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# To Know Dying



Identifying research areas in  
palliative and end of life care for  
the social sciences and humanities

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PARTNERED WITH



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# Foreword

**D**ying, death and bereavement are issues that will affect all of us, at multiple times and in multiple ways throughout our lives. Palliative care offers physical, emotional and practical support to people with a terminal illness, and those caring for them. Across every nation of the UK, most people who die would benefit from palliative care, yet we know that the majority of dying people are not able access this support, and that experiences of dying vary greatly.

In the UK, and internationally the population is aging, and the needs of patients are growing in complexity along with it. Despite this, only 0.23% of a total of £2.8 billion of UK health-related, non-commercial research project and programme grant funding was allocated to palliative and end of life care in 2022 (UK Clinical Research Collaboration, 2023). Now is the time to act to ensure that the inequities in dying are addressed and are not perpetuated.

As the largest charitable funder of palliative care research in the UK, Marie Curie recognises the need to work alongside researchers from a range of disciplines, including social scientists, policy makers and research funders to challenge the inequities that exist in end of life experiences and to promote positive change. We must come together to listen and respond to the voices of people affected by terminal illness to help us direct our limited funds to where they are needed most.

This report drew together insights from researchers from diverse disciplines to identify five research areas for social sciences and humanities, based on over 1,000 ideas for palliative and end-of-life care research provided by people affected by serious life limiting illness. These research areas, alongside the priorities for palliative and end of life care identified in the 2025 James Lind Alliance Palliative and End Of Life Care Priority Setting Partnership, can lay the foundations for a path towards helping us know dying as best we can in years to come.



**Dr Sam Royston**  
Executive Director,  
Policy and Research,  
Marie Curie

# Executive summary

**W**hat do we need to know about dying and why do we need to know it? A simple answer might be, we need to know enough to ensure everyone has a ‘good death’. But even within this response there are a multitude of issues that make this topic very complex.

Despite the wider implications dying has for all aspects of life, questions about dying often understandably focus on immediate concerns of the ailing person, along with the people and organisations who are closest to help. It is not always evident to those involved how their experiences of dying are connected to:

- socio-cultural preferences for how information is communicated
- the historical reasons why we turn to medicine to help
- how differences in what is valued are shared

or why any of these issues matter.

But social scientists and humanities scholars have expertise in these concerns. And their expertise will be fundamental to shaping future research on understandings of dying and improving experiences of the end of life.

In 2025 Marie Curie and other organisations, in partnership with the James Lind Alliance (JLA) published a set of priorities for future palliative and end of life care research, which was the result of the Palliative and End of Life Care Priority Setting Partnership. This report is the output of a project that brought together academics from a wide variety of social science and humanities disciplines. They provided a secondary analysis of the initial survey data to generate research areas for social sciences and the humanities.

We identified the following five interlinked, non-hierarchical, research areas:

- **Experience, practice and education**  
Social sciences and humanities can show how experiences of delivering or receiving palliative care are connected to multiple levels of the social and cultural context, and use these insights to better inform practice and education.
- **Awareness, communication and planning**  
We identified how social sciences and humanities can show how communication about dying is multi-directional and multi-layered. This is important when planning for the end of life, which involves value-laden dynamics about what is possible and what is needed.
- **Power, ethics and transitions**  
Social sciences and humanities are particularly well equipped to explore the different dynamics of power, as well as the ideas, judgements and rules about what is right or wrong — especially when they affect the changing body, care, or relationships when dying.
- **Time, space and care**  
We described the ways social sciences and humanities research can show how people can navigate, make or interrogate the different systems, relations and illnesses at different times and locations of care at the end of life.
- **Diversity, equity and society**  
Social sciences and humanities are crucial in ensuring the inequities and inequalities experienced within healthcare are connected to differences made through the cultural, political and economic systems in which people live and die.

It is our intention that **this report's findings will guide funders when setting their research priorities** to ensure future research into dying has clear and strong foundations in the social sciences and humanities.

In particular, we expect our findings to be read alongside the 2025 JLA PEO LCPS P report: we hope future researchers can use our research areas, and work with social science and humanities researchers, to address the 24 priorities identified in the 2025 JLA PEO LCPS P report. We also hope that **researchers in social sciences and humanities will be encouraged to actively and confidently contribute to research and public discussions on dying.**

We see this report as the beginning of a process that bridges the gap between social sciences and humanities research and health and medical investigations into lived experiences. **Further work is needed both to elaborate on the research areas we have identified**, but also to explore how the various disciplines and fields can better and more equitably collaborate. This includes urging the JLA and those they collaborate with to consider how they can **involve the social sciences and humanities in future priority setting initiatives.**

This report is therefore a reminder to funders that dying is as much – if not more – an issue of (social) justice, education, politics, economics, history, location, and relations that can affect experiences of dying and caring for those at the end of life. It is also a call to social science and humanities researchers to continue to advocate for the value of their insights and the difference they can make to how we know dying.

# Introduction

**T**his report is predicated upon the observation that dying is a social and political issue, that healthcare is sometimes involved with (Kellehear, 2007). This is not to dismiss the crucial role that health and social care has played since mid-twentieth century in shaping experiences of dying and how it is understood as a problem in need of research (Clark, 2007). But we need to remember that how we think about dying is affected by the people closest to us – spatially and emotionally – as well as the culture, politics, economy and history of the communities we live and die in.

Therefore, if we want to know what it is to die well, to have a ‘good death’, and find ways to improve how people die, we need to attend to the multitude of issues affecting the dying person (Broom, 2015). We must explore how care is shaped by the society and culture in which it is experienced, as much as how medicine affects the way we think about dying (Borgstrom & Visser, 2025). And as societies change, we should recognise that what was previously important, may hold a different value now or in the future (Lewis, 2007).

Research about dying and death is inherently informed by what is considered important at the time of the study, within the society and disciplines that the researcher(s) are located within. There has been a growing recognition in the UK and other countries that public, patient, and clinical perspectives of what is important should be considered in identifying questions and research design (JLAPSP, 2021; Nicholls & Campbell, 2024). One way to identify what issues around dying are important to those with life-limiting illnesses, those who care for them and the public, is to ask them.

## Research grounded in patient and public priorities

The JLA is an initiative that aims to identify and prioritise what questions patients, carers and clinicians have about a range

of healthcare issues. It carries out this work by bringing together an expert group of patients, carers and clinicians in a Priority Setting Partnership (PSP). The PSP then carries out surveys, which are open to people affected by the issue being studied, to gather as many evidence uncertainties about that topic as possible. Once the questions are collected, the PSP carries out exercises with those who are directly affected by the issue to summarise the uncertainties and to prioritise them.

In 2015 Marie Curie worked with a number of organisations including the JLA to identify the top ten research priorities for palliative and end of life care (PEoLCPSP). These priorities covered themes related to care settings, access to care, care practices, training, and clinical outcomes (PEoLCPSP, 2020 [2015]).

