)
Age				
Median (IQR)	45 (40-52)	52 (42-60)	51 (42-57.5)	55 (49.5-67)
Range (Min-Max)	47 (28-75)	53 (29-82)	60 (24-84)	53 (31-84)
Gender				
Female	39 (86.7)	34 (79.1)	34 (75.6)	12 (70.6)
Male	5 (11.1)	8 (18.6)	11 (24.4)	5 (29.4)
Prefer not to say	1 (2.2)	-	-	-
Non-binary	-	1 (2.3)	-	-
Self-assigned ethnic group				
Arab	1 (2.2)	-	-	-
African background	6 (13.3) Including (where specified): African - 1 (2.2) Kenya - 1 (2.2) Southern Africa - 1 (2.2) Zimbabwean - 1 (2.2)	4 (9.3) Including (where specified): Nigerian - 1 (2.3) Zimbabwean - 2 (4.6)	7 (15.6) Including (where specified): Black – 1 (2.2) Ghanaian – 1 (2.2) Kenyan – 1 (2.2) Nigerian – 2 (4.4) Zimbabwean – 1 (2.2)	-
Bangladeshi	1 (2.2)	1 (2.3)	-	-
Caribbean	-	2 (4.7)	2 (4.4)	2 (11.8)
Chinese	1 (2.2)	1 (2.3)	1 (2.2)	1 (5.9)
English, Welsh, Scottish, Northern Irish or British	27 (60.0)	20 (46.5)	18 (40.0)	7 (41.2)
Irish	-	1 (2.3)	-	-
Indian	3 (6.7)	4 (9.3)	6 (13.3)	2 (11.8)
Pakistani	2 (4.4)	3 (7.0)	3 (6.7)	2 (11.8)
Any other Asian background	-	-	1 (2.2) Including (where specified): Nepalese – 1 (2.2)	1 (5.9) Including (where specified): Nepalese – 1 (5.9)
Any other Black, Black British, Black Welsh,	-	1 (2.3) Including (where specified):	-	-

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Black Scottish or Caribbean background		Black British African - 1 (2.3)		
Any other White background	3 (6.7) Including (where specified): Ashkenazi Jewish - 1 (2.2) Mixed - 2 (4.4)	3 (7.0) Including (where specified): Ashkenazi Jewish - 1 (2.3) Italian - 1 (2.3) Parents were USA citizens - 1 (2.3)	7 (15.6) Including (where specified): Ashkenazi Jewish – 1 (2.2) Born Switzerland, US Parentage – 1 (2.2) From USA, mixed white ethnic background – 1 (2.2) Italian – 1 (2.2) Part Jewish – 1 (2.2) South African – 1 (2.2) Turkish Cypriot – 1 (2.2)	2 (11.8) Including (where specified): Born in Switzerland – 1 (5.9) Italian – 1 (5.9)
Any other Mixed or multiple ethnic backgrounds	-	2 (4.7) Including (where specified): Latino and White - 1 (2.3) Nepalese - 1 (2.3)	-	-
Any other ethnic group	1 (2.2) Including (where specified): Turkish Cypriot - 1 (2.2)	1 (2.3) Including (where specified): Turkish Cypriot - 1 (2.3)	-	-
Role				
Clinician	13 (28.9) Including (where specified): Nurses (Dementia, Cancer, Palliative Care) – 4 (8.8) Clinical Academic Pharmacist – 1 (2.2) Consultants (Palliative Care/Medicine) – 5 (11.0) Geriatric Medicine – 1 (2.2) GP – 1 (2.2)	11 (25.6) Including (where specified): Nurses (Dementia, Cancer, Palliative) – 4 (9.2) Consultants (Palliative Care/Medicine) – 4 (9.2) Doctor, previously a GP – 1 (2.3) Project Officer – 1 (2.3)	7 (15.6) Including (where specified): Admiral Nurse (Dementia) - 1 (2.2) Consultant and Medical Director – 1 (2.2) Consultant in Palliative Medicine/Care – 3 (6.6) Lead Research Nurse, Cancer – 1 (2.2) Post F1 – 1 (2.2)	3 (17.6) Including (where specified): Cancer research nurse – 1 (5.9) Palliative Medicine Consultant – 1 (5.9)
Researcher/Academic	39 (86.7) Including (where specified): Cancer – 1 (2.2) Clinical Academic	20 (46.5) Including (where specified): Academic/Research – 2 (4.6) Applied Health – 1 (2.3)	22 (48.9) Including (where specified): Associate Professor Palliative Medicine – 1 (2.2)	3 (17.6) Including (where specified): Professor of Palliative Medicine – 1 (5.9)

