Inequity in palliative and end-of-life care and bereavement support: An umbrella review

UNIVERSITY OF BIRMINGHAM

Because no one should face death or grief alone

Contents

Executive Summary 3

Recommendations 3

Introduction 4

Methodology 5

Findings 6

1. How has existing research defined different population groups and are these groups helpful? 6

2. Which population groups have a more advanced evidence base around their needs, where do the gaps in knowledge for these population groups remain, and which population groups need further research and engagement? 7

3. To what extent has research engaged with population groups identified as experiencing inequity? 10

4. What are the common experiences across population groups that experience inequity? 10

5. What are the structural determinants that increase a person's likelihood of experiencing inequity in palliative and end-of-life care and bereavement support? 12

6. Can needs be themed, and can these transcend population groups? 12

7. What has been recommended to reduce inequity through further research, practice and policy? 14

Conclusion 16

Executive Summary

Towards the end of life, everyone should receive the care they need to be able to live well for as long as possible. This is not currently the case. As many as one in four people in the UK die without the care and support they need at the end of life.[1] Inequity in access to palliative care means that certain groups of the population are more likely to experience unmet need, many of which will have already faced disadvantage throughout their lives. Previous Sue Ryder research has identified high levels of unmet need for bereavement support, as well as clear disparities in the availability of and access to bereavement services.[2] Understanding and addressing inequity is therefore key to closing the gap on unmet need.

Findings from this review indicate that **population groups who experience inequity in palliative and end-of-life care and bereavement support have more commonalities than differences**. Shared experiences across the different population groups include communication challenges and cultural insensitivity, medical mistrust acting as a barrier to engagement with the healthcare system and poorer outcomes.

The review has identified a range of common needs across the population groups which must be met to facilitate equitable access, experience and outcomes. Such needs include compassionate and culturally sensitive end-of-life care, health literacy in palliative and hospice care and appropriate access to healthcare and primary care. **Any approach to tackling inequity should seek to address these shared needs, making care more inclusive for all**. If common needs are consistently addressed then ensuring care is tailored for individual needs, irrespective of the population group they belong to, will be much easier to achieve.

Efforts to tackle inequity, however, must go further than the provision of inclusive services. Socio-economic inequalities such as low economic status, social exclusion and low health literacy increase a person's likelihood of experiencing inequity in palliative and end-of-life care and bereavement support. **A collaborative, whole-system approach which tackles the wider determinants of health is therefore crucial to reducing variation in access to services and quality of care.**

Recommendations

Researchers

As research into inequity continues, researchers should:

- Consider how population groups who experience inequity in PEoLC and bereavement support have been defined by academics and policymakers elsewhere, making it clear how studies meet recognised criteria and where they might go beyond them.
- Address evidence gaps by undertaking systematic reviews on bereavement and under researched population groups identified within this review.
- Increase research into interventions that reduce inequities.
- Ensure research engages directly with people receiving palliative and end-of-life care and experiencing bereavement, particularly groups who have historically had less research involvement.

Hospices and Integrated Care Boards

- Hospices and Integrated Care Boards should ensure all commissioned care addresses shared needs across population groups who experience inequity in PEoLC and bereavement support.
- Integrated Care Boards should seek to measure and address the shared vulnerabilities that increase a person's likelihood of experiencing inequity in PEoLC and bereavement support.

1 ONS (2018), 2016-based National Population projections, 2016-2041 projections and based on the Palliative Care Funding Review, July 2011. English data.
2 Sue Ryder (2022). A better route through grief. https://media.sueryder.org/documents/A_better_route_through_grief_report.pdf

Introduction

It is well known that inequalities exist across healthcare, and palliative and end-of-life care (PEoLC) and bereavement support are no exception. Many people who are approaching the end of their life or living with grief do not get the support they need, with certain population groups finding it harder to access appropriate services and experiencing lower standards of care.

Efforts are being made across the PEoLC sector to reduce inequity, with individual hospices taking a proactive approach to address disparities and widen access to care. Charitable hospices are well-placed to facilitate more equitable provision of care within their local communities, and it is only right that they seek to do so. However, hospice services cannot tackle systemic healthcare inequalities alone. Preventing variation in access to and quality of PEoLC must also be a priority at an Integrated Care System (ICS) and national level.

The introduction of the Health and Care Act in 2022 was an important step forward. The Act includes a legal duty for Integrated Care Boards (ICBs) to commission PEoLC services that meet the needs of their populations and accompanying statutory guidance states that this should include bereavement services.[3] However, two years after the Act's introduction, persistent inequalities remain.

Marie Curie's 2023 survey exploring how ICSs are responding to the Health and Care Act found that only a minority (35%) of ICB respondents feel they significantly or fully understand their PEoLC population health needs.[4] This aligns with findings on how ICSs are responding to the wider challenge of improving the way health and care systems take action to address health inequalities. When surveyed in 2023, tackling inequalities ranked as the primary ambition ICS leaders would like to have achieved in five years' time. Yet one in five ICSs stated they did not feel confident in their ability to tackle inequalities, and none were 'very confident'.[5]

It is within this context that Sue Ryder commissioned the University of Birmingham to evaluate what is currently known about the needs of population groups who experience inequities in palliative and end-of-life care and bereavement support. This review seeks to answer the questions below in order to provide learnings that the PEoLC sector, researchers and those commissioning care can use to inform their approach to understanding need.

1. How has existing research defined different population groups and are these groups helpful?
2. Which population groups have a more advanced evidence base around their needs? Where do the gaps in knowledge for these population groups remain and which population groups need further research and engagement?
3. To what extent has research engaged with population groups identified as experiencing inequity?
4. What are the common experiences across population groups that experience inequity in palliative and end-of-life care and bereavement support?
5. What are the structural determinants that increase a person's likelihood of experiencing inequity?
6. Can needs be themed, and can these transcend population groups?
7. What has been recommended to reduce inequity through further research, practice and policy?

