AIIHPC
All Ireland Institute of
Hospice and Palliative Care

All Ireland Palliative and End-of-Life Care Research Priorities 2025-2030




Identified and Prioritised by People with Lived and/or Professional Experience.

Final Report from the All Ireland James Lind Alliance Palliative and End-of-Life Care Priority Setting Partnership Refresh 2025

In Partnership With

Marie Curie

James Lind Alliance
Priority Setting Partnerships

HRB Health Research Board

HSC Public Health Agency
Research and Development

Contents

Background

The All Ireland Institute of Hospice and Palliative Care (AIIHPC) is a leading organisation with national and international influence promoting excellence in palliative care. AIIHPC is a collaborative of hospices, health and social care organisations, charities and universities on the island of Ireland. AIIHPC's aim, with our **member organisations**, is to ensure excellent palliative care is available for everyone at the right time and place across the island of Ireland.

AIIHPC established the Palliative Care Research Network in 2012 to address the need for more collaborative multidisciplinary research in palliative care on the island of Ireland. The PCRN offers the palliative care research community on our shared island opportunities to create and engage within a collaborative environment, supporting the development of excellent, high quality, clinically relevant and innovative research projects that reflect, inform, and contribute to the advancement of AIIHPC's work programmes. AIIHPC Palliative Care Research Network is the recognised HRB Collaborative Research Network in Palliative Care on the island of Ireland with infrastructure support from the Health Research Board in Republic of Ireland and Health and Social Care R&D Division, Public Health Agency in Northern Ireland.

Since 2023 AIIHPC, as a member of the Steering Group for the Palliative and End-of-life care Priority Setting Partnership led by **Marie Curie UK**, was involved in the project that in 2025 refreshed the Research Priorities for Palliative and End-of-life care across the UK[1]. This partnership brought together organisations and people with Lived Experience across the UK and was undertaken in partnership with the **James Lind Alliance**[2]. In addition, data was also collected from people in the Republic of Ireland.

Introduction

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-limiting conditions. With an ageing population and people living longer with serious illness, the predicted growth for palliative care on the island is 75% in Republic of Ireland by 2046 and 31% in Northern Ireland by 2040[3,4]. The implementation of the National Adult Palliative Care Policy in Republic of Ireland (2024), Recommendation 6 centres on the concept of 'universality' – that is everyone who needs palliative care services should be able to access them[3]. In Northern Ireland, the Department of Health's Regional Palliative Care in Partnership Programme and the Living Matters Dying Matters Strategy prioritises health investment in care including supporting people to access palliative care[6].

It is acknowledged internationally that palliative and end-of-life care research, though supported by WHO and other organisations, is an underfunded area. In the Republic of Ireland, from 2019 - 2023 it is estimated that 0.5% of available national healthcare research funding was for palliative care research and in Northern Ireland 1.9% for the same period[7]. The latest UK Health Research Analysis showed that research into palliative and end-of-life care made up only 0.23% percent of a total of £2.8 billion of UK health-related, non-commercial research project and programme grant funding in 2022[8].

It is important that we prioritise research in palliative and end-of-life care to maximise the impact of limited resources and direct funding to the most important areas that can improve the quality of life and death for our ageing population and people living longer with life limiting conditions, impacting over 80% of the population, with benefits for the wider health care.

Aim and Scope

This Palliative Care Research Priority Setting Project for the island of Ireland, led by AIIHPC with Marie Curie UK and James Lind Alliance drew on data from respondents across the island of Ireland to:

1. Identify the unanswered ranked questions about palliative and end-of-life care from patient, carer and health and social care perspectives on the island of Ireland.
2. Prioritise those that patients, carers and health and social care professionals agree are the most important for research to address on the island of Ireland.

Research Priorities 2025-2030

Below the top 24 priorities for palliative and end-of-life care research as prioritised by people with lived and/or professional experience across the island of Ireland in order, starting with the highest priority.