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	Pharmacist – 1 (2.2) Community Engagement Officer – 1 (2.2) Dementia Care and Support – 3 (6.6) Ethnic Inequalities – 2 (4.4) Evidence Synthesis – 1 (2.2) Health Equity Informatics – 1 (2.2) Healthcare – 1 (2.2) Health Services Research – 1 (2.2) Hospice – 1 (2.2) Complex Health Needs – 1 (2.2) Nursing – 2 (4.4) Palliative Care, End-of-Life, Bereavement – 14 (31.0) Patient and Public Involvement – 1 (2.2) Postgraduate Student – 1 (2.2) Public Health – 1 (2.2) Social Science – 2 (4.4) Third Sector Research Lead – 1 (2.2)	Cancer Inequalities – 1 (2.3) Dementia – 1 (2.3) Evidence Synthesis – 1 (2.3) Healthcare – 1 (2.3) Healthcare Improvement Studies – 1 (2.3) Palliative Care/Medicine – 9 (20.9) Postgraduate Student – 1 (2.3) Public and Patient Involvement – 1 (2.3)	Cancer Inequalities – 1 (2.2) Epidemiology, healthcare, end-of-life care – 1 (2.2) Ethnic Inequalities in Health – 1 (2.2) Evidence Synthesis – 1 (2.2) Health and Social Care – 1 (2.2) Methodology – 1 (2.2) Palliative Care/End-of-Life/Bereavement – 6 (13.3) Professor in Palliative Care – 1 (2.2) Research Lead, Hospice/Palliative Care - 1 (2.2) Professor in Dementia Care – 1 (2.2) Social Science – 1 (2.2) Social Scientist of Health – 1 (2.2)	Palliative Care – 1 (5.9) Patient and public involvement – 1 (5.9)
Patient, caregiver, or representative from a community or faith-based organisation	2 (4.4) **Ethnicity breakdown; n=2 (100):** African background – 1 (50.0) English, Welsh, Scottish, Northern Irish or British – 1 (50.0)	20 (46.5) Including (where specified): Carer – 3 (7.0) Community Organisation – 1 (2.3) Dementia – 1 (2.3) Multiple – 1 (2.3) Patient and carer – 1 (2.3) Patient representative – 1 (2.3) University representative – 1 (2.3) **Ethnicity breakdown; n=20 (100):** African background – 1 (5.0)	18 (40.0) Including (where specified): Carer – 2 (4.4) Dementia – 1 (2.2) Ex-carer, End-of-Life Doula – 1 (2.2) Patient and caregiver – 1 (2.2) PPI Member/Coordinator – 3 (6.6) Representative from a community – 1 (2.2) Service user researcher – 1 (2.2)	12 (70.6)

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		Bangladeshi – 1 (5.0) Caribbean - 2 (10.0) English, Welsh, Scottish, Northern Irish or British - 6 (30.0) Indian – 3 (15.0) Pakistani – 2 (10.0) Any other Black, Black British, Black Welsh, Black Scottish or Caribbean background – 1 (5.0) Any other Mixed or multiple ethnic backgrounds – 2 (10.0) Any other white background – 2 (10.0)	**Ethnicity breakdown; n=18 (100):** African background – 2 (11.1) Caribbean – 2 (11.1) English, Welsh, Scottish, Northern Irish or British – 6 (33.3) Indian – 3 (16.7) Pakistani – 2 (11.1) Any other Asian background – 1 (5.6) Any other white background – 2 (11.1)	
Number of individuals self-reporting as Clinicians *and* Academics	9 (20.0)	7 (16.3)	2 (4.4)	1 (5.9)
Number of individuals self-reporting as Clinicians, Academics, *and* Patient representatives	-	1 (2.3)	-	-

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Table 2 - Statements included in Rounds 2 and 3