Being equipped to understand need is even more pressing at a time when demand for PEoLC is increasing. In England, demand for palliative care is projected to rise by 55% by 2031 due to an ageing population and increasing complexity of patient care.[6] If ICBs are not able to measure and commission

3 NHS England (2022). Palliative and end of life care: Statutory guidance for integrated care boards. https://www.england.nhs.uk/publication/palliative-and-end-of-life-care-statutory-guidance-for-integrated-care-boards-icbs/

4 Marie Curie (2023). Palliative and end of life care in Integrated Care Systems. https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2023/015529-mc-peolc-discovery-a4-report.survey.finalv1.pdf

5 NHS Confederation (2024). Putting money where our mouth is? Exploring health inequalities funding across systems. https://www.nhsconfed.org/system/files/2024-04/Putting-money-where-mouth-is-health-inequalities-funding.pdf

6 Sue Ryder (2021). Modelling demand and costs for palliative care services in England. https://media.sueryder.org/documents/Modelling_Demand_and_Costs_for_Palliative_Care_Services_in_England_1.pdf

services in line with this demand, there is a serious risk that people will miss out on the PEoLC they need and national Government will not be able to measure the effectiveness of their plans.

Ensuring the increase in demand for PEoLC can be met in a way that addresses inequity is vital if the Labour Government can meet their ambition to shift the focus of healthcare from the hospital and into the community.[7] The proportion of people dying at their usual place of residence has increased from 35% in 2004 to 50% in 2022,[8] and this trend is set to continue. However, there are known challenges associated with understanding and meeting PEoLC needs in the community. Last year, a King's Fund report on commissioning quality end-of-life care at home found that commissioners were aware that there were likely to be inequalities and unmet need in their local area, but without better use of information they could not gauge the extent of these gaps or develop plans to address them.[9]

Sue Ryder's vision is for a society that supports everyone through dying and grief - breaking down the barriers which prevent communities from accessing services is central to this. Our inequity work takes both a local and national approach. At a local level, we have conducted a pilot project in Peterborough and Cambridgeshire that engaged communities living in the region who are less likely to access the care delivered by our Thorpe Hall hospice. The project sought to understand the barriers to accessing care and what is important to different communities at the end of life in order to inform Sue Ryder's ability to meet the needs of our local population. We are now expanding this work and engaging with underrepresented communities in our other service areas.

Alongside this, we have worked with national and local policymakers to support their approach to planning and delivery of PEoLC – whether that is through highlighting necessary improvements to data collection, sharing learnings around best practice or advising how to involve the voluntary, community and social enterprise (VCSE) sector.

We hope this report will act as a guide to all levels of the system working to break down inequity and meet the challenges faced in the access to and experiences of people in need of palliative and end-of-life care and bereavement support.

Methodology

Due to the breadth of research around inequity in PEoLC and bereavement support, we took the decision to conduct an umbrella review, which is a comprehensive analysis of systematic reviews. This approach aims to provide a robust, macro-level summary of existing research and highlight areas where evidence is lacking.

Using a defined set of inclusion and exclusion criteria, the University of Birmingham searched six academic databases in order to identify systematic reviews on any populations who experience inequities in palliative and end-of-life care and bereavement support. The database search was conducted in November of 2023. To ensure an up-to-date evidence base, we limited the scope to systematic reviews published between 2012-2023. Reviews also had to be reported in English. Exclusion criteria set out that the following systematic reviews would not be considered:

- Conducted without a reported methodology
- Focused on children (under 18 years of age)
- Focused on death without a palliative phase (such as sudden death)
- Focused on disparity in mortality rates
- Focused on supportive care only

After the application of exclusion criteria, 36 systematic reviews were identified for inclusion in the umbrella review. Relevant data was extracted from the systematic reviews and synthesised, with the aim of answering the seven research questions.

7 https://labour.org.uk/change/build-an-nhs-fit-for-the-future/ (last accessed 01.11.2024)
8 Nuffield Trust (2024). End of life care. https://www.nuffieldtrust.org.uk/resource/end-of-life-care#:~:text=The%20proportion%20of%20people%20dying%20at%20their%20usual%20place%20of,)%20to%2043%25%20in%202022
9 The King's Fund (2023). Dying well at home: commissioning quality end-of-life care. https://www.kingsfund.org.uk/insight-and-analysis/reports/dying-well-home-commissioning-quality-end-life-care

Findings

1. How has existing research defined different population groups and are these groups helpful?

Research has studied people experiencing inequity by grouping them in a variety of ways. The groupings have some value, but their heterogeneity limits their usefulness in commissioning to reduce inequity.

Systematic reviews have focused on a range of population groups known to experience inequity in palliative and end-of-life care and bereavement support. We can broadly categorise the research into the following groups:[10]

- Racialised communities
- People experiencing economic deprivation
- People with learning disabilities
- People who are gender and/or sexually diverse
- People with mental health illness
- Older people, people with frailty and people with dementia
- People with other non-malignant disease (non-malignant disease that is not mental health illness or dementia)
- People experiencing homelessness

This list is not exhaustive. Groups who are often excluded from accessing and receiving high quality PEoLC, such as people living in remote and rural areas[11], may not feature because they have not yet been the subject of a systematic review. Inequity research has become more prevalent in recent years – the majority (69%) of reviews included in this umbrella review were published between 2020-2023. If research interest in inequity continues at this rate, future systematic reviews will likely identify and explore additional population groups.

There are benefits to grouping people in this way when exploring inequity. For example, it can enable us to identify barriers or challenges which are unique to a specific population group. However, a level of caution must be applied when forming conclusions about individual population groups due to the limitations of this approach.