Table 1. The Top 24 Priorities for Palliative and End-of-Life Care Research on the Island of Ireland

1	What are the best ways to provide personalised palliative and end-of-life care that meets all the physical, mental, practical, social and spiritual needs of a person with a serious life-limiting illness?
2	How can communication and care co-ordination be improved across the teams of health and social care professionals caring for people with any serious life-limiting illness?
3	What are the best ways to provide emotional and psychological support to people with a serious life-limiting illness, from diagnosis through to end of life?
4	What kinds of palliative and end-of-life care and support need to be in place to enable people to die well at home? What skills do staff need? What helps or hinders the delivery of care at home?
5	How can it be ensured that everyone has access to the palliative and end-of-life care they want or need?
6	What are the best ways to provide support to children (e.g. psychological and social support) when someone important to them is dying, or has died?
7	What are the best ways to train and support staff who provide care at the end of life - either at home, in care homes or nursing homes?
8	How can palliative and end-of-life care better meet the needs of people with illnesses other than cancer e.g. chronic obstructive pulmonary disease (COPD), pulmonary fibrosis, organ failure, motor neuron disease (MND)?
9	How can the quality of palliative and end-of-life care in hospital be improved? What helps or hinders improvement?
10	What skills, training and information do carers, friends and family members need to be able to care for someone who is dying at home (e.g. giving medicines safely by injection, managing incontinence, moving people)? What is the impact (pros and cons) of upskilling the people giving care?

11	How can palliative and end-of-life care better meet the needs of people who have communication difficulties (e.g. people with learning disabilities, or people who have lost their speech or language)?
12	When and how can people with a serious life-limiting illness best be supported to make decisions about their future care, e.g. advance care planning?
13	How do people with dementia experience end of life? How can palliative and end-of-life care better meet their needs and those of their carers, friends and families?
14	How can symptoms at the end of life be managed in a timely way, including by rapid access to medicines?
15	How can palliative and end-of-life care better meet the needs of people who live alone, or are socially isolated?
16	What are the best ways to provide palliative and end-of-life care, support and advice at all hours (24/7 or out of hours)?
17	How can palliative and end-of-life care better meet the complex needs of people with multiple health needs?
18	How can health, social services and charities work more collaboratively to provide joined-up care that better meets the needs of people with a serious life-limiting illness and their friends and families?
19	What are the best ways to ensure adequate pain relief for people with a serious life-limiting illness?
20	What stops people's wishes from being acted upon (e.g. with future or advance care plans)? How can any barriers be overcome?
21	What are the best ways to meet the palliative and end-of-life care needs of teenagers/ young adults moving into adult services?
22	What are the best ways to manage people who are restless, agitated or experience sudden confusion (delirium) at the end of life?
23	What are the best ways to identify that a person is dying or is near to death (in their last year, months, weeks, days of life)? How can health professionals better recognise these stages in people with any serious life-limiting illness?
24	How can discharge from hospital be improved for people with any serious life-limiting illness?

Outline of the Process

In 2023, Marie Curie UK, in collaboration with the James Lind Alliance, with co-funding support from Motor Neurone Disease (MND) Association and the Economic and Social Research Council (ESRC) as part of UK Research and Innovation, initiated a refresh of the Palliative and End-of-life care Priority Setting Partnership (PEoLCPSP) that was first undertaken in 2015[9].

AIIHPC was a member of the Steering Group for the initial Priority Setting Partnership in 2015 for the UK and led the development of the priorities for the island of Ireland. This refresh launched in 2023 included a lived experience group who supported the Priority Setting Partnership through the following steps, outlined in the Figure 1.

Figure 1. James Lind Alliance Methodology for Palliative and End-of-life care Priority Setting Partnership

Palliative and End-of-Life Care Priority Setting Project

Survey One - Identifying Questions

Survey One was developed based on the 2015 survey and refined with feedback from the Steering Group and the Lived Experience Group. The survey was piloted with the Steering Group, the Lived Experience Group, and the Marie Curie Research Voices Group. A project webpage was created to share the survey link, project details, and a communications pack for organisations wishing to promote the survey[11]. AIIHPC promoted the survey through its networks and newsletter to ensure participation in the survey across Northern Ireland and the Republic of Ireland.