In 2025 Marie Curie, in partnership with the JLA, and co-funded by the Economic and Social Research Council (ESRC) and the Motor Neurone Disease Association, published a full ‘refresh’ of these research priorities, following the established James Lind Alliance approach. The refresh produced 79 questions and a shortlist of 24 priorities for research into palliative and end of life care that were focused upon a range of issues, some of which were disease specific (for example dementia), others focused on optimising care in different locations (eg in acute settings or at home), while others recognised the need for individualised care (eg supporting people with multiple morbidities, people who live alone).

This is crucial work that affects how national organisations who fund research such as the National Institute for Health and Social Care Research, UK Research and Innovation and charity funders such as Marie Curie focus their resources and decide what kind of research they invest in.

The priorities identified through the 2025 JLA PEoLC provide



insights into the issues that people affected by serious life-limiting illnesses and those that care for them feel are important for research to address. But to fully investigate those issues, further work is needed to identify the social and cultural contexts, norms, values, systems and structures – within health and social care, but also in the wider lives of those involved – that might be affecting those who are dying and the people who care for them. To do this, insights from the social sciences and humanities are also required.

## Identifying future research areas for social science and humanities

The need to care for and support those who are dying is expected to increase in the coming decades (Bone et al., 2018; Etkind et al., 2017; Fantoni et al., 2024). As well the need to reprioritise clinical health services research to address changing needs of those at the end of

life, it will be important to attend to the shifting meanings and contexts in which palliative, end of life, and health and social care develops and is delivered. There is a long standing engagement with dying from social science and humanities perspectives (Borgstrom et al., 2018), which has generated insights that have helped to inform health and social policy and improve experiences of dying.

The 2025 refresh of the research priorities for palliative and end of life care therefore presented a unique opportunity to identify the social and cultural issues currently affecting people's experiences of dying, palliative care and bereavement. By reflecting upon the issues and questions raised in the survey we will provide a clear link between public-identified topics and social science and humanities contribution to dying, palliative and end of life care research.

### What are the social sciences and humanities?

The description 'social sciences and humanities' brings together multiple disciplines, approaches, and methodologies that do not always share assumptions or processes. One of the strengths of engaging researchers from social sciences and humanities is that they will challenge how you see the world!

#### Examples of social sciences:

Anthropology, archaeology, sociology, economics, (social or human) geography, linguistics, management, media and communication studies, psychology (including critical and social), disability studies, gender studies, culturology, political science, social policy, society and technology studies (STS).

#### Examples of humanities:

Architecture, design, philosophy, ethics, religion/theology, history, medical humanities, language, arts (literature, writing, oratory, rhetoric, poetry, etc.), performing arts (theatre, music, dance, etc.), and visual arts (painting, sculpture, photography, filmmaking, etc.)

When writing this report, we have sought to represent the diversity of approaches contained across these many disciplines, while using terms like "society and culture" to keep the report reader-friendly for its diverse audiences. Such turns of phrase should be read to include the range of interests that the social sciences and humanities have, including ones we have not had space to mention.

# Project scope

**T**he aim of the project was to use the anonymised data collected in the initial JLA survey of the 2025 refresh to identify areas for future social science and humanities research into dying, palliative care and bereavement. From this, we can provide the framework for multi-disciplinary approaches to improving palliative and end of life care, practice and policy.

We believe this report is important and timely. Most of the challenges facing humanity, including aging populations, pandemics, conflicts, and climate change, directly relate to issues of dying and death (Walter, 2022). These are not issues science, technology and healthcare can hope to successfully address on their own. The social sciences and humanities will have a crucial role in identifying how problems are framed, as well as bringing insights and knowledge when questioning the systems and structures of

interventions (Pickersgill et al., 2018). Indeed, a recent analysis found that involving social science and humanities researchers increases the impact of health and medical research (Wagner et al., 2024).

It is in this spirit that this report is written and therefore should be considered a starting point for researchers and funders. We want to represent the diverse – and sometimes conflicting – range of interests that social sciences and humanities have in dying, palliative care and bereavement. It would be inappropriate to claim we could distil several millennia of literature to apply them to issues of today by posing a single research question or questions. But like the social sciences and humanities at their best, we do not seek to tell our audience what to think; but we wish to show you how it is possible to think differently about dying.

# What we did

**T**he study involved three phases: (1) Secondary analysis of data collected in the initial survey of the 2025 JLA PEoIC PSP; (2) An online collaborative workshop; and, (3) Reflection and refinement.

The secondary analysis involved taking the 1,032 responses and organising them under 37 broad labels (see MacArtney et al., 2025). The main purpose of this activity was to reduce the workload for the workshop participants by grouping responses into broadly similar categories.

We shared this table with the workshop participants the week before the event. The workshop was held online in September 2024. It lasted for five hours and was attended by 15 participants and seven facilitators (drawn from project team members, advisory group members and a research assistant). The workshop involved academics with backgrounds in social epidemiology, architecture, theology, anthropology, psychology, sociology, philosophy, ethnography, political science, economics, disability studies, and social policy.

The workshop comprised of three activities (for a full protocol see MacArtney et al., 2025). First participants grouped the 37 categories

into 'buckets', which produced five areas. In the second phase participants worked through a series of tasks in subgroups. They were asked to identify the features of each bucket they were assigned to and provide a name for it. Then they translated this into a fully described research area, including developing potential exemplar research questions. Participants returned to the full group at regular intervals to share how their area was developing, which included opportunities to compare, contrast and comment on other groups' area. In the final activity each sub-group presented for discussion with the other participants an overview of their research area and the key multidisciplinary issues they had identified.

The workshop, including sub-groups, was recorded. For the final phase, each facilitator was tasked with reviewing the recording and their notes to produce a written draft of their group's findings. These were then collated and edited to be included in this report. Both the initial workshop findings and a draft of the report were shared with the advisory group for their input.

# What we found

The project identified 37 categories that the survey responses submitted to the JLA could be grouped into (MacArtney et al., 2025). The workshop organised these categories into five different research areas relevant to the social sciences or humanities. These research areas are interlinked, but not hierarchical. They are:

- Experience, practice and education
- Awareness, communication and planning
- Power, ethics and transitions