Statement	Round 2 Number (%) rating statement very/extremely important	Round 2 Median (IQR) on Likert Scale	Round 2 Consensus reached	Round 3 Number (%) rating statement very/extremely important	Round 3 Median (IQR) on Likert Scale	Round 3 Consensus reached
Q1. Research that focuses on ethnicity and palliative care should consider the following:						
1.1. The lived experience and palliative care needs of different minority ethnic groups.	34 (79.1)	3 (3-3)	Y	39 (86.7)	3 (3-3)	Y
1.2. An equity-driven approach to assessing need and delivering palliative care (and improving quality of life) to promote fairness for all.	37 (86.0)	3 (3-3)	Y	41 (91.1)	3 (3-3)	Y
1.3. Improving cultural competency across the whole palliative care treatment and support experience.	37 (86.0)	3 (3-3)	Y	40 (88.9)	3 (3-3)	Y
1.4. Promoting diversity among the research team including Patient and Public Involvement (PPI) members.	38 (88.4)	3 (3-3)	Y	35 (77.8)	3 (3-3)	Y
1.5. Identifying, monitoring, and understanding the reasons for differences between different ethnic groups.	32 (74.4)	3 (2-3)	N			
1.6. Understanding issues of accessibility of services.	38 (88.4)	3 (3-3)	Y	40 (88.9)	3 (3-3)	Y
1.7. Identifying consequences of socio-economic discrimination.	40 (93.0)	3 (3-3)	Y	39 (86.7)	3 (3-3)	Y
Q2. The main responsibilities of researchers studying ethnicity and palliative care include:						
2.1. Individuals from minority ethnic groups should be involved in the research design (through co-design, co-production, community engagement, or other participatory methods), giving a voice to those involved by meaningful engagement and appropriate dissemination (via academic, community, and public channels).	38 (88.4)	3 (3-3)	Y	43 (95.6)	3 (3-3)	Y
2.2. To improve equitable end-of-life care.	39 (90.7)	3 (3-3)	Y	39 (86.7)	3 (3-3)	Y
2.3. To reflect and monitor the ethnic diversity in research teams, allowing a greater understanding of cultural sensitivity.	31 (72.1)	3 (2-3)	N			
2.4. There should be an emphasis on evidence generation leading to practice, policy, and academic impact.	41 (95.3)	3 (3-3)	Y	43 (95.6)	3 (3-3)	Y
Q3. Palliative care research that focuses on people from minority ethnic communities should consider the following:						
3.1. To be aware of and understand discriminatory practices.	38 (88.4)	3 (3-3)	Y	39 (86.7)	3 (3-3)	Y

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3.2. To include and empower those from minority ethnic communities as participants, PPI members, lay researchers, or other members of the research team.	40 (93.0)	3 (3-3)	Y	43 (95.6)	3 (3-3)	Y
3.3. To increase and promote the accessibility and understanding of palliative care research through appropriate study materials (e.g. in different languages, culturally appropriate environment).	38 (88.4)	3 (3-3)	Y	41 (91.1)	3 (3-3)	Y
3.4. To understand palliative care experiences and priorities of minority ethnic communities and the intersection of ethnicity with other social factors like socioeconomic deprivation, gender, disability, employment, and education.	39 (90.7)	3 (3-3)	Y	39 (86.7)	3 (3-3)	Y
3.5. Diversifying palliative care research (from the majority population to include those from diverse backgrounds) to understand and promote change.	38 (88.4)	3 (3-3)	Y	37 (82.2)	3 (3-3)	Y
3.6. Promote the inclusion and involvement of communities with different cultures and languages.	38 (88.4)	3 (3-3)	Y	39 (86.7)	3 (3-3)	Y
Q4. Researchers working in the field of palliative care and ethnicity should consider ideas and beliefs related to the following:						
4.1. Those undertaking research should have a greater understanding of ethnicity and different cultures.	34 (79.1)	3 (3-3)	Y	36 (80.0)	4 (3-3)	Y
4.2. Researchers should be open-minded, not make assumptions/generalisations, be aware of conscious and unconscious bias, discrimination, prejudice, and be reflective/reflexive.	41 (95.3)	3 (3-3)	Y	43 (95.6)	3 (3-3)	Y
4.3. There should be better inclusivity of access to research for all, particularly those underserved/marginalised, considering different methods and barriers to recruitment.	38 (88.4)	3 (3-3)	Y	41 (91.1)	3 (3-3)	Y
4.4. There should be a greater understanding of palliative care and the impact of other variables, for example age, gender, and deprivation.	37 (86.0)	3 (3-3)	Y	38 (84.4)	3 (3-3)	Y
4.5. There should be greater ethnic diversity in research teams, including PPI members and lay researchers, where co-design and participatory research should be considered to increase participation.	36 (83.7)	3 (3-3)	Y	38 (84.4)	3 (3-3)	Y
Q5. When studying the relationship between ethnicity and palliative and end-of-life care, the right research approaches should consider the following:						
5.1. Study designs that increase understanding of differences.	32 (74.4)	3 (2-3)	N			