A total of 1,032 responses were received from across the UK including 76 responses from Northern Ireland (7%) and an additional 60 responses from the Republic of Ireland (6%) were also collected. The dataset included input from people living with serious life-limiting illness, current carers, bereaved family or friends, and health and social care professionals. A final longlist of 79 questions was developed from the data and evidence checked to ensure that they had not been fully answered by research, and which is available as an open access dataset[12].

Survey Two - Prioritising Questions

Survey Two aimed to prioritise the 79 questions generated from Survey One. AIIHPC promoted the survey through its networks and newsletter to ensure participation in the survey across Northern Ireland and the Republic of Ireland. A total of 626 responses were received from across the UK including 34 responses from Northern Ireland (5%), and an additional 3 responses from the Republic of Ireland (<1%) were also collected. The 20 highest-priority questions from each group were carried forward to the UK wide prioritisation workshop, resulting in a longlist of 24 questions[12].

UK Wide Prioritisation Workshop

In November 2024, an in-person workshop was attended by 20 people who had a range of lived and professional experiences of palliative and End-of-life care. The James Lind Alliance methodology was used to prioritise the 24 questions identified in Survey Two, to produce a ranking of the priorities for across the UK[12].

Identifying priorities for the Island of Ireland

To identify which of the questions from the UK wide Priority Setting Project and additional data collected from the Republic of Ireland should be considered for an Island of Ireland workshop, the data was considered in a number of ways. Rankings of the 79 longlisted questions generated in Survey Two from respondents from the Island of Ireland and respondents from UK and Republic of Ireland were compared. The rankings from the UK prioritisation workshop and the rankings of respondents from the island of Ireland in Survey Two were also considered and reanalysed separately by AIIHPC with support from Marie Curie and the James Lind Alliance Adviser to check for any disparities in the rankings due to how services are provided in the different jurisdictions.

This analysis showed that 21 of the 24 questions tabled at the UK workshop also reflected the rankings in the island of Ireland and were also carried forward to the workshop. However, two of the UK workshop questions ranked lower overall in comparison to the rankings in the island of Ireland and were replaced to take account of the island of Ireland's perspective on specific issues related to their existing provision of care and support both in Northern Ireland and the Republic of Ireland. One of the questions tabled at the UK workshop was not included in the island of Ireland workshop as the topic was already covered by another question.

The Final Workshop Island of Ireland

A one-day in person workshop took place 16 October 2025 in Dublin with people with lived and/or professional experience of palliative and end-of-life care from diverse backgrounds across the island of Ireland. The aim of the workshop was to determine the Top 10 research questions for palliative and end-of-life care in the Republic of Ireland and Northern Ireland. The workshop focused on a list of 24 questions, derived from survey two (see above section) that compared UK rankings and Northern Ireland and Republic of Ireland rankings to produce the final list.

Twenty-two participants with varied experiences in palliative and end-of-life care took part in the workshop, including people living with advanced cancer (n=3), people living with heart failure (n=2), bereaved carer relatives (n=4), and interested citizens (n=2) and health and social care professionals (n=11); with 68% female and 32% male from across the island of Ireland.

Participants with professional experience included a nurse, palliative medicine consultant, occupational therapist, pharmacist, physiotherapist, psychologist, social worker, speech and language therapist, chaplain, and complementary therapist.