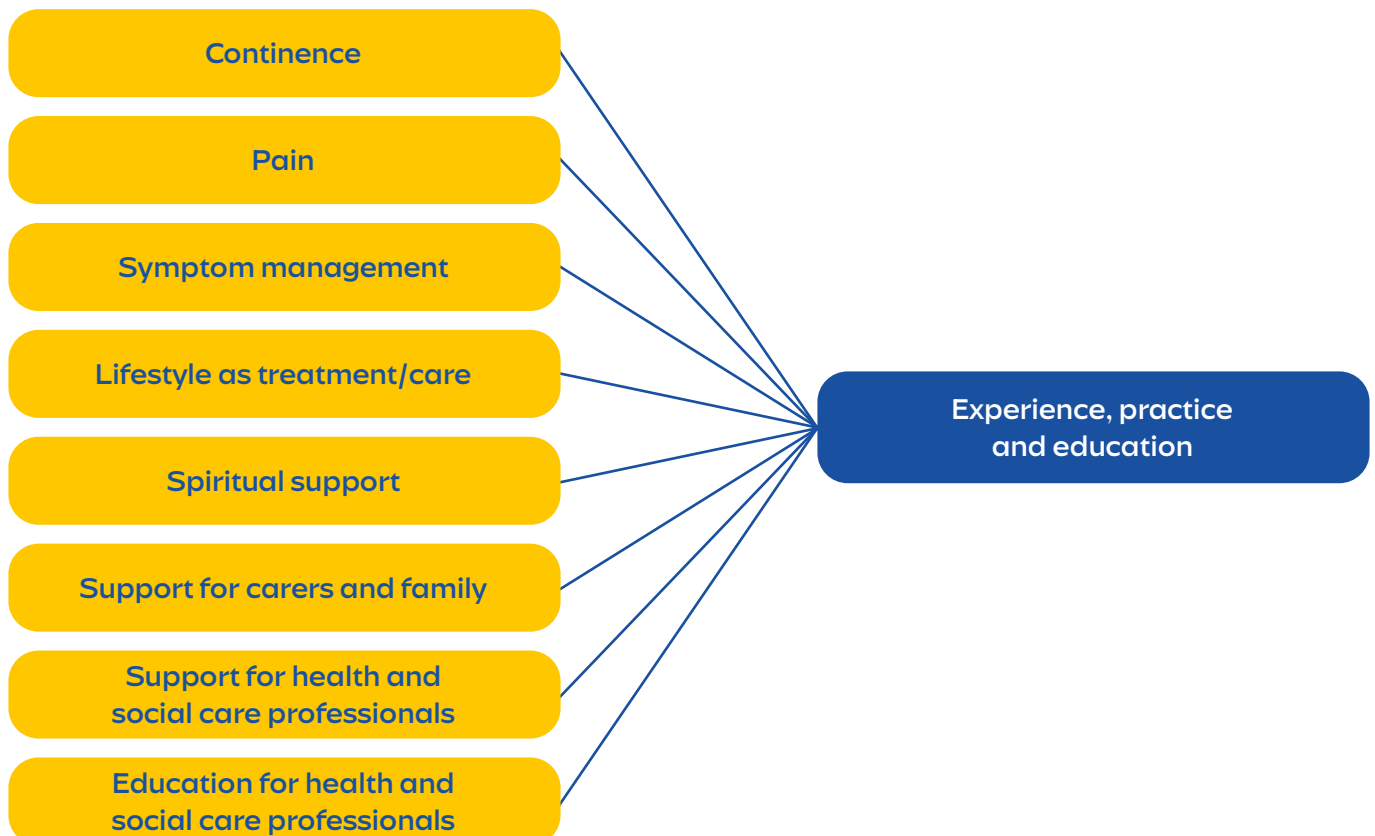
- Time, space and care
- Diversity, equity and society

Each exploration of a research area begins with a descriptive summary and a diagram that shows what categories were grouped together to form it. In our exploration of the research area we draw upon exemplar quotes from the JLA survey data, as well as reflections from the workshop Participants, to highlight how social sciences and humanities can contribute to each area.

## Research area one – Experience, practice and education

### Summary:

Experiences of delivering or receiving palliative care need to be related to their social and cultural context, so they can better inform practice and education



This research area emphasises the importance of lived experiences for understanding dying and care, as well as the crucial role this knowledge can play in educating people about palliative and end of life care. In particular, it is important to understand that how people live and die, and their interpretations of this, expand well beyond any particular medical framework or clinical relationship.

We can see this in survey responses such as “length of time you can be waiting for pain relief”, “symptom control is so poor” and “spiritual support is rarely touched on”. These draw attention to the disconnect between respondents’ experiences of a range of symptoms and the ways they were understood by those seeking to help and support them, or the person they were caring for.

In the workshop, participants noted how the multitude of issues in this research area – from concerns about who could or could not issue pain medication in the home, to how experiences of dying were expressed and understood as a good as well as a bad thing – needed to be grounded in a wider nexus of decisions and relationships. They reflected that responses like these are important because they show how symptoms and the body are understood and interpreted and are significantly affected by the social, cultural, economic, technological, historical and legal contexts individuals found themselves in.

The workshop participants also reflected upon how best to use lived experiences in education for health and social care professionals and informal carers. It was felt it was important

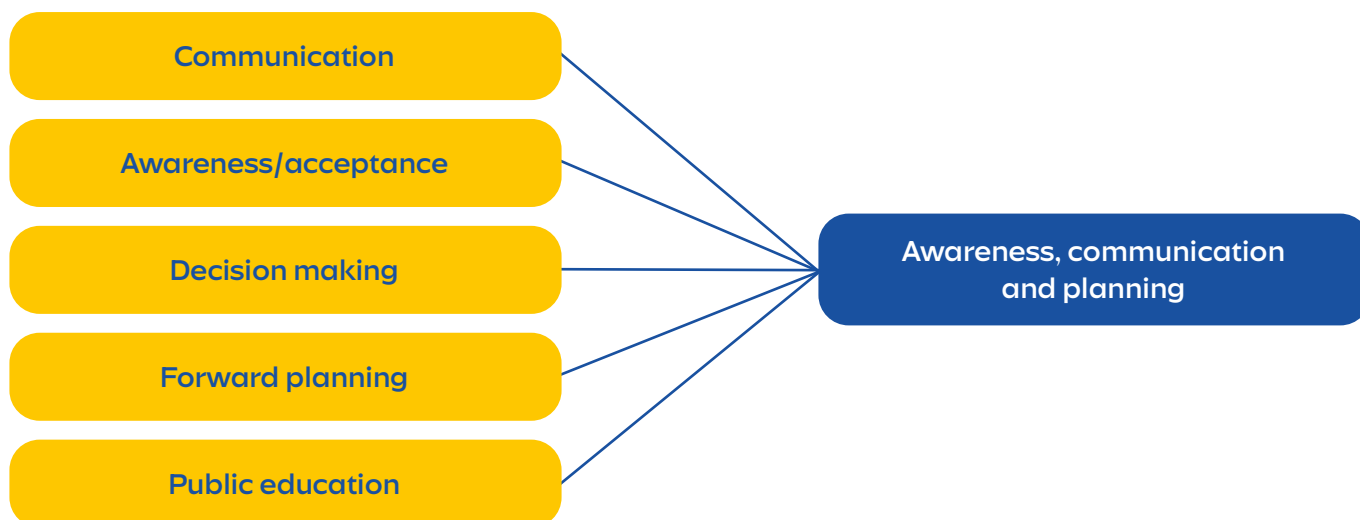
to acknowledge the important place peoples’ experiences already have in innovative approaches to healthcare interventions, as well as education aimed at professionals. But it was also noted that when lived-experiences get described as “anecdote” or “subjective” it can be to devalue, delegitimise or prevent improvements based on research that focus on the lives of those affected. Again, insights from the social sciences and humanities can help to highlight in education and medical practices the importance of power dynamics relating to “who speaks (for whom)”. Recognising this could help to broaden and deepen understanding of what dying is, how it is experienced by a wide range of people, and how particular forms of care and support come to be valued.