This systematic approach overlooks the fluidity of population groups, which can lead to incorrect assumptions

Several of the systematic reviews could be classsified within more than one group such as reviews on Gypsy, Roma and Traveller communities – who might be classed as ethnic minorities or people without fixed housing. Furthermore, inequity may not pervade across all individuals within a population group. For example, there will be people with mental health conditions who experience comparatively good PEoLC. Failing to acknowledge the heterogeneity of population groups can lead to inaccurate assumptions about need and missed opportunities to provide personalised care.

Definitions used throughout the research differ and overlap, limiting the usefulness of grouping populations when exploring inequity

Across the research, there is no singular, consistent definition for each population group. For example, one systematic review which aimed to 'investigate the attitudes of the public and healthcare professionals to advance care planning with frail and older people' does not outline who classifies as 'frail' and 'older'. Whereas another review which seeks to 'understand the palliative care needs of community-dwelling people aged >60 living with multi-morbidity in the last two years of life' not only sets age criteria, but also defines multi-morbidity (the co-occurrence of at least two long-term conditions in the same individual) and frailty (as per NICE guidelines on assessment – 2016) for the purposes of the review. Both systematic reviews explore the needs and experiences of 'older people' yet use different criteria for this population group when defining their scope.

10 We have used the groups identified in Hospice UK's report, Equality in hospice and end of life care: challenges and change, as a guide when categorising the research.
11 Hospice UK (2021). Equality in hospice and end of life care: challenges and change. https://www.hospiceuk.org/publications-and-resources/equality-hospice-and-end-life-care-challenges-and-change

The diverse range of definitions used throughout the systematic reviews make it challenging to apply conclusions about population groups reliably. Identifying commonalities across a single population group would be more straightforward with consistent definitions as to who falls within each category. **As research into inequity continues, researchers should consider how the subject of a study has been defined by academics and policymakers elsewhere, making it clear how studies meet recognised criteria and where they might go beyond them.**

Intersectional research is valuable, but can make firm conclusions about population groups problematic

Some systematic reviews examine intersectional groups, such as people with dementia from ethnic minorities. Such research is important and necessary – an intersectional approach **recognises that people's social identities can overlap, creating compounding experiences of inequality and disadvantage.** However, it can create difficulties when attempting to establish whether the findings are true of everyone who falls into a certain population group, or only those who also experience the specific intersection explored within the review.

2. Which population groups have a more advanced evidence base around their needs, where do the gaps in knowledge for these population groups remain, and which population groups need further research and engagement?

The evidence base is more advanced in some population groups and areas of care than others. Racialised communities are heavily researched in palliative and end-of-life care, whereas people with other non-malignant disease and people experiencing homelessness are underrepresented within systematic reviews. There is a comparative lack of bereavement research.

The number of published systematic reviews on inequity has increased over time (see figure 1), indicating a growing interest in this area. Despite this increase, there is still a limited evidence base for some population groups. There are many potential reasons why certain population groups are more commonly researched than others – some may be more difficult to engage with using traditional research methods, there could be greater interest in larger population groups due to the number of people affected and so forth. Nevertheless, it is important to recognise where evidence gaps exist and to consider future research priorities.

See Fig. 1 below

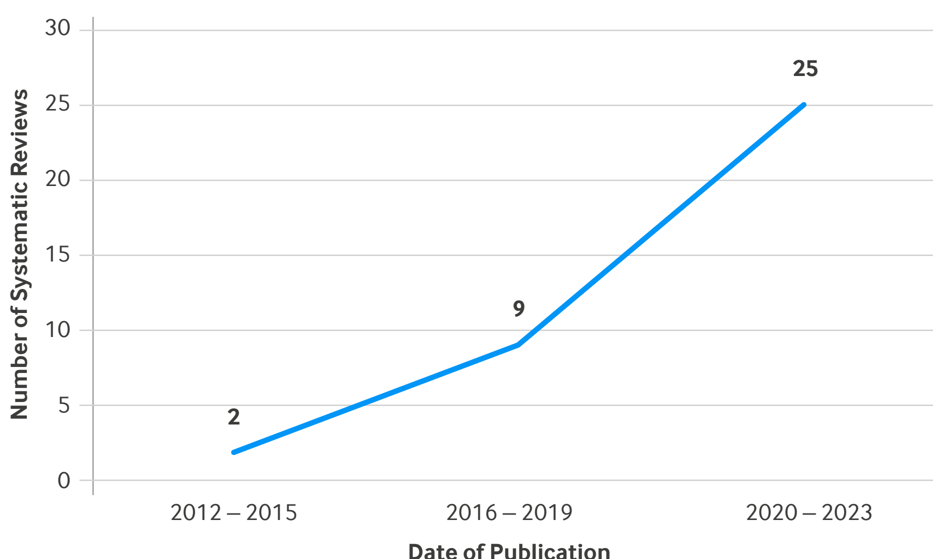

Fig. 1 – Number of systematic reviews published over time

Racialised communities are heavily researched in comparison to other population groups

To date, research has largely concentrated on racialised communities, with half of systematic reviews focusing on race or ethnicity. For systematic reviews conducted in the USA, this is even higher, at 65%. This level of research interest is to be expected, given the well-evidenced health inequalities that racialised communities face. The wide range of sub-groups which fall within the category of 'racialised communities' also creates potential for extensive and varied systematic reviews.

Inequity experienced by people with mental health illness and people experiencing economic deprivation is still far less reviewed than racialised communities. People with other non-malignant disease and people experiencing homelessness are particularly underrepresented within existing research.

See Fig. 2 below

Systematic reviews conducted in the UK present a more balanced picture, but evidence gaps remain

Systematic reviews conducted in the UK are less weighted towards racialised communities, though they remain the most researched population group (when classifying research by primary population group).