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5.2. Routine data collection to identify and monitor differences in the population.	30 (69.8)	3 (2-3)	N			
5.3. Mixed methods approaches using a combination of quantitative and qualitative methods, involving ethnic diversity in research teams (researchers, participants, and PPI members).	35 (81.4)	3 (3-3)	Y	36 (80.0)	3 (3-3)	Y
5.4. In-depth qualitative (e.g. participatory research, interviews, focus groups, ethnography) approaches that provide detailed insights into the lived experiences of those from minority ethnic communities.	36 (83.7)	3 (3-3)	Y	40 (88.9)	3 (3-3)	Y
5.5. Acknowledgement of the 'world view' of the researcher in studies.	30 (69.8)	3 (2-3)	N			
5.6. Use of creative methods (e.g. photo voice, photo journalling, arts-based activities) that increase engagement and trust.	31 (72.1)	3 (2-3)	N			
5.7. PPI and co-production in research and adequate remuneration and environment for those involved are important.	40 (93.0)	3 (3-3)	Y	41 (91.1)	3 (3-3)	Y
Q6. There may be ethical issues present when studying ethnicity and palliative care, such as the following:						
6.1. Participants may feel pressurised to participate in a study. Therefore, informed consent is vital.	39 (90.7)	3 (3-3)	Y	40 (88.9)	3 (3-3)	Y
6.2. There needs to be transparency regarding the use of data and understanding of how it will be reported, as well as what the anticipated impact will be for services and service users.	40 (93.0)	3 (3-3)	Y	39 (86.7)	3 (3-3)	Y
6.3. Ethical issues such as psychological factors (distress, fear, anxiety), respect, trust, and confidentiality are important and need to be considered and managed as these may influence study participation experiences.	41 (95.3)	3 (3-3)	Y	37 (82.2)	3 (3-3)	Y
6.4. There needs to be greater awareness of cultural and family differences, allowing the development of respectful relationships with members of the community/participants.	39 (90.7)	3 (3-3)	Y	42 (93.3)	3 (3-3)	Y
6.5. Background and personal view of the researcher must be considered.	28 (65.1)	3 (2-3)	N			
6.6. Whilst ethical issues are the same across all research they may be understood differently by some minority ethnic groups.	31 (72.1)	3 (2-3)	N			
Q7. Research teams conducting studies that focus on ethnicity and palliative and end-of-life care should include the following:						

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7.1. Individuals with lived experience from the populations/communities being studied.	35 (81.4)	3 (3-3)	Y	38 (84.4)	3 (3-3)	Y
7.2. Teams should strive to be ethnically diverse (as appropriate for the research and intended participants).	31 (72.1)	3 (2-3)	N			
7.3. Teams should be multidisciplinary, including those with expertise in topic, design, knowledge, and understanding, and from a range of clinicians, academics, service leads, policymakers, and those with lived experience.	37 (86.0)	3 (3-3)	Y	40 (88.9)	3 (3-3)	Y
7.4. PPI representatives and co-production must be integral to the team, and funding bodies should provide sufficient resources (time, money, and tools) to adequately compensate them.	39 (90.7)	3 (3-3)	Y	42 (93.3)	3 (3-3)	Y
7.5. There must be appropriate accessibility and practical support as standard (e.g. translators, interpreters, minimisation of digital exclusion).	39 (90.7)	3 (3-3)	Y	42 (93.3)	3 (3-3)	Y
Q8. Research institutions (e.g. universities) can support voluntary and community organisations who work with minority ethnic communities when they work together in research in the following ways:						
8.1. Listen to community organisations and take their concerns seriously.	36 (83.7)	3 (3-3)	Y	40 (88.9)	3 (3-3)	Y
8.2. Build trusting relationships/partnerships with members of minority ethnic communities.	38 (88.4)	3 (3-3)	Y	41 (91.1)	3 (3-3)	Y
8.3. There should be appropriate reimbursement and funding for time provided to permit research to take place.	38 (88.4)	3 (3-3)	Y	42 (93.3)	3 (3-3)	Y
8.4. There should be training opportunities and mentoring schemes developed between universities and community organisations to help develop co-researching and co-working arrangements, where training and capacity building can be incorporated into the research itself.	35 (81.4)	3 (3-3)	Y	38 (84.4)	3 (3-3)	Y
8.5. There should be flexibility and transparency in activities.	35 (81.4)	3 (3-3)	Y	42 (93.3)	3 (3-3)	Y
8.6. There should be an appreciation of different ways of working.	33 (76.7)	3 (3-3)	Y	38 (84.4)	3 (3-3)	Y
Q9. We can support the needs and preferences (knowledge, information, confidence, skills, etc) of people from minority ethnic communities to be more involved in research in the following ways:						
9.1. Building relationships and engaging in community involvement initiatives (e.g. health promotion days) and outreach (e.g. co-production/co-research).	35 (81.4)	3 (3-3)	Y	35 (77.8)	3 (3-3)	Y