Examples include historians who might explore the economic and political trends that have contributed to current framings of illness experiences that emphasise individual responsibility, rather than how it might be determined by a state or sovereign. Ethicists could bring their attention to people feeling, or being made to feel, responsible for matters well beyond anything they might be able to control, from disease progression to the financial limitations of a healthcare service. And sociologists and anthropologists can provide further analysis of how responsibility comes to be understood as “shared,” when knowledge of diseases and treatments are so scientifically advanced as to be only understandable after decades of study.

## Research area two – Awareness, communication and planning

### Summary:

Communication about dying is multidirectional and planning for the end of life involves value laden dynamics about what is possible and what is needed.



This research area is concerned with how dying is talked about, when and by whom. This is important because although dying is something that comes to all, it is something that is often associated with uncertainty and ambiguity about what it entails. It is also something that can have considerable emotional effects upon those thinking about their own, or someone else's, end of life and death. Some do not wish to think or speak about it at all. While some are familiar with thinking about these issues at an individual level, this research area draws attention to how we should understand awareness, communication and planning as social and cultural issues.

The survey responses highlighted the importance of “communication” in palliative and end of life care, especially improving health and social care professionals’ conversations “with relatives and carers,” which one respondent found “isn’t always great”. Communication about dying with health and social care professionals was seen to be particularly valuable because it helped with “having a plan”, whether that was in general or a specific advance or anticipatory

care plan. Not only was good communication associated with having a plan, but it was part of understanding what the right thing to do was, which helped people “dealing with [our] decision”.

While communication – especially in healthcare settings – can sometimes be approached in matter-of-fact ways, talking about how someone might die involves evaluations of what is right or wrong, good or bad, better or worse. Not everyone felt ready to make such decisions and some survey respondents suggested efforts be made to increase “death literacy and dispel myths” about dying. But this should not just be aimed at the public: many of the communication and awareness issues were associated with health and social care professionals even though they may be expected to have a lot of experience of talking about dying.

The workshop participants discussed how the survey responses helped to demonstrate the problem with the idea that communication in clinical contexts is largely unidirectional and that, once undertaken, leads to consensus about what to do. For example,

health and social care professionals share information with a patient and their close persons, who are then clear about what needs to be done and why. Participants also questioned the assumption that (more) communication, awareness, and planning are inherently beneficial.

In contrast, workshop participants highlighted that communication can be multidirectional, involving a back-and-forth with the dying person as well as being affected by the wishes of family and friends. Moreover, it is important to note how and why more communication may lead to conflict and open ended resolutions. This is because communication is not simply a transaction of information, but is value laden and permeated with (mis)understandings of norms many of which are implicit to those involved.

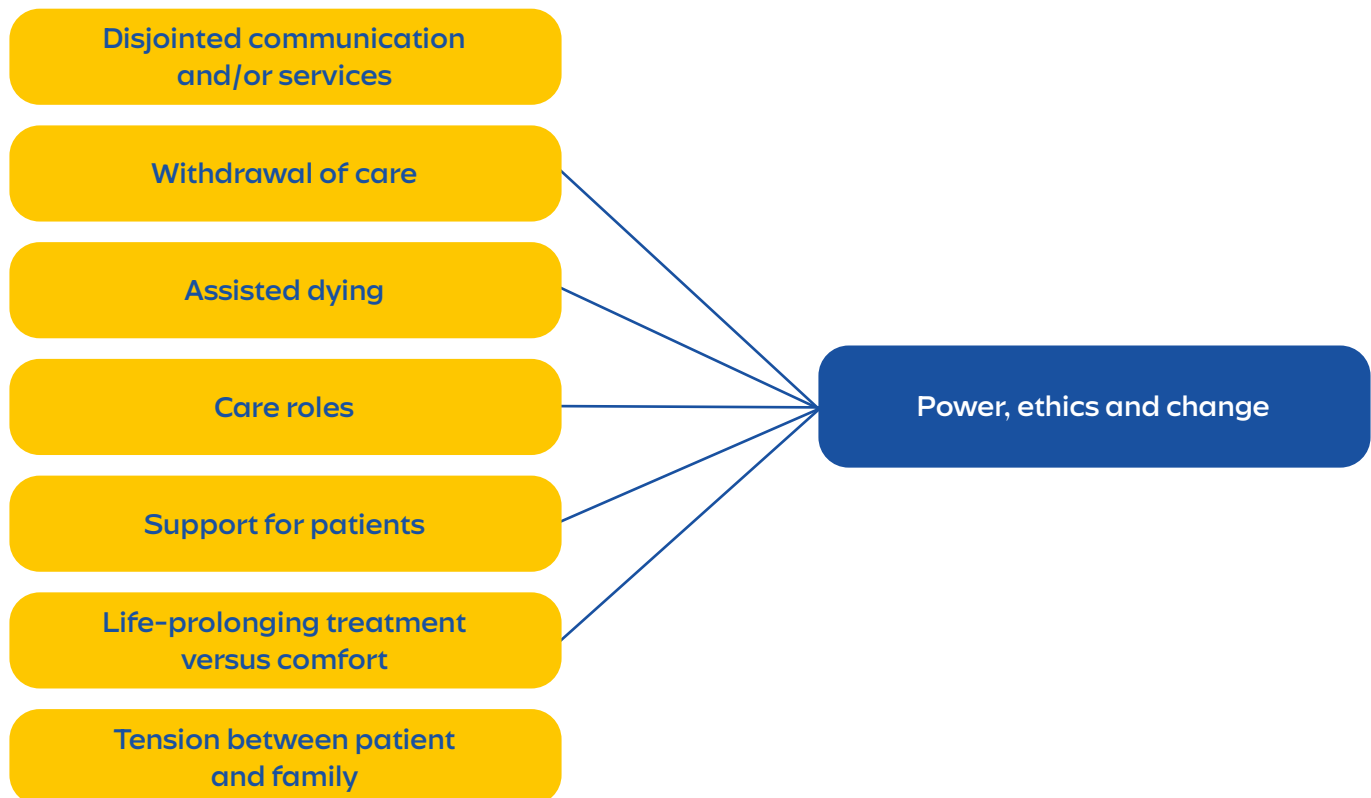
This research area highlights how social sciences and humanities are needed to provide insight into the practices and assumptions through which awareness, communication and planning for the end of life takes place. This might include critical psychological research that addresses individual emotional wellbeing

effects of dying, both positive and negative, as well as sociological or historical explorations of the normative culture within medicine and society that is predicated on talking, accepting and planning for dying, death and bereavement. Applied linguists and communication studies can examine the effects of specific language in terms of conveying messages, facilitating relationships and actions. Research from social studies of science and technology can help to explore the role of innovations – from digitising health records or using artificial intelligence in prognostication to using video consultations or virtual reality to improve access – to further complicate what is communicated, how and when. Moreover, social sciences and humanities perspectives should push to explore expectations and experiences of awareness, communication and planning across demographic, cultural and national differences, as well as how such priorities are affected when dying is widened to less considered age groups, including younger parents, children, or miscarriages and stillbirths.