There are no UK systematic reviews with a focus on people who are gender and/or sexually diverse, meaning there's no overarching view of what is known about these population groups and the research gaps that remain to be addressed. Hospice UK research has found that, in many instances, the end-of-life care that trans and gender diverse people receive is not inclusive of them or their needs.[12] **Future systematic reviews in this area are therefore much needed.**

See Fig. 3 below

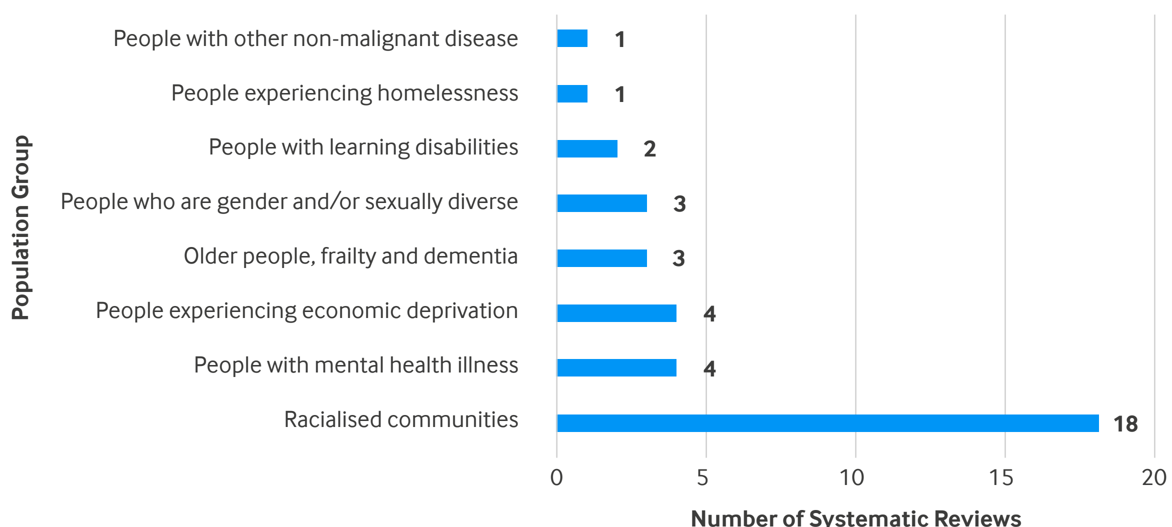

Fig. 2 - Population groups represented in systematic reviews (as classified by primary population group)

12 Hospice UK (2023). 'I Just Want to be Me': End of life care for trans and gender diverse communities. https://www.hospiceuk.org/latest-from-hospice-uk/i-just-want-be-me-end-life-care-trans-and-gender-diverse-communities

Bereavement research is currently lacking, but gaining traction

The majority of systematic reviews within the umbrella review focus on palliative and end-of-life care. Three systematic reviews on palliative and end-of-life care include bereavement, but there is just one systematic review focusing exclusively on bereavement. The review highlights that social and structural inequalities may contribute to disadvantaged individuals experiencing poorer care than others following bereavement. This aligns with wider findings from across the research about the role of structural inequalities, discussed later in the report. However, further reviews could help to substantiate findings about the specific relationship between structural inequalities and bereavement inequity.

Previous Sue Ryder research has identified high levels of unmet need for bereavement support, as well as clear disparities in the availability of and access to services.[13] Around 600,000 people die in the UK each year, and for every death, nine people on average are affected by bereavement.[14] **Given the scale of people impacted by bereavement in the UK and what is known about unmet need through existing evidence, there is an unequivocal need for more research in this area.**

Over the last few years, we have seen a peak in bereavement research as greater societal and parliamentary interest in the topic, prompted by the COVID-19 pandemic, has shone a light on the impact bereavement can have on public health. Significant steps have been taken to improve understanding and support in bereavement, including a proposal of a right to take bereavement leave, and the undertaking of major research projects from organisations like the National Institute of Healthcare Research around bereavement inequalities. Given the recent surge in primary research, we can reasonably expect to see more systematic reviews on bereavement inequity in the future, which should prompt further positive changes across society.

Not enough is known about interventions that reduce inequities, with research disproportionately focusing on describing inequity in disadvantaged population groups

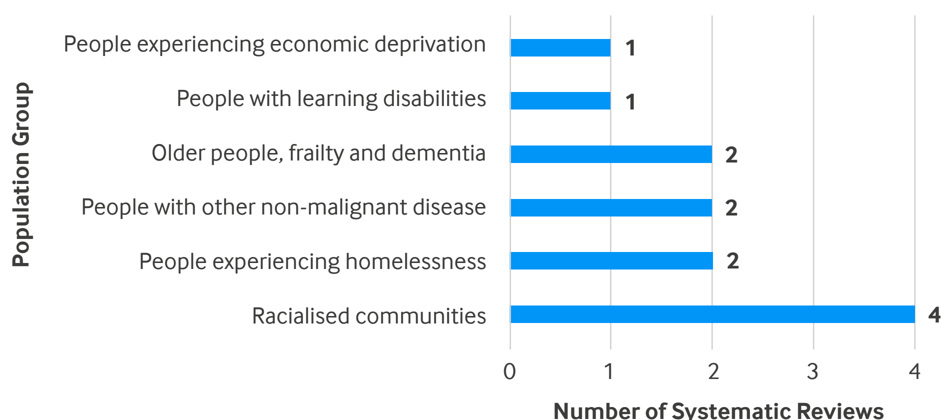

Fig. 3 – Population groups represented in UK-based systematic reviews (as classified by primary population group)

13 Sue Ryder (2022). A better route through grief. https://media.sueryder.org/documents/A_better_route_through_grief_report.pdf
14 https://www.sueryder.org/get-involved/fundraise-for-us/corporate-partnerships/choose-your-partnership/invest-in-sue-ryder-services/

There is little evidence of effective interventions to reduce inequity. For the most part, existing evidence describes its presence. Both types of research are necessary – interventions aimed at addressing inequity cannot be designed and tested without first understanding where inequity exists. Yet the current evidence base disproportionately focuses on describing inequity in disadvantaged population groups. **There is a need to expand the evidence base with more intervention research, so as to understand how to reduce inequities within and beyond specified populations.**

3. To what extent has research engaged with population groups identified as experiencing inequity?

There is limited research involving patient voice and population experience, with caregivers, family members and health and social care professionals often being used as a proxy. This is most evident in groups who have cognitive impairment.