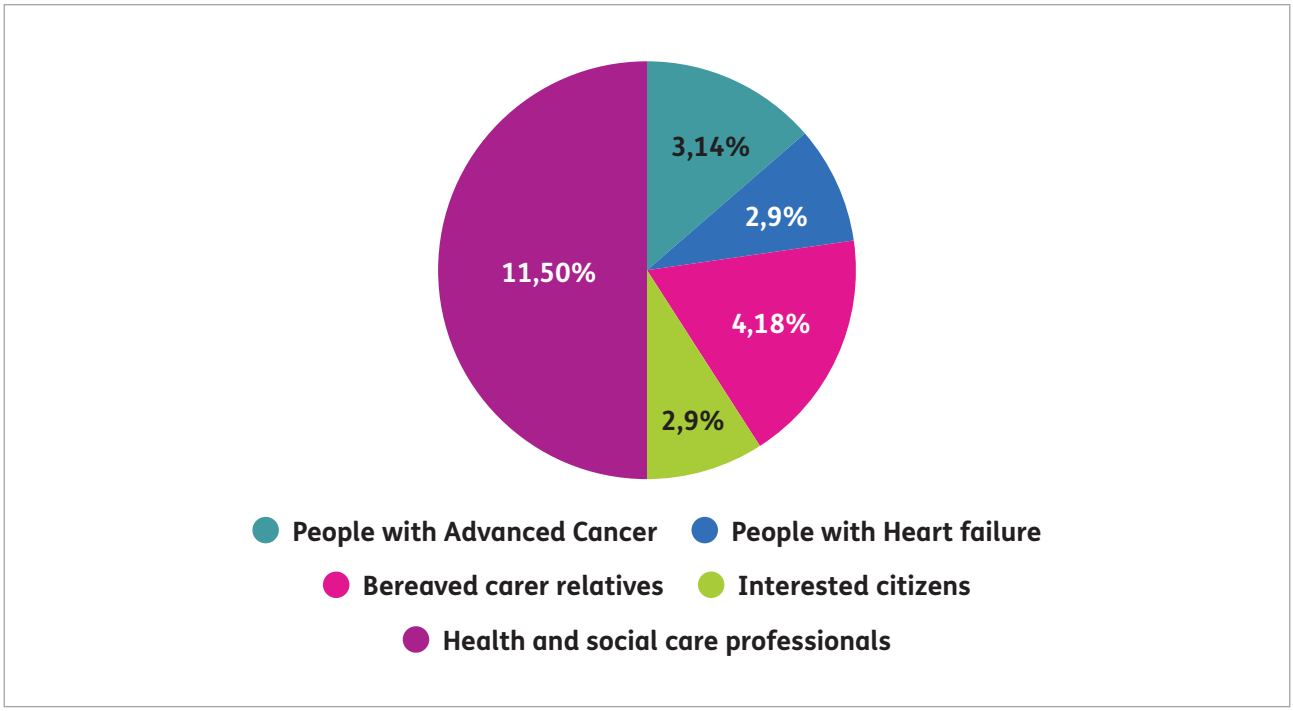

Figure 2. Distribution of Final Workshop Participants

Six observers attended the workshop, to follow the process without influencing it, from the Health Research Board (n=1), Health and Social Care R&D, Public Health Agency (n=1), Department of Health Republic of Ireland (n=1) and AIIHPC (n=3).

The workshop followed the James Lind Alliance priority setting methodology and was facilitated by James Lind Alliance facilitators, Maryrose Tarpey (Lead), Caroline Magee, and Toto Grunlund. An adapted Nominal Group Technique was used to generate discussion, ranking, consensus and agreement which involved a series of small group activities[13].This process mirrored the Final Prioritisation Workshop undertaken in London in November 2024.

Prior to the workshop, participants were invited to review the list and rank the questions from 1 to 24, with 1 representing the most important and 24 the least important priority for future research. A set of guiding principles was shared with participants to ensure that discussions during the workshop would be inclusive, respectful, and productive.

During the workshop participants were encouraged to express their personal and professional opinions and experiences regarding which research questions could make the greatest difference to people with palliative and end-of-life care needs. Participants were divided into three small groups of 7/8 people and worked together to make decisions about the research questions they considered most important.

The groups were designed to include a mix of individuals representing diversity in lived experience, gender, jurisdiction, and professional background. In the first discussion, participants used their worksheets (see Appendix 2) to share their top three and bottom three priorities.

The same groups worked together to rank the 24 research questions in order of priority, using printed cards laid out on a table to guide the process from most to least important. The facilitators then combined the rankings from all three groups to produce an overall ranking of the 24 questions. Participants were then reorganised into three new small groups and focused on the top 10 questions and made adjustments where the group agreed (see Appendix 3: Final Workshop Ranking).

The facilitators then combined the groups' question rankings to produce an overall ranking list. In the final session, the ranked order of the questions was shared with the participants reviewed and Top 10 research priorities finalised (Table 1).