## Research area three – Power, ethics and change

### Summary:

Exploring the different dynamics of power, from the interpersonal to systemic, as well as the ideas, judgements and rules about what is right or wrong, especially when they affect the changing body, care, or relationships when dying.



As a person dies, there are many changes that occur: this research area is concerned with the people involved during these changes. This may include changes to their personal, professional, familial or social roles, at times when those around them are similarly experiencing transformations in their lives. These changes can become particularly difficult during periods of what the medical literature often calls “care transitions” eg from curative, through to life-prolonging, and then maximising quality of life. Palliative care may be introduced to patients and those close to them at one or more of these transition points. Importantly, it was how these changes are valued, judged or enacted, from their interpersonal emotional effects to notions of what is the right thing to do as a society, that was focused on.

Survey responses for this research area, such as “care (...) was withdrawn”, “unnecessary investigations”, and “focus on prolonging end of life instead of comfort” demonstrate how in periods of change respondents can feel passive, unable to make a difference, or that care is being done to them or the person they care for. Similarly, when a respondent said that his mother’s support for his dying father “became all-consuming (...) the bleakness and stress for her” it provides insight into how caring for someone who is dying can negatively affect a person’s life and their relationships. Along with recognising how “support [provided] maybe does not go far enough” we can also see how transformations to interpersonal relationships are related to the availability of health and social care resources. In turn, acknowledging the wider



context of the practical and emotional difficulties people experienced helps us to hear the value judgements when respondents described how the changes had “repercussions on family” and that those involved “didn’t want to be a burden” whether that might be on those around them, the health and social care system or society. Perhaps in contrast to these observations that healthcare and society can allow “the end of life [to] be so cruel”, some respondents valued the option to take control over how and when they die: “end of life options should be given.”

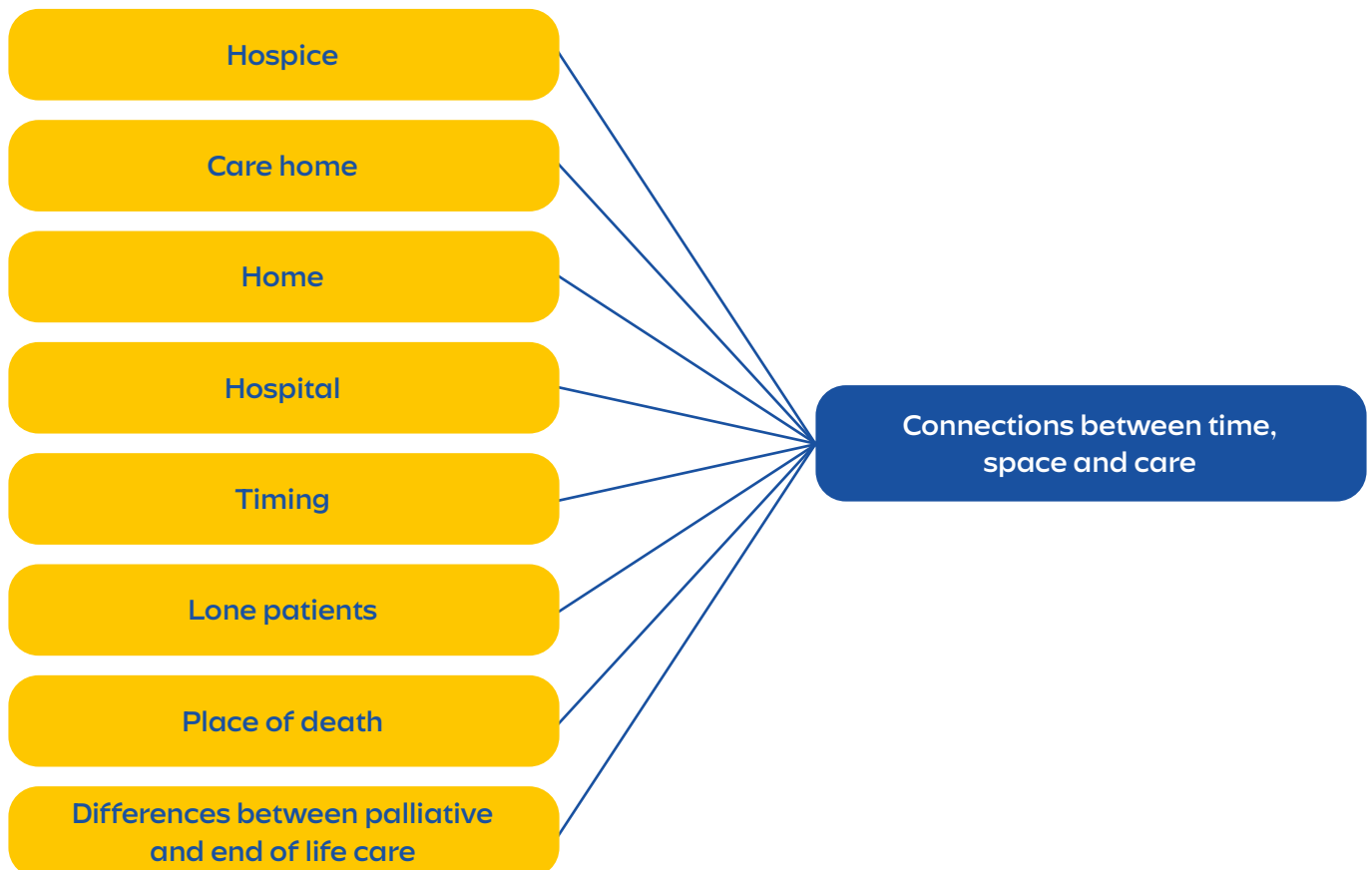
When reflecting upon this research area the workshop participants noted how “dynamic” the changes were. Such changes are often paradoxical as many parts of life slow down and are seen to be coming to an end. Many changes, from bodily and interpersonal to bioscientific and technological, can take place “really rapidly”. Similarly, contrasts between examples of “formal and informal powers” in the survey responses, from “relationship dynamics” to “policy [and] law” were noted. In particular, participants observed how the contrasting degrees of control or influence what was happening came to be related to emotional responses (eg overwhelmed) and social evaluations (eg burdens) and ways of “conceptualising [good] support”. Questions were also raised about the changing relationship between doctors and patients, or citizens and the state, and how they were affecting ideas of what is good care.