Over half (53%) of primary studies included in the systematic reviews fail to provide information about engagement with population groups identified as experiencing inequity, which strongly indicates that direct engagement did not form part of the research process.

Integrating the experiences and insights of people with lived experience is critical within research that seeks to address palliative, end of life and bereavement inequity - a lack of patient voice can lead to incomplete understandings of the challenges faced by marginalised groups. There are understandable barriers to patient and public involvement and engagement (PPIE) when people are nearing the end of life, however future research must seek to mitigate these challenges, particularly within academia where recognised critical appraisal tools may need reconsideration to ensure PPIE is a criterion of quality.

When research included within the umbrella review engaged with population groups, it was often alongside other key individuals (28% of primary studies also engaged with caregivers, family members and health and social care professionals). 19% of primary studies engaged with the population group only. While it is important to capture the opinions and experiences of caregivers, family members and health and social care professionals, this can often be used as a proxy, which is not the same as direct engagement.

There is a need to ensure research engages directly with the people receiving palliative and end-of-life care and experiencing bereavement.

Population groups who have cognitive impairment have less research involvement

Population groups who have cognitive impairment, such as dementia or a learning disability, have less research involvement than others. This is unsurprising given potential challenges regarding capacity to take part, but it is nevertheless important to recognise and to consider how this research gap can be addressed in the future. Within one systematic review considering the palliative care needs of people with learning disabilities, just 1% of the 2970 participants across all studies were people with learning disabilities. A further 1.3% were family members of people with learning disabilities and the remaining 97% of participants were health and social care professionals. **It is reasonable to expect that people with cognitive impairment have differing, specific needs when it comes to palliative and end-of-life care and bereavement support. We cannot fully understand those needs, and ensure services meet them, without greater representation within research.**

4. What are the common experiences across population groups that experience inequity?

The review identified a range of shared experiences across population groups who experience inequity in palliative and end-of-life care and bereavement support, many of which are commonly experienced by disadvantaged population groups throughout the healthcare sector. Shared experiences include: communication challenges and cultural insensitivity, medical mistrust acting as a barrier to engagement with the healthcare system and poorer outcomes.

The review revealed that misunderstandings due to language barriers and inconsistent interpreters are a common experience among population groups who experience inequity in PEoLC and bereavement support. Staff stereotyping and lack of respect, with conflicts

arising from cultural misunderstandings, also transcend different population groups. Such experiences are common for disadvantaged population groups when engaging with healthcare,[15.] so it is of little surprise they are prevalent when people are nearing the end of life – a time when sensitive discussions must take place to provide optimal PEoLC. Additionally, views and practices regarding the end of life and bereavement are often culturally rooted so good care requires cultural competence.

Wider evidence shows that, in some instances communication challenges not only impact patient experience, but directly lead to worse health outcomes. Research from the University of Leeds has found that language barriers result in people from South Asian communities experiencing more pain at the end of life.[16] It is also not uncommon for communication challenges and cultural insensitivity to act as a barrier to accessing care altogether. Previous Sue Ryder research has found that the most common barriers to accessing formal bereavement support were a lack of culturally relevant services and because a service could not be provided in the recipient's language.[17]

Another consistent theme across the different population groups was a fear of mistreatment and loss of agency in healthcare settings. As with communication challenges and cultural insensitivity, medical mistrust among marginalised communities is a widespread issue throughout the healthcare sector. Its prevalence within racialised communities is particularly well-evidenced.[18]

There can be many reasons for medical mistrust, but for population groups who have been historically marginalised, it may be borne out of past experiences.[19]

Mistrust shapes how people engage with the healthcare system. This was brought to light during the COVID-19 pandemic, where vaccine hesitancy was higher within racialised communities.[20] This review found that mistrust in the healthcare system acted as a barrier to advance care planning across different population groups. Advance care planning can support people to die in their preferred location and informs care and treatment decisions at the end of life. Importantly, it can also help to break down taboos on death and dying on a wider scale. Despite the benefits of advance care plans, uptake remains low across the board – Sue Ryder has found that almost nine out of ten people in the UK have not written an advance care plan.[21] It is important to consider and address the various reasons for this.

The review also found that poor outcomes were commonplace across the different population groups. Specifically, disadvantaged individuals face higher hospitalisation rates before hospice admission and have limited primary care visits. Limited access to essential medicines and healthcare services, exacerbated by stigma and fear of discrimination, is also a shared experience. These findings echo analysis from Nuffield Trust, which shows that people from the most deprived areas of England who die at home are left with less NHS care in the final months of their lives.[22] Nuffield Trust's research also found that people who died at home in areas of deprivation had 50% fewer outpatient appointments than those in affluent areas and that

15 https://www.england.nhs.uk/long-read/a-national-framework-for-nhs-action-on-inclusion-health/ (last accessed 01.11.2024)
NHS Race & Health Observatory (2022). Ethnic Inequalities in Healthcare: A Rapid Evidence Review.
https://www.nhsrho.org/wp-content/uploads/2023/05/RHO-Rapid-Review-Final-Report_.pdf

16 Clarke, G., Crooks, J., Bennett, M.I. et al. (2023). Experiences of pain and pain management in advanced disease and serious illness for people from South Asian communities in Leeds and Bradford: a qualitative interview study. BMC Palliat Care 22, 90. https://doi.org/10.1186/s12904-023-01208-2

17 Sue Ryder (2022). A better route through grief. https://media.sueryder.org/documents/A_better_route_through_grief_report.pdf