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9.2. Increase the relevance and appropriateness of research to those with lived experience and impact.	34 (79.1)	3 (3-3)	Y	42 (93.3)	3 (3-3)	Y
9.3. There should be self-reflection amongst researchers on how they conduct research studies.	34 (79.1)	3 (3-3)	Y	40 (88.9)	3 (3-3)	Y
9.4. Increase training, mentorship, and research ambassadors for members of the communities.	32 (74.4)	3 (2-3)	N			
9.5. Consider barriers to recruitment, including reimbursement/funding, and practical solutions to involvement (e.g. financial backfill for participants with caring responsibilities, accessibility, locations used, and childcare facilities).	39 (90.7)	3 (3-3)	Y	42 (93.3)	3 (3-3)	Y
9.6. Incorporating patient and public involvement.	39 (90.7)	3 (3-3)	Y	43 (95.6)	3 (3-3)	Y
9.7. Attempt to include researchers with similar ethnicities as those being researched.	30 (69.8)	3 (2-3)	N			
Q10. When looking at the relationship between palliative care and people from minority ethnic communities, the following kind of information (data) is most important to collect:						
10.1. Self-described or identified ethnicity (consider disaggregated data).	33 (76.7)	3 (3-3)	Y	38 (84.4)	3 (3-3)	Y
10.2. Health literacy (Skills, knowledge, understanding and ability to use healthcare information and services).	30 (69.8)	3 (2-3)	N			
10.3. Language/literacy.	33 (76.7)	3 (3-3)	Y	40 (88.9)	3 (3-3)	Y
10.4. All demographic details, socioeconomic position, and information regarding protected characteristics.	33 (76.7)	3 (3-3)	Y	36 (80.0)	3 (3-3)	Y
10.5. The extent of integration with the majority population, family support/social networks, community involvement, generation (e.g. 1st/2nd/3rd), and social networks.	28 (65.1)	3 (2-3)	N			
10.6. Religious/cultural belief systems, health beliefs/health seeking behaviour/views on culture and religion/beliefs about death and dying.	33 (76.7)	3 (3-3)	Y	40 (88.9)	3 (3-3)	Y
10.7. Own/family experience of palliative care, views on UK palliative care system, health care needs and preferences.	31 (72.1)	3 (2-3)	N			
10.8. Data that helps address intersectionality.	34 (79.1)	3 (3-3)	Y	40 (88.9)	3 (3-3)	Y
10.9. Rationale or justification for data collected or analysed.	31 (72.1)	3 (2-3)	N			
Q11. When collecting data for research studies that look at the relationship between palliative care and people from minority ethnic communities, there may be some practical issues to consider, such as the following:						

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11.1. Language and provision of translation and interpreter services.	37 (86.0)	3 (3-3)	Y	40 (88.9)	3 (3-3)	Y
11.2. Use of terminology, cultural sensitivity/awareness, and addressing cultural needs appropriately.	38 (88.4)	3 (3-3)	Y	41 (91.1)	3 (3-3)	Y
11.3. Awareness of family involvement and confidentiality/dynamics within families.	34 (79.1)	3 (3-3)	Y	41 (91.1)	3 (3-3)	Y
11.4. Time commitment to research when other roles are present.	33 (76.7)	3 (3-3)	Y	36 (80.0)	3 (3-3)	Y
11.5. Differing views about death and dying.	35 (81.4)	3 (3-3)	Y	40 (88.9)	3 (3-3)	Y
11.6. Awareness of trust/power and building appropriate relationships within communities.	36 (83.7)	3 (3-3)	Y	40 (88.9)	3 (3-3)	Y
11.7. Mistrust of the research process and questions asked.	34 (79.1)	3 (3-3)	Y	41 (91.1)	3 (3-3)	Y
11.8. Understanding the correct use of the most appropriate data and its generalisability/transferability (not stigmatising/misinterpreting).	32 (74.4)	3 (2-3)	N			
Q12. When analysing data that might show us inequalities related to ethnicity and palliative and end-of-life care, there may be some concerns that need considering, such as the following:						
12.1. Financial concerns or financial exclusion.	32 (74.4)	3 (2-3)	N			
12.2. Extent of social support including its absence.	33 (76.7)	3 (3-3)	Y	38 (84.4)	3 (3-3)	Y
12.3. Demographics, use/quality of data, being respectful of data and terminology when reporting findings.	32 (74.4)	3 (2-3)	N			
12.4. Information regarding citizenship, immigration, and migration status.	31 (72.1)	3 (2-3)	N			
12.5. Inequity and inequality of services, consideration of intersectionality, and impact of experiences and outcomes of care.	33 (76.7)	3 (3-3)	Y	41 (91.1)	3 (3-3)	Y
12.6. Presence of bias including conscious and unconscious bias, systemic or structural bias.	36 (83.7)	3 (3-3)	Y	41 (91.1)	3 (3-3)	Y
12.7. Health, disability, lived and cultural experiences, interpretation/translation.	34 (79.1)	3 (3-3)	Y	38 (84.4)	3 (3-3)	Y
12.8. Being open to limitations of data collected, analysed and reported.	35 (81.4)	3 (3-3)	Y	38 (84.4)	3 (3-3)	Y
Q13. When researchers are ready to share their findings from studies looking at the relationship between ethnicity and palliative care, there may be several issues to consider, such as the following:						
13.1. Focus on inequalities and intersectionality.	33 (76.7)	3 (3-3)	Y	37 (82.2)	3 (3-3)	Y