Social sciences and humanities approaches can help investigate these areas, asking questions about how and why some changes are understood as better or worse and the changing influence of different groups – such as health and social care professionals, patient advocate groups, or judges – that helped to shape those ideas, values or norms. Social sciences and humanities researchers are particularly well equipped to provide these analysis as they can draw on a rich literature that provides a complex and nuanced understanding of both power and ethics that will be crucial to future research of dying. For example, legal scholars could interrogate which social mores become interpolated within legal judgements. Or philosophers could bring insights to what it means for the professional-patient relationships to change (including within a multidisciplinary team or patient-in-a-network relationship), while sociologists can examine the diversity of contexts in which changes about care, life and dying take place, from the idealised “clinical encounter” where the specialist palliative care team have plenty of time to talk to all those concerned, to those sudden or rushed discussions with close persons of people dying from sudden traumas. Alternatively, how these issues are envisioned and represented are areas ripe for exploration by performing and visual art practitioners and researchers.

## Research area four – Time, space and care

### Summary:

We described the ways social sciences and humanities research can show how people can navigate, make or interrogate the different systems, relations and illnesses at different times and locations of care at the end of life.



This research area draws attention to how different spaces and places became associated with different moments and processes of dying. It raises questions about what those associations might mean. For example, for many people, hospices remain strongly connected to care provided in a building in the last weeks of life, even though many hospices support people in the community for months, even years before they die.

The survey responses for this research area draw attention to the “difficulty identifying when palliative care should begin”, but also how that timing and provision can be related to the location the dying person is being

cared for in. For example, it was observed that that care in “the hospice it was so much easier,” and that the “NHS (...) does not offer the level of support and understanding that hospices (...) do.” However, respondents recognised there were resource issues with supporting the dying and providing (specialist) palliative care in multiple locations, suggesting further thought is given to the “cost-effectiveness of specialist support in different settings”. Questions about what care is provided, where, and by whom were related to understandings of a person’s social situation, as the following respondent asked, “how to best support people who have no family”.

In the workshop participants discussed how some places have come to be perceived as better (eg home) or worse (eg hospital) places to be cared for and to die in, which can affect decisions about what, how, when and where care is provided or received. This was felt to become particularly problematic when the type of care that is desired cannot be provided in the location in which the person wants to reside. Concerns were raised about the “social and material conditions of care”, including who provides care, whether professionals, family or close persons, and where they are located in relation to the dying person. Especially in cases where the provision of care is not available, for instance if there is no hospice in the region or no family or close persons to support them at home.

It is therefore important to consider how dying is related to the personal, social, healthcare and economic resources available, and how those resources become allocated to particular people in certain spaces. Moreover, it is necessary to explore how, when and why those resources come to be understood as being important or meaningful at different times throughout the last days, weeks or even years of life.

Social sciences and humanities research in this area can assist in terms of timing by providing situated accounts of both individual experiences and the changing circumstances that affects dying occurring across different

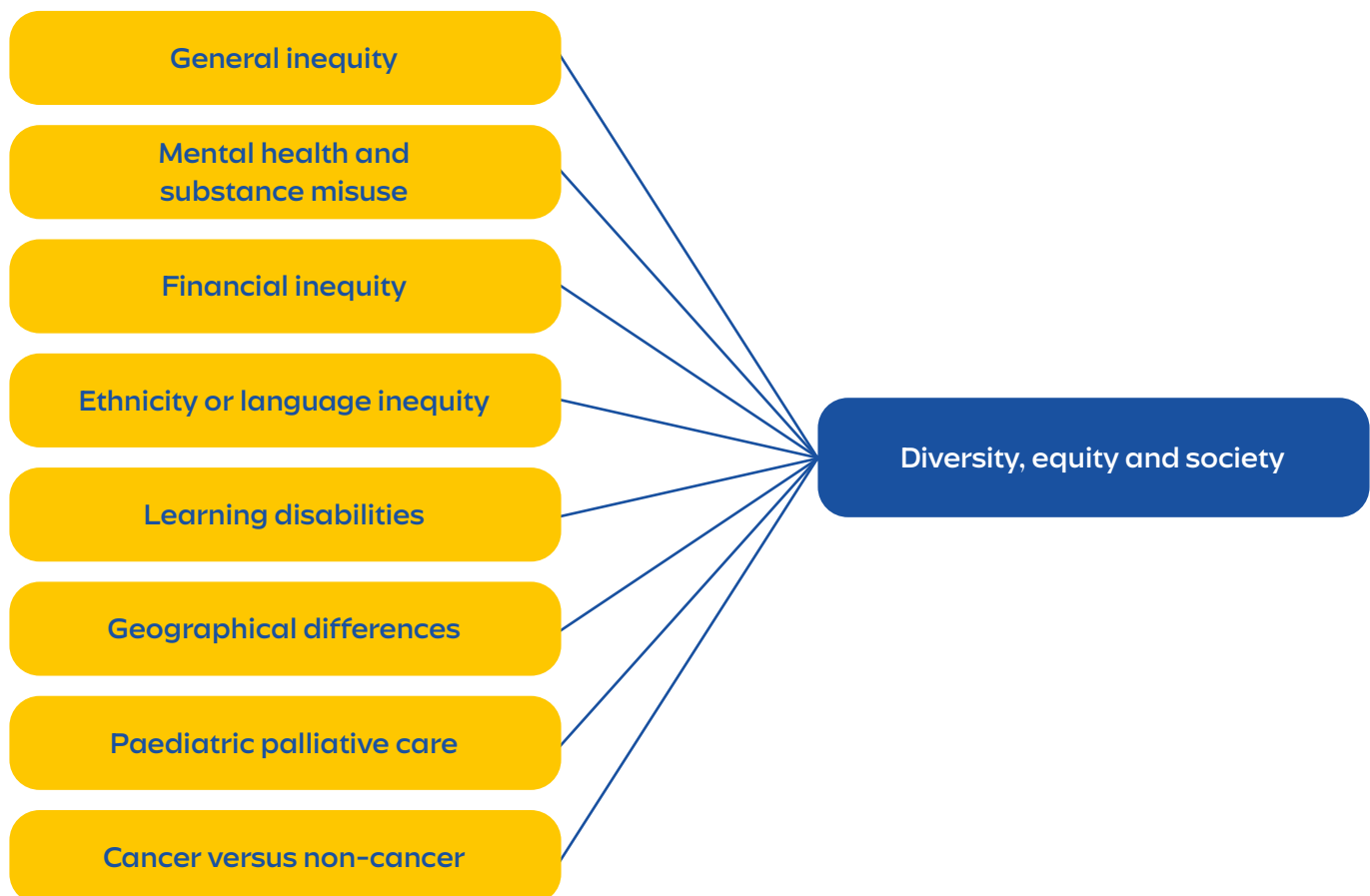
spaces. This could take many forms of enquiry. For example, historical considerations of the role of types of expertise in dying and how that has come to affect understandings of who dies where. Social geographers could examine how certain spaces become imbued with particular ideas or meanings around dying, or draw on international or intercultural experiences. Architects and design studies can help interrogate the aesthetic and the functional aspects of the places people die in. Sociological or anthropological research may need to examine the impact of having care advocacy provided by different groups of people, with differing notions of expertise – such as clinicians, end of life doulas, or family and friends – on navigating and timing different kinds of care and the locations in which it is to be experienced.