18 NHS Race & Health Observatory (2022). Ethnic Inequalities in Healthcare: A Rapid Evidence Review.
https://www.nhsrho.org/wp-content/uploads/2023/05/RHO-Rapid-Review-Final-Report_.pdf
https://www.bma.org.uk/news-and-opinion/rebuilding-trust-in-medicine-among-ethnic-minority-communities#:~:text=As%20a%20result%20of%20this,building%20trust%20with%20ethnic%20minority (last accessed 01.11.2024)

19 Bazargan M, Cobb S, Assari S. (2021). Discrimination and Medical Mistrust in a Racially and Ethnically Diverse Sample of California Adults. Ann Fam Med.
https://pmc.ncbi.nlm.nih.gov/articles/PMC7800756/#:~:text=For%20racial%2Fethnic%20minorities%2C%20medical,patients'%20past%20experience%20of%20discrimination.&text=An%20extensive%20review%20of%20the,behaviors%2C%20and%20undesired%20health%20outcomes

20 https://www.ucl.ac.uk/news/2022/apr/covid-19-vaccine-uptake-among-minority-groups-was-driven-mistrust (last accessed 01.11.2024)
Hussain B, Latif A, Timmons S, Nkhoma K, Nellums LB. (2022). Overcoming COVID-19 vaccine hesitancy among ethnic minorities: A systematic review of UK studies. https://pmc.ncbi.nlm.nih.gov/articles/PMC9046074/
https://www.england.nhs.uk/south-east/wp-content/uploads/sites/45/2021/05/Vaccination-and-race-religion-and-belief-A4.pdf
(last accessed 01.11.2024)

21 Attitudes to palliative care research conducted by Censuswide and commissioned by Sue Ryder, March 2024

22 Nuffield Trust (2023). Deaths at home during the Covid-19 pandemic and implications for patients and services.
https://dmscdn.vuelio.co.uk/publicitem/6d053011-629a-45d7-b70f-77a45f010a4c

during the pandemic, white people saw the biggest increase in medications prescribed at the end of life, while people of mixed ethnicity received less medication.

5. What are the structural determinants that increase a person's likelihood of experiencing inequity in palliative and end-of-life care and bereavement support?

The review identified a number of shared vulnerabilities across the different population groups that increase a person's likelihood of experiencing inequity, such as low economic status, social exclusion and low health literacy.

See Fig 4. opposite

It is widely recognised that the conditions in which we are born, grow, live, work and age can impact on our health and wellbeing. This was brought into sharp focus by the COVID-19 pandemic, which had a disproportionate impact on many who already faced disadvantage and discrimination.[23] Well-established models suggest that clinical care accounts for 20% of health outcomes, while social and economic factors and physical environment together make up 50%.[24] **Addressing the wider determinants of health is therefore crucial to reducing inequity within PEoLC and bereavement.**

This prompts a broader discussion about the role of individual hospices, ICSs and the wider system. Hospices can strive to deliver inclusive services that mitigate the impact of socio-economic inequalities, but addressing the root causes requires a whole-system approach. ICSs, which have a core aim of helping the NHS to support broader social and economic development, are central to this. ICSs are well-placed to deliver against this aim because they bring together NHS organisations and other partners who have a critical role in addressing the wider determinants of health. This includes upper-tier local authorities, who provide housing, planning, transport, education services and adult social care. NHS Trusts are overwhelmingly positive about their ability to influence the wider determinants of health in their area – 72% of respondents to an NHS Providers survey reported that they 'somewhat' influence these factors.[25] However, as recognised by NHS Providers, only cross-government action to address the wider determinants of health will bring about real change.[26]

It is important to consider this finding against the context of the current hospice funding model. Evidence to the APPG on Hospice and End of Life Care emphasised how the reliance on donations deepens socio-economic inequalities, with communities in the most economically deprived areas least likely to be able to donate to their local hospice. As a result, their local hospice may have a lower income than hospices in more affluent areas and its community may have poorer access to services.[27]

6. Can needs be themed, and can these transcend population groups?

While disparities do exist, there appears to be more similarities across disadvantaged population groups than there are differences when it comes to need. Addressing these common needs within palliative and end-of-life care and bereavement support would therefore make care more inclusive for all.

The review revealed an array of policy solutions, practices and interventions that would support equitable access, experience and outcomes across different population groups. These facilitators, or 'needs', include:

- Access to appropriate healthcare and primary care
- Inclusive practices
- Accessibility and support for vulnerable populations

23 BMA (2022). The impact of the pandemic on population health and health inequalities. https://www.bma.org.uk/advice-and-support/covid-19/what-the-bma-is-doing/the-impact-of-the-pandemic-on-population-health-and-health-inequalities https://www.england.nhs.uk/about/equality/equality-hub/national-healthcare-inequalities-improvement-programme/what-are-healthcare-inequalities/action-required-to-tackle-health-inequalities-in-latest-phase-of-covid-19-response-and-recovery/ (last accessed 01.11.2024)

24 https://www.england.nhs.uk/blog/acting-on-the-wider-determinants-of-health-will-be-key-to-reduced-demand/ (last accessed 01.11.2024)

25 NHS Providers (2024). United Against Health Inequalities: Moving in the Right Direction. https://nhsproviders.org/united-against-health-inequalities-moving-in-the-right-direction/addressing-the-wider-determinants-of-health

26 Ibid.

27 APPG on Hospice & End of Life Care (2024). Government funding for hospices. https://hukstage-new-bucket.s3.eu-west-2.amazonaws.com/s3fs-public/2024-02/APPG%20Report%20-%20Government%20funding%20for%20Hospices%20HUK.pdf?VersionId=0I8T4jC5V2C0zRKQLFs9CIZ5QZ5xEiOs