Figure 3. Stages of Nominal Group Technique Used in Workshop

Comparison of Priorities from the Island of Ireland from 2025 and 2015

Below shows a comparison of the priorities identified in the All Ireland refresh in 2025 compared with the priorities that were originally identified in the 2015 work across Ireland and includes details of original ranking where relevant.

Table 2. Comparison of 24 Priorities in 2025 to 24 Priorities in 2015 on the Island of Ireland

	Ranked Priorities 2025	Priorities 2015 and Rank
1	What are the best ways to provide personalised palliative and end-of-life care that meets all the physical, mental, practical, social and spiritual needs of a person with a serious life-limiting illness?	Not present
2	How can communication and care co-ordination be improved across the teams of health and social care professionals caring for people with any serious life-limiting illness?	What are the best ways to make sure there is continuity for patients at the end of life, in terms of the staff that they have contact with, and does this improve quality of palliative care? Would having a designated case-coordinator improve this process? (6) What are the best ways to facilitate communication across services and between healthcare professionals, including effective IT systems, team meetings and remote technology? (22)
3	What are the best ways to provide emotional and psychological support to people with a serious life-limiting illness, from diagnosis through to end of life?	Not present
4	What kinds of palliative and end-of-life care and support need to be in place to enable people to die well at home? What skills do staff need? What helps or hinders the delivery of care at home?	What are the benefits, and best ways, of providing care in the patient's home and how can home care be maintained as long as possible? Does good co-ordination of services affect this? (2)

5	How can it be ensured that everyone has access to the palliative and end-of-life care they want or need?	What are the core palliative care services that should be provided no matter what the patients' diagnosis is? (12) How can patients, carers and families easily access care services, equipment and statutory welfare benefits? How can people learn what resources are available and limit the time it takes to access these? (13)
6	What are the best ways to provide support to children (e.g. psychological and social support) when someone important to them is dying, or has died?	What are the best ways to support children and young people when someone close to them is dying or has died? This includes communicating with them about the diagnosis and dying process, enabling them to talk about their experience and providing bereavement support.(7)
7	What are the best ways to train and support staff who provide care at the end of life - either at home, in care homes or nursing homes?	Are hospices, hospitals and care homes providing adequate staff training to deliver specialist palliative care, and to what extent does funding affect this? How can high quality trained staff be ensured no matter where the care is being delivered? (10)
8	How can palliative and end-of-life care better meet the needs of people with illnesses other than cancer e.g. chronic obstructive pulmonary disease (COPD), pulmonary fibrosis, organ failure, motor neuron disease (MND)?	What are the best ways to begin and deliver palliative care for patients with non-cancer diseases (such as COPD, heart failure, MND, AIDS, multiple sclerosis, Crohn's disease and stroke)? (9) How can we best determine a person's palliative care needs, particularly for patients with non-cancer diseases such as Motor Neurone Disease (MND), Parkinson's disease, Dementia and heart failure? (20)

9	How can the quality of palliative and end-of-life care in hospital be improved? What helps or hinders improvement?	Not Present
10	What skills, training and information do carers, friends and family members need to be able to care for someone who is dying at home (e.g. giving medicines safely by injection, managing incontinence, moving people)? What is the impact (pros and cons) of upskilling the people giving care?	What information and training do carers and families need to provide the best care for their loved one who is dying? (8)
11	How can palliative and end-of-life care better meet the needs of people who have communication difficulties (e.g. people with learning disabilities, or people who have lost their speech or language)?	Not Present
12	When and how can people with a serious life-limiting illness best be supported to make decisions about their future care, e.g. advance care planning?	What are the benefits of Advance Care Planning and other approaches to listening to and incorporating patients' preferences? Who should implement this and when? (5)
13	How do people with dementia experience end of life? How can palliative and end-of-life care better meet their needs and those of their carers, friends and families?	What is the best way to give palliative care to patients with dementia and their carers and families? This includes communicating about their diagnosis when they are being cared for at home or elsewhere? (15)
14	How can symptoms at the end of life be managed in a timely way, including by rapid access to medicines?	Are outcomes (for example, symptom control and incidental prolonging of life) better for terminally ill patients the sooner palliative care is introduced and services are accessed? (18)
15	How can palliative and end-of-life care better meet the needs of people who live alone, or are socially isolated?	How can people who live alone and do not have friends or family nearby receive adequate palliative care, particularly if they wish to stay in their homes? (11)