Greater attention is also needed to the different societal norms, values, ethics, politics and jurisprudence that affect how dying in different spaces come to be understood as having better or worse forms of end of life care. This may relate to questions around how decisions are made in terms of timing interventions and care, and who they are made by. But it also needs to recognise the western-centric, biomedical, and financially laden assumptions that many ideas of right and wrong ways to die are predicated upon.

## Research area five – Diversity, equity and society

### Summary:

The inequities and inequalities experienced within healthcare are linked to the ways differences are made to symbolically and materially matter through the cultural, political and economic systems in which people die.



Everyone will die, but not all will die equally, nor will all end of life care be equitable. This research area draws attention to the multiple ways that ideas and experiences of difference become problematic for a person seeking care and support when they are dying or supporting someone with a life-limiting condition.

The survey highlighted multiple concerns that might affect a person's "access" to health, supportive and palliative care. These included:

- their demographic characteristics eg ethnicity, gender, sexuality or age
- socio-economic situation eg low income, structural vulnerability
- geographic location eg rural or inner city

- religious, spiritual, or cultural beliefs
- their terminal condition, especially if not a cancer eg dementia or motor neurone disease
- the effects of co-existing disability or mental health condition
- the services provided, eg hospice or 24-hour home care and support.

As one respondent said, "People don't have simple lives that slot into this service".

In the workshop, participants emphasised the importance of the issues raised in the survey responses for all the previous research areas. They also noted that it is important to recognise that many people

will experience multiple inequities in their lifetime or at the same time eg someone may be LGBTQIA+ and also experience financial difficulties. Participants reflected upon their experiences of how there can be a “reluctance [within healthcare] to actually explore issues in relation to inequity and inequality” suggesting this might be because of the complexity of the systemic and structural issues involved, the time it can take to understand what is happening and why, and that there are not always easy solutions to help “fix the problem”.

This is why social sciences and humanities approaches can be helpful when addressing issues related to inequality and inequity in healthcare and society. Economists and social epidemiologists can contextualise current issues within macro trends or longitudinal narratives, including the effects upon different groups of care being delivered via third sector or private providers. Those in disability studies can investigate the ways that social and health policy and practice are imbued with ableist assumptions, and systematically discriminate against those with disabilities. Gender, ethnicity and cultural studies can draw attention to questions about what research is carried out, by whom, and who for. This might include bringing different perspectives to research design that better connect lived experiences

to the society and culture affecting dying. Such approaches can also bring language and frameworks to understand dying that can help to problematise medical approaches and models of care and disrupt apolitical values that come to be associated with caring for the dying.

Participants from the workshop stressed that it is important to recognise that people’s identities and characteristics can be used to create divisions and hierarchies of need within health and social care. Social science and humanities research can help to explore how and when differences come to matter, and to whom. They can also identify potentially problematic approaches to research in this space that may (unwittingly) create or perpetuate divisions between groups or in access to services. By drawing on social science and humanities approaches, research into dying can move beyond reducing inequity as a problem to be fixed, and recognise the societal, historical and political features of inequality as part of modern healthcare and society. In this aspect, social science and humanities approaches might be more “solution focused”.

# What this study means

**T**his report has drawn upon data generated via the 2025 JJLA Palliative and End of Life Care Priority Setting Partnership. This process involved over a thousand contributions from people with personal or professional experiences of dying, death and bereavement. After initial sifting, these contributions were categorised and analysed by 22 people from multiple academic disciplines and interests during a five hour workshop, generating over a hundred hours of expert insight. We have condensed and presented the findings into this report to address one of society's most important questions: **how can we know dying?**

To answer this, we identified the following five interlinked, non-hierarchical, research areas:

- **Experience, practice and education**  
Social sciences and humanities can show how experiences of delivering or receiving palliative care are connected to multiple levels of the social and cultural context, and use these insights to better inform practice and education.
- **Awareness, communication and planning**  
We identified how social sciences and humanities can show how

communication about dying is multi-directional and multi-layered. This is important when planning for the end of life, which involves value-laden dynamics about what is possible and what is needed.

- **Power, ethics and transitions**  
Social sciences and humanities are particularly well equipped to explore the different dynamics of power, as well as the ideas, judgements and rules about what is right or wrong — especially when they affect the changing body, care, or relationships when dying.
- **Time, space and care**  
We described the ways social sciences and humanities research can show how people can navigate, make or interrogate the different systems, relations and illnesses at different times and locations of care at the end of life.
- **Diversity, equity and society**  
Social sciences and humanities are crucial in ensuring the inequities and inequalities experienced within healthcare are connected to differences made through the cultural, political and economic systems in which people live and die.

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## Championing a different type of report for the future of research into dying

The aim of this report was to identify areas for future social science and humanities research into dying, palliative care and bereavement and use this to provide the basis for generating a richer appreciation for, and use of, multi-disciplinary approaches to improving palliative and end of life care, practice and policy. To do this we needed to embrace the difficulties of working with and within social sciences and humanities by writing a report that exemplified the different types of benefit they bring.

By not prioritising one research area, disciplinary perspective, or specifying research questions we were able to emphasise the range of contributions that different disciplines might have. Moreover, our approach has allowed us to demonstrate how any research into dying involves interlinked multidisciplinary issues. We were then able to show how any concern with experiences of dying were also concerns with interpersonal relations and groups, as well as the systems and structures of society.

By recognising this we can see the limitation of any analysis that focuses upon face value forms of description, but also that there is a need for the expertise that social scientist and humanities scholars have in interpreting, extrapolating or connecting individuals to society (Sheard, 2022).

The value of the social sciences and humanities is that they provide a diverse range of perspectives on any topic. We therefore recognise that the descriptions of the research areas provided, along with the potential contribution that social sciences and humanities can make, have not done justice to this extensive literature. As such, the five research areas should not be seen as definitive. We anticipate the development of other research areas that will demonstrate the value and utility of including social science and humanities perspectives in palliative and end of life care research. But we believe this report contributes to a wider literature that helps to provide a richer appreciation of the need to engage social sciences and humanities in health and social care research (Clarke et al., 2019; Pickersgill et al., 2018), especially if the aim is to improve how dying is experienced (Borgstrom et al., 2018).

For those who want to take the next step in reading about any of the research areas, we have provided a bibliography starter pack (Appendix 1). But it is important to recognise that, like their subject matter (humans), it can

take time to understand what this field has to offer and, even then, any insights might not be easily applied. However, as we have shown in this report, social sciences and humanities can assist in helping to ask better informed questions, provide important insights into the social and cultural contexts that affect health and social care practice, and contribute to policy development that might be better attuned to provide improvements to support the dying.