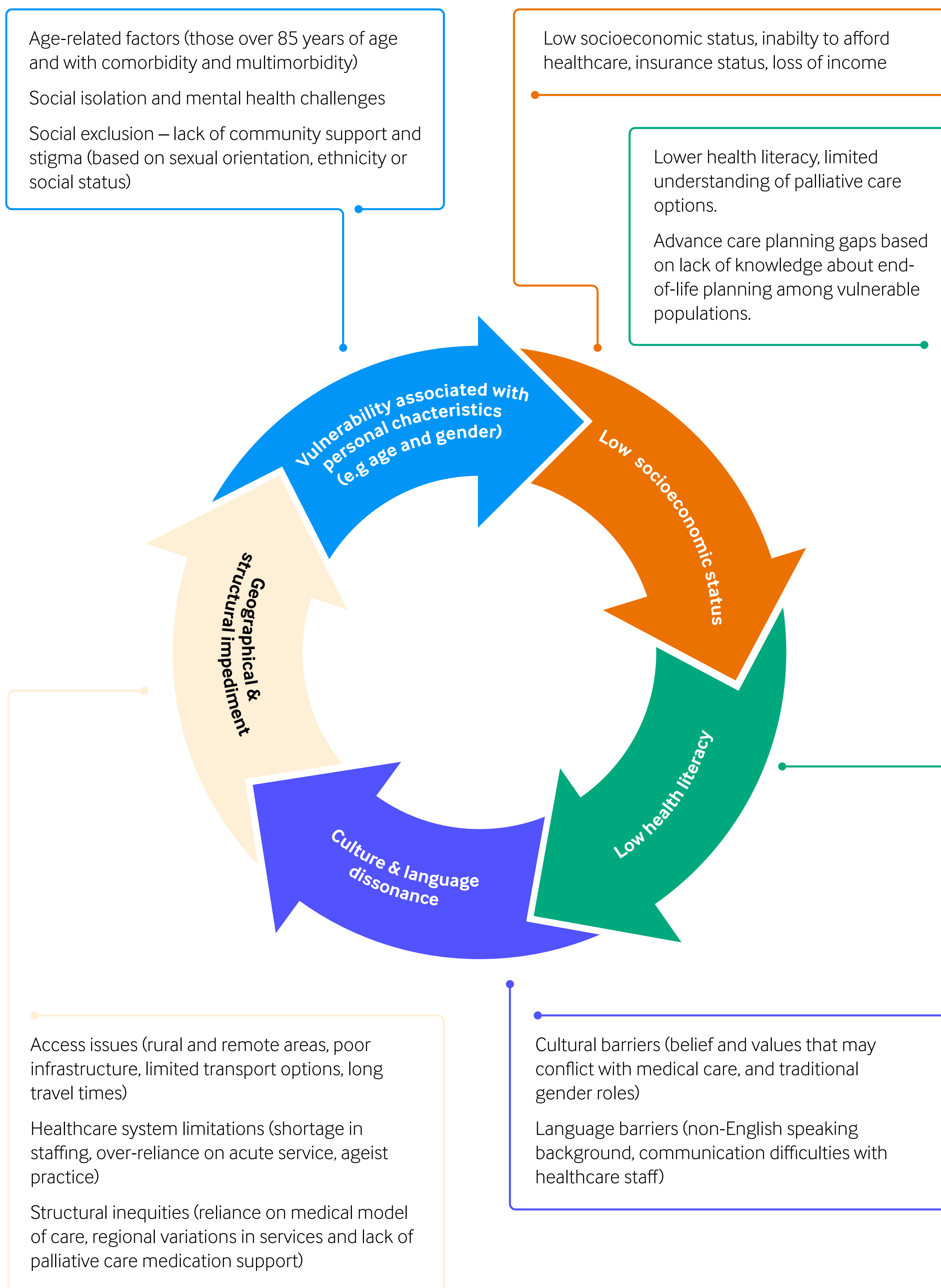

Figure 4: Structural determinants that transcend population groups experiencing inequity

- Health literacy and communication in palliative and hospice care
- Equity and elimination of healthcare disparities
- Cultural competency and respect in healthcare
- Compassionate and culturally sensitive end-of-life care

Such a collective range of shared needs suggests there is more that links different population groups than separates them. Findings from Sue Ryder's community engagement project in Peterborough and Cambridgeshire are consistent with this view – there were very clear common needs across different communities, many of which are included in the list above. For example, participants emphasised the need for referral routes which do not have to include a GP or other healthcare professional, as well as the importance of staff and volunteer education on cultural needs and beliefs. They also stressed the role of health literacy – promoting awareness of what is available so that people know what to ask for, in widening access to PEoLC.

Addressing these shared needs would make care more inclusive for all. This is not to dismiss the need for personalised care. The NHS made personalised care a key part of its previous long-term plan[28], the core idea being that people have choice and control over the way their care is planned and delivered, based on what matters to them and their individual strengths and needs. NHS England specifically committed to introduce proactive and personalised care planning for everyone identified as being in their last year of life in the long-term plan and has sought to enhance personalised palliative and end-of-life care by using the Comprehensive Personalised Care Model.[29]

The holistic nature of PEoLC means the sector is in a strong position to deliver personalised care to patients. However, the evidence suggests there are specific issues that need to be prioritised in order to create inclusive care, within which a personalised approach would sit.

Any approach to tackling inequity should address these issues in a consistent way to create an inclusive care approach, as opposed to designing services for a certain population group. The holistic idea of personalisation within a more inclusive landscape should provide more equitable and appropriate care.

7. What has been recommended to reduce inequity through further research, practice, and policy?

Recommendations from the systematic reviews cover a range of themes, including structural inequalities, cultural competency training and tailored end-of-life care. For the most part, recommendations call for the introduction of different interventions, policies and approaches, as well as further research (see figure 5). Going forward, we need to consider how appropriate these individual recommendations are in the context of this review.

See Fig. 5 opposite

This umbrella review provides a comprehensive overview of palliative, end of life and bereavement inequity research, and findings suggest there is more that links different population groups than separates them. Recommendations that address common needs and adverse experiences, such as cultural competency training, will therefore make care more inclusive for all. This will in turn reduce the need for recommendations which target interventions at specific population groups.