16	What are the best ways to provide palliative and end-of-life care, support and advice at all hours (24/7 or out of hours)?	What are the best ways of providing palliative care outside of 'working hours' to avoid crises and help patients to stay in their place of choice? This includes symptom management, counselling and advice, GP visits and 24-hour support, for patients, carers and families? (1)
17	How can palliative and end-of-life care better meet the complex needs of people with multiple health needs?	Not present
18	How can health, social services and charities work more collaboratively to provide joined-up care that better meets the needs of people with a serious life-limiting illness and their friends and families?	Not present
19	What are the best ways to ensure adequate pain relief for people with a serious life-limiting illness?	What are the best ways to make sure that palliative care patients receive adequate pain and symptom relief and which drugs for pain management are best in terms of side-effects, such as drowsiness? (3)
20	What stops people's wishes from being acted upon (e.g. with future or advance care plans)? How can any barriers be overcome?	Not present
21	What are the best ways to meet the palliative and end-of-life care needs of teenagers/ young adults moving into adult services?	Not present
22	What are the best ways to manage people who are restless, agitated or experience sudden confusion (delirium) at the end of life?	What are the best ways to diagnose and treat delirium, agitation, distress, and restlessness in people at the end of life? (24)

23	What are the best ways to identify that a person is dying or is near to death (in their last year, months, weeks, days of life)? How can health professionals better recognise these stages in people with any serious life-limiting illness?	What are the signs that a person will die in the next few days and how can detection of these signs be improved? How can families be made aware? (19)
24	How can discharge from hospital be improved for people with any serious life-limiting illness?	Not present

Strengths and Limitations

Diversity and motivation of respondents

Increasingly, it is recognised that there are specific population groups that experience inequitable access to, or experience with, palliative care on the island of Ireland, and internationally. Recommendation 6 of the National Adult Palliative Care Policy (2024) in the Republic of Ireland centres on the concept of 'universality' – that is everyone who needs palliative care services should be able to access them[3].

A diverse mix of participants were identified and participated in the workshop across the Island of Ireland who completed the pre-workshop exercises and ensured their voices were heard during the prioritisation exercise. The strong representation of people with life-limiting conditions, carers, and range of health and social care professional disciplines ensured a rich discussion and prioritisation process, allowing the workshop to capture a wide range of perspectives and experiences.

Methodological Considerations

The 24 questions taken to the All Ireland prioritisation workshop were generated from surveys which formed part of the Marie Curie James Lind Alliance Palliative and End-of-Life Care Priority Setting Project. This survey was open to respondents from across the UK and Republic of Ireland. Within the Marie Curie UK Wide Priority Setting Project including Republic of Ireland, in Survey One and Two respondents from Northern Ireland were overrepresented (7% of the entire sample in Survey One and 5% in Survey Two) while respondents from the Republic of Ireland were slightly underrepresented in Survey Two (less than 1%).

Observations from the workshop highlighted the effectiveness of the in-person prioritisation process. In some small groups, it was noted that reaching consensus took slightly longer than planned in the second round. However, the facilitators agreed there was an unusually high level of consensus across the groups around the Top 10 priorities. These experiences further demonstrated the rigour of the method, the active and wholehearted engagement of participants, and the robustness of the prioritisation process.

Reflections from Workshop Participants

Below some quotes received from workshop participants from the post-workshop evaluation.

I was influenced, informed and educated by the discussions in the groups which were very valuable and changed my perspective on some of my priorities

– Person with lived experience

The placing of the last question was very difficult as one person felt very strongly about its placement as they were directly affected by how a bad discharge from hospital affected them. All of the questions deserve to be researched, but the idea that they are the top 24 highlights that they are all important to society

– Person with professional experience

I found it hard to prioritise between questions that were broad and over-arching, and others that were more discrete questions... Nonetheless I think we took the best approach as a group, in putting the broader questions on top

– Person with lived experience

The group process was very worthwhile. I feel the agreed top 10 questions are solid and relevant topics to explore

– Person with professional experience

Conclusion and Recommendations

AIIHPC value the importance of this work in shaping the future development of palliative and end-of-life care research on the Island of Ireland through AIIHPC Palliative Care Research Network. AIIHPC will seek to address these priority areas through discussion and consideration of their implications with research funders, researchers, service providers, and policy makers. It is paramount that research focuses on areas that has been prioritised by people with life-limiting conditions, their families, carers, and health and social care professionals. AIIHPC will through the Palliative Care Research Network seek to develop more specific research questions from these research priorities.