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13.2. Understand reasons why different minority ethnic groups encounter different experiences and outcomes of care.	35 (81.4)	3 (3-3)	Y	40 (88.9)	3 (3-3)	Y
13.3. Provide clarity of definitions and terminology used in research.	35 (81.4)	3 (3-3)	Y	40 (88.9)	3 (3-3)	Y
13.4. Inclusive dissemination strategies also comprising expert stakeholders from minority ethnic communities and PPI.	39 (90.7)	3 (3-3)	Y	40 (88.9)	3 (3-3)	Y
13.5. Reporting findings in a culturally sensitive, accessible, and respectful manner.	37 (86.0)	3 (3-3)	Y	41 (91.1)	3 (3-3)	Y
13.6. Being mindful not to make minority ethnic groups appear exotic.	36 (83.7)	3 (3-3)	Y	42 (93.3)	3 (3-3)	Y
13.7. Co-authorship with non-academic community-based or PPI partners.	34 (79.1)	3 (3-3)	Y	35 (77.8)	3 (3-3)	Y
13.8. Dissemination of findings outside normal academic channels, e.g. community groups newsletters/social media, animation, and illustration.	40 (93.0)	3 (3-3)	Y	40 (88.9)	3 (3-3)	Y
13.9. Accountability of research including being critically reflective.	35 (81.4)	3 (3-3)	Y	39 (86.7)	3 (3-3)	Y
13.10. When reporting or interpreting findings avoid stereotyping.	37 (86.0)	3 (3-3)	Y	41 (91.1)	3 (3-3)	Y
13.11. Translation of research into feasible recommendations owned by the community researched.	37 (86.0)	3 (3-3)	Y	41 (91.1)	3 (3-3)	Y
Q14. The main priorities and future directions for research with minority ethnic communities when looking at palliative and end-of-life care issues can include the following:						
14.1. Increase engagement with communities, including better access to services, understanding of intersectionality and addressing inequalities.	36 (83.7)	3 (3-3)	Y	42 (93.3)	3 (3-3)	Y
14.2. A better understanding of concerns, preferences, and needs of communities, appreciation of their culture/faith concerning death/dying, and understanding of lived experience.	37 (86.0)	3 (3-3)	Y	40 (88.9)	3 (3-3)	Y
14.3. Provide more, well-funded research, with greater accountability of policymakers.	36 (83.7)	3 (3-3)	Y	36 (80.0)	3 (3-3)	Y
14.4. Co-design/co-production/collaboration with dissemination to all, from multi-disciplinary, and diverse teams.	36 (83.7)	3 (3-3)	Y	39 (86.7)	3 (3-3)	Y
14.5. Development and provision of effective culturally competent palliative and end-of-life care and person-centred care.	36 (83.7)	3 (3-3)	Y	41 (91.1)	3 (3-3)	Y

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14.6. Understanding training and support needs in the workforce when caring for members of minority ethnic communities.	36 (83.7)	3 (3-3)	Y	42 (93.3)	3 (3-3)	Y
14.7. Ethics committees should be challenged on issues which prevent research from taking place.	33 (76.7)	3 (3-3)	Y	41 (91.1)	3 (3-3)	Y
14.8. There should be more adequate and longer funding for this research, and a commitment to funding in this area.	37 (86.0)	3 (3-3)	Y	42 (93.3)	3 (3-3)	Y

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PALLIATIVE MEDICINE AUTHOR SUBMISSION CHECKLIST

Please complete this checklist for all papers submitted. Please indicate, very briefly, how this has been addressed. This checklist is a mandatory upload on submission.