We hope that this report has provided insight into how social science and humanities are necessary for any research into dying, palliative care and bereavement. We also hope we can inspire further work that will help to develop understanding into the research areas we have identified. As well as primary research on the themes, topics, issues and with people affected, research is also needed to identify and synthesise the existing literature. This could involve providing a more comprehensive picture about what is already known and identify avenues for further research. But that research need not be restricted to the UK. Although this project was UK-based, the research areas were concerned with problematising the ideas, concepts and framings used in those domains. So, we anticipate that this report will resonate with social science and humanities research into the way dying is experienced and understood in many other countries.

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## Recommendations for funders and researchers

The research areas identified in this project can be used in multiple ways. The primary use of this project's findings will be to guide funders. Along with the main outcomes from the 2025 PEOLC with the JLA, this will help to ensure that the research they fund is grounded in the concerns of those who are dying and those that care for them. What this project also draws attention to is the need to ensure that future research into those priorities has a clear and strong foundation in the social sciences and humanities if it is to hope to result in individually profound, systemically productive

and societally meaningful change.

We also invite researchers in social sciences and humanities to actively and confidently contribute to research and public discussions on dying. Just as it is important to hear the voices of those with personal experiences of dying, their close persons or clinicians, we also need people who can help to reflect upon the meanings of what is said and relate people's experiences to wider issues in society. We believe that the research areas we have identified will help researchers make those connections and so will inform future

research proposals, both from within social science and humanities disciplines as well as from health and medical researchers.

As such, this project represents a fresh attempt to bring together existing social science and humanities work on dying with health-based research. But further work to bridge the gap between social sciences and humanities research and health and medical investigations into lived experiences is needed. If we want to understand dying and improve people's experiences of the end of life, then recognising that asking better questions, ones informed by a multitude of disciplines, will help with developing better insights, interventions and policy.

Finally, this study represents the first time that JLA data has been used to directly promote engagement with and research by social

science and humanities. This report therefore marks an important moment for researchers and funders. This is because it both demonstrates a need for social science and humanities that is explicitly grounded in public concerns, as well as represents the diversity of difference to how we can understand problems in society and health that researchers from those disciplines can make. We therefore urge the JLA and those they collaborate with to consider how they can involve the social sciences and humanities in future priority setting initiatives and offer this report and workshop protocol (MacArtney et al., 2025) as inspiration for future collaborations.



# Conclusion

How people think about and experience dying is often related to the circumstances and context in which they find themselves. This is true for those who are dying, but also those who seek to know and improve experiences of the end of life. In the UK, it can mean that talk and experiences of dying are heavily related to health and social care, with clinicians and patients being seen as having the greater interest and influence on what, and how, is

researched. This report is therefore a reminder to funders that dying is as much – if not more – an issue of (social) justice, education, politics, economics, history, location, and relations that can affect experiences of dying and caring for those at the end of life. It is also a call to social science and humanities researchers to advocate for the value of their insights and the difference they can make to how we know dying.

# Appendix 1: Bibliographic starter pack

The following items have been recommended by the report authors, advisory group members and/or workshop participants as literature from the social science and humanities that provides a useful basis for exploring one or more of the five research areas listed in the report, especially the suggested books. Whilst there are many 'seminal' texts across these

fields that speak to the five research areas, for this reading list we have focused on items published within the last 20 years to emphasise contemporary research and scholarship. This is not intended to be an exhaustive reading list. It is offered as a starting point to those new to the field or who are wishing to broaden the disciplinary perspectives they engage with.

## Books (authored and edited):

Allen, R.S., Carpenter, B.D. & Eichorst, M., editors (2018). *Perspectives on Palliative and End-of-Life Care: Disease, Social and Cultural Context*. Routledge.

Bishop, J.P. (2011). *The Anticipatory Corpse: Medicine, Power, and the Care of the Dying*. Notre Dame, IN. University of Notre Dame Press.

Bleakley, A. (2024). *Medical Humanities: Ethics, Aesthetics, Politics*. Routledge.

Borgstrom, E. & Visser, R. (2025). *Critical Approaches to Death, Dying and Bereavement*. Routledge.

Broom, A. (2018). *Dying: A Social Perspective on the End of Life*. Routledge.

Cholbi, M. & Timmerman, T., editors (2021). *Exploring the Philosophy of Death and Dying: Classical and Contemporary Perspectives*. Routledge.

Clark, D. (2016). *To Comfort Always: A History of Palliative Medicine from the Nineteenth Century*. Series: Oxford Medical Histories. Oxford University Press.

Conway, S., editor (2011). *Governing Death and Loss: Empowerment, Involvement and Participation*. Oxford University Press.

De Nardi, S., Orange, H., High, S. & Koskinen-Koivisto, E., editors (2021). *The Routledge Handbook of Memory and Place*. Routledge.

Gott, M. & Ingleton, C., editors (2011). *Living with Ageing and Dying: Palliative and End of Life Care for Older People*. Oxford University Press.

Hagger, L. & Woods, S., editors (2020). *A Good Death?: Law and Ethics in Practice*. Routledge.

Kellehear, A., editor (2009). *The Study of Dying: From Autonomy to Transformation*. Cambridge University Press.

Mallon, S. & Towers, L., editors (2025). *Death, Dying and Bereavement: New Sociological Perspectives*. Routledge.

Moreman, C. (2018). *The Routledge Companion to Death and Dying*. Routledge.

Pasveer, B., Synnes, O., & Moser, I., editors (2021). *Ways of Home Making in Care for Later Life*. Palgrave Macmillan.

Schott, G.R., editor (2023). *The Art of Dying: 21st-century Depictions of Death and Dying*. Palgrave Macmillan.

Servaty-Seib, H.L. & Chapple, H.S., editors (2021). *The Handbook of Thanatology: The Essential Body of Knowledge for the Study of Death, Dying, and Bereavement., 3rd edn*. Association for Death Education and Counselling.

Stillion, J. & Attig, T., editors (2014). *Death, Dying, and Bereavement: Contemporary Perspectives, Institutions, and Practices*. Springer.

Toulson, R. & Wagner, S., editors  
(expected 2025) *Cambridge Handbook of the Anthropology of Death*.  
Cambridge University Press.

## Articles:

Broom, A., Kirby, E., Good, P., Wootton, J. & Adams, J. (2013) The art of letting go: Referral to palliative care and its discontents. *Social Science and Medicine*, 78, 9–16. DOI: [10.1016/j.socscimed.2012.11.008](https://doi.org/10.1016/j.socscimed.2012.11.008).

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Gillis, C.M. (2006) “Seeing the Difference”: An interdisciplinary approach to death, dying, humanities, and medicine. *Journal of Medical Humanities*, 27, 105–115. DOI: [10.1007/s10912-006-9009-6](https://doi.org/10.1007/s10912-006-9009-6).

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McCarthy, J. R., Woodthorpe, K., and Almack, K. (2023) The Aftermath of Death in the Continuing Lives of the Living: Extending ‘Bereavement’ Paradigms through Family and Relational Perspectives, *Sociology*, 57: 6, 1356–1374 DOI: [10.1177/00380385221142490](https://doi.org/10.1177/00380385221142490).

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