28 https://www.longtermplan.nhs.uk/areas-of-work/personalised-care/ (last accessed 01.11.2024)
29 https://www.england.nhs.uk/eolc/personalised-care/ (last accessed 01.11.2024)

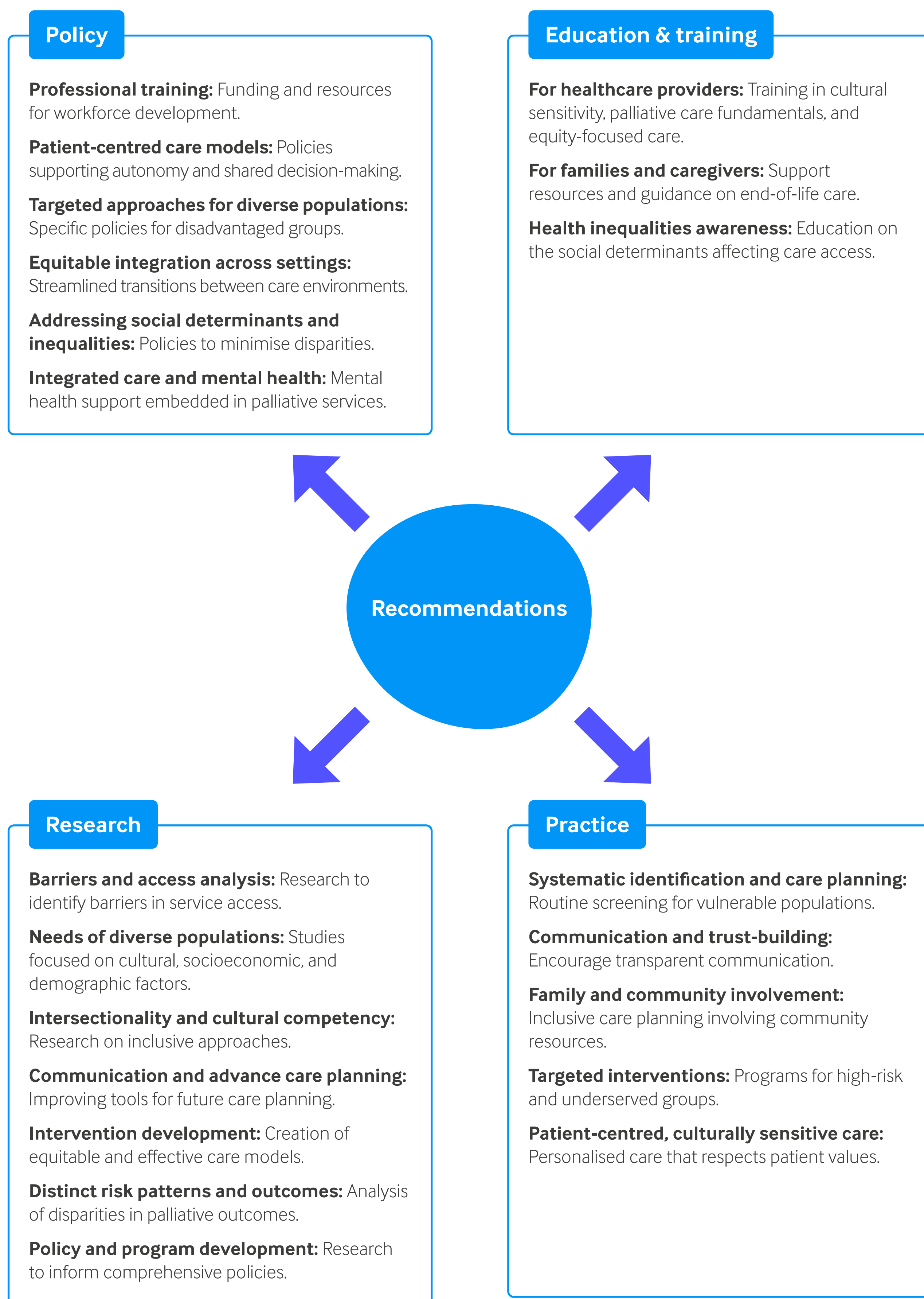

Fig. 5. Recommendations for education, research, practice and policy

Conclusion

The umbrella review confirms much of what is known in the PEoLC sector about inequity. It has tested existing knowledge through robust evaluation of a broad evidence base and brought all relevant research together in one place. However, it presents questions around the lack of patient voice within existing studies and how future inequity research can be more inclusive.

Findings from the review suggest there is more that links population groups that experience inequities in PEoLC and bereavement support than separates them. Systematically addressing the common needs across these groups will therefore likely have the biggest impact in terms of creating inclusive care. It would also pave the way for the delivery of personalised care. This finding should help to prevent commissioning to address inequity being overly focused on one specific population group, which will in turn benefit wider groups experiencing inequity. However, it poses a challenge for parts of the sector that have researched different population groups by indicators such as race and gender, and presents a need to consider how such research should translate for commissioning.

The review also identifies a number of intersectional vulnerabilities which increase a person's likelihood of being at risk of inequity. If ICBs seek to measure and address these shared vulnerabilities, they will be in a stronger position to meet the PEoLC needs of their populations. However, we acknowledge there will be tensions between the short-term operational pressures that health systems face and the long-term nature of social and economic development. We also recognise that there is only so much a single part of the system can do to address the wider determinants of inequity. In order to drive forward progress, a cross-government approach is needed.

For more information about Sue Ryder

call: **0808 164 4572**

email: **info@sueryder.org**

visit: **sueryder.org**

/SueRyderNational

@sueryder charity

Sue Ryder, 183 Eversholt Street, London NW1 1BU

This document is available in alternative formats on request.

Because no one should face death or grief alone

Sue Ryder is a charity registered in England and Wales (1052076) and in Scotland (SC039578). Ref. 07880. © Sue Ryder. November 2024.