Item	Explanation	How this has been addressed (briefly, a sentence will suffice)
Article title	***WHY: Because we want readers to find your work.*** Have you followed our guidelines on writing a good title that will be found by search engines? (E.g. with methods in the title, use of common words for the issue addressed, no country names, and possibly indicating findings). If your study has an acronym is it included in the title?	Principles for developing, undertaking, and reporting research with minority ethnic populations in palliative and end of life care: a modified Delphi study
Abstract	***WHY: Because structured abstracts have more detail for readers and search engines.*** Have you followed our guidelines on writing your structured abstract? Please remember we have separate abstract structures for original research, different types of reviews and case reports/series. There should be **no** abbreviations in the abstract, EXCEPT a study acronym which should be included if you have one. If a trial (or other design formally registered with a database) have you included your registration details?	We have included a structured abstract which does not include any abbreviations.
Key statements	***WHY: Because readers want to understand your paper quickly.*** Have you included our key statements within the body of your paper (after abstract and before the main text is a good place!) and followed our guidelines for how these are to be written? There are three main headings required, and each may have 1-3 separate **bullet** points. Please use clear, succinct, single sentence separate bullet points rather than complex or multiple sentences.	We have incorporated key statements within the body of the paper after the abstract and followed appropriate guidelines.
Keywords	***WHY: Because MeSH headings mean it is properly indexed.*** Have you given keywords for your study? We ask that these are current **MeSH** headings unless there is no suitable heading for use (please give explanation in cover letter). https://meshb.nlm.nih.gov/search	We have considered and included appropriate keywords relevant to our study.

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International relevance	***WHY: We have readers from around the world who are interested in your work.*** Have you contextualised your work for an international audience and explained how your work contributes to an international knowledge base? Avoid drawing from policy from one context only, think how your work could be relevant more widely. Do define terms clearly e.g. hospice has a different meaning in many countries.	Evidence, both national and international, has highlighted deficiencies in research focused on minority ethnic populations. Our focus is on developing research principles when undertaking studies in this field of inquiry, leading to better science that will lead to patient benefit for all.
Publishing guidelines	***WHY: Because clear and robust reporting helps people interpret your work accurately*** Have you submitted a completed checklist for a relevant publishing guideline as a supplementary file? http://www.equator-network.org/ These include CONSORT, PRISMA, COREQ checklists, but others may be more relevant for your type of manuscript. If no published checklist exists please create one as a table from the list of requirements in your chosen guideline. If your study design does not have a relevant publishing guideline please review closest matches and use the most appropriate with an explanation.	
Word count	***WHY: Because readers want to find the core information quickly.*** Does your paper adhere to our word count for your article type? Please insert number of words in the box to the right. Remember that tables, figures, qualitative data extracts and references are not included in the word count.	3,152
Figures and tables and/or quotations	***WHY: Because readers want to find the core information quickly.*** Have you adhered to our guidelines on the number of tables and figures for your article type? Data (e.g. quotations) for qualitative studies are not included in the word count, and we prefer that they are integrated into the text (e.g. not in a separate table).	We have adhered to the permitted number of tables and figures for our article
Study registration	***WHY: Because this means readers understand how you planned your study*** Where appropriate have you included details (including reference number, date of registration and URL) of study registration on a database e.g. trials or review database. If your study has a published protocol, is this referenced within the paper?	N/A

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Other study publications?	***WHY: So readers can understand the full context of your study*** If there are other publications from this study are these referenced within the body of the paper? Please do not reference papers in preparation or submitted, but in-press publications are acceptable.	N/A
Scales, measures or questionnaires	***WHY: So readers can understand your paper in the context of this information*** If your study primarily reports the development or testing of scales/measures or questionnaires have you included a copy of the instrument as a supplementary file?	N/A
Abbreviations	***WHY: Because abbreviations make a paper hard to read, and are easily misunderstood*** Have you removed **all** abbreviations from the text except for extremely well known, standard abbreviations (e.g. SI units), which should be spelt out in full first? We do not allow abbreviations for core concepts such as palliative or end of life care.	We have not included abbreviations.
Research ethics and governance approvals for research involving human subjects	***WHY: We will only publish ethically conducted research, approved by relevant bodies*** Have you given full details of ethics/governance/data protection approvals with reference numbers, full name of the committee(s) giving approval and the date of approval? If such approvals are not required have you made it explicit within the paper why they were not required. Are details of consent procedures clear in the paper?	We have supplied full details of research ethics relevant to this study accompanied by a reference number and the full name of the research Ethics Committee including the date of approval.
Date(s) of data collection	***WHY: So readers understand the context within which data were collected*** Have you given the dates of data collection for your study within the body of your text? If your data are over 5 years old you will need to articulate clearly why they are still relevant and important to current practice.	We have included the dates of data collection within the main text of the manuscript.
Structured discussion	***WHY: So readers can find key information quickly*** Papers should have a structured discussion, with sub headings, summarising the main findings, addressing strengths and limitations, articulating what this study adds with reference to existing international literature, and presenting the implications for practice.	We have incorporated a structured discussion, including subheadings with reference to existing international literature. We have also presented the implications for practice and future research

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Case reports & Case Series Practice Reviews	***WHY: So that participants are protected, and its importance made clear*** If your study is a case report, series or practice review have you followed our clear structure and detailed author instructions, including highlighting what research is needed to address the issue raised? Have you made clear what consent was required or given for the publication of the case report? Have you provided evidence of such consent as a supplementary file to the editor? Is your practice review formatted with the requisite 'Do's, Don'ts and Don't knows'?	N/A
Acknowledgements and declarations	***WHY: So readers understand the context of the research*** Have you included a funding declaration according to the SAGE format? Are there acknowledgements to be made? Have you stated where data from the study are deposited and how they may be available to others? Have you conflicts of interest to declare?	We have included a funding declaration according to the SAGE format. We have no conflicts of interest to declare.
Supplementary data and materials	***WHY: So the context is clear, but the main paper succinct for the reader*** Is there any content which could be provided as supplementary data which would appear only in the online version of accepted papers? This could include large tables, full search strategies for reviews, additional data etc.	N/A
References	***WHY: So people can easily find work you have referenced*** Are your references provided in SAGE Vancouver style? You can download this style within Endnote and other referencing software.	The references that we have included in the manuscript add here to the sSage Vancouver style.
Ownership of work.	Can you assert that you are submitting your original work, that you have the rights in the work, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you.	We do have rights and ownership to our work and it is not being considered for publication elsewhere, nor has it been published elsewhere previously.

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CREDES Checklist:

Guidance on Conducting and Reporting Delphi Studies (CREDES) Checklist [1]	
Rationale for Delphi Technique	
Justification. The choice of the Delphi technique as a method of systematically collating expert consultation and building consensus needs to be well justified.	Page 6
Planning and Design	
Planning and process. The Delphi technique is a flexible method and can be adjusted to the respective research aims and purposes. Any modifications should be justified by a rationale and be applied systematically and rigorously	Page 8
Definition of consensus. Unless not reasonable due to the explorative nature of the study, an a priori criterion for consensus should be defined. This includes a clear and transparent guide for action on (a) how to proceed with certain items or topics in the next survey round, (b) the required threshold to terminate the Delphi process and (c) procedures to be followed when consensus is (not) reached after one or more iterations	Pages 8
Study Conduct	
Informational input. All material provided to the expert panel at the outset of the project and throughout the Delphi process should be carefully reviewed and piloted in advance in order to examine the effect on experts' judgements and to prevent bias	Page 9
Prevention of bias. Researchers need to take measures to avoid directly or indirectly influencing the experts' judgements. If one or more members of the research team have a conflict of interest, entrusting an independent researcher with the main coordination of the Delphi study is advisable	Page 10-13
Interpretation and processing of results. Consensus does not necessarily imply the 'correct' answer or judgement; (non)consensus and stable disagreement provide informative insights and highlight differences in perspectives concerning the topic in question	Page 11-13
External validation. It is recommended to have the final draft of the resulting guidance reviewed and approved by an external board or authority before publication and dissemination	Done
Reporting	
Purpose and rationale. The purpose of the study should be clearly defined and demonstrate the appropriateness of the use of the Delphi technique as a method to achieve the research aim. A rationale for the choice of the Delphi technique as the most suitable method needs to be provided	Page 6
Expert panel. Criteria for the selection of experts and transparent information on recruitment of the expert panel	Page 7
Description of the methods. The methods employed need to be comprehensible; this includes information on preparatory steps, piloting of material and survey instruments, design of the survey instrument(s), the number and design of survey rounds, methods of data analysis, processing and synthesis of experts' responses to	Pages 7-9

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inform the subsequent survey round and methodological decisions taken by the research team throughout the process	
Procedure. Flow chart to illustrate the stages of the Delphi process, including a preparatory phase, the actual 'Delphi rounds', interim steps of data processing and analysis, and concluding steps	Page 9
Definition and attainment of consensus. It needs to be comprehensible to the reader how consensus was achieved throughout the process, including strategies to deal with non-consensus	Page 8
Results. Reporting of results for each round separately is highly advisable in order to make the evolving of consensus over the rounds transparent. This includes figures showing the average group response, changes between rounds, as well as any modifications of the survey instrument such as deletion, addition or modification of survey items based on previous rounds	Page 14-25
Discussion of limitations. Reporting should include a critical reflection of potential limitations and their impact of the resulting guidance	Page 36
Adequacy of conclusions. The conclusions should adequately reflect the outcomes of the Delphi study with a view to the scope and applicability of the resulting practice guidance	Page 37
Publication and dissemination. The resulting guidance should be clearly identifiable from the publication, including recommendations for transfer into practice and implementation. A dissemination plan should include endorsement of the guidance by professional associations and health care authorities to facilitate implementation	Done

1. Jünger S, Payne SA, Brine J, Radbruch L, Brearley SG. Guidance on Conducting and REporting DElphi Studies (CREDES) in palliative care: Recommendations based on a methodological systematic review. Palliat Med. 2017;31: 684–706. doi:10.1177/0269216317690685

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