Recommendations for Key Stakeholders

Research Funders

As funding for palliative and end-of-life care is a recognised underfunded research area, it is important that funding is targeted towards the priority areas identified by people with lived and/or professional experience of palliative and end-of-life care. In seeking to address these priorities, the research funders should co-ordinate their efforts and seek to address these priority areas together.

Research Community

These priorities will support researchers from AIIHPC Palliative Care Research Network and AIIHPC Early Career Researcher Forum and other researchers to identify areas for future research and demonstrate that existing research is in an area that matters most to people who will use or benefit from this research. The priorities will also support the delivery of AIIHPC's Palliative Care Research Network Strategic Plan 2023-2027 and they will inform the development of the subsequent plan.

Policy Makers and Charities

It is anticipated that policy makers and charity funders in the area will be able to use the priorities to demonstrate the need for further funding and focus on palliative and end-of-life care. AIIHPC will use and disseminate the priorities to influence these stakeholders on research that has been prioritised by people with life-limiting conditions, their families, carers, and health and social care professionals.

Acknowledgments

We would like to thank all the people with palliative care needs, families and carers, people who are bereaved, health and social care professionals and wider community who gave their time to share their thoughts regarding priorities for palliative and end-of-life care research and those who helped us to prioritise them. We thank Dr Briony Hudson and Dr Sabine Best from Marie Curie UK for involving us in the Palliative and End-of-life care Priority Setting Partnership project and Maryrose Tarpey (Lead), Caroline Magee and Toto Grunlund from James Lind Alliance for facilitating this Island of Ireland project. Finally, thank you to the Health Research Board and Health and Social Care R&D Division, Public Health Agency who provided funding support for this project. This report was compiled by Dr Mary Rabbitte, Research Programme Manager with support of Dr Busra Ertugrul, Research Support and Knowledge Translation Lead and Jane Clare, PCRN Project Manager at AIIHPC.

References

1. Palliative and End-of-life care research priorities project | Marie Curie **https://www.mariecurie.org.uk/research-and-policy/research/palliative-end-of-life-care-research-priorities-project?preview=true**
2. James Lind Alliance **https://www.jla.nihr.ac.uk/**
3. May P, Johnston BM, Normand C et al. Population-based palliative care planning in Ireland: how many people will live and die with serious illness to 2046? HRB Open Research. 2020;2:35 **https://doi.org/10.12688/hrbopenres.12975.2**
4. McKeaveney, C, McConnell T, Craig Harrison, Stone V, and Reid J. Population based projects of place of death for Northern Ireland by 2040. Palliative Medicine and Hospice Care. 2021;6:2. **https://pure.qub.ac.uk/en/publications/population-based-projections-of-place-of-death-for-northern-irela/**
5. Department of Health 'National Adult Palliative Care Policy'. Dublin, October 2024. **https://assets.gov.ie/static/documents/national-adult-palliative-care-policy.pdf**
6. Department of Health 'Living Matters Dying Matters'. Belfast, March 2010. **https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/living-matters-dying-matters.pdf**
7. Hudson B, Best S, Ashcroft P et al. Research priorities for palliative and end-of-life care - Final report from the 2025 James Lind Alliance palliative and end-of-life care priority setting partnership refresh [version 1; not peer reviewed]. Health Open Research 2025;7:2
8. James Lind Alliance 'Palliative and End-of-life care Refresh'. **https://www.jla.nihr.ac.uk/priority-setting-partnerships/palliative-and-end-of-life-care-refresh#tab-about-this-priority-setting-partnership**
9. Information provided by HRB and HSC R&D, PHA in relation to request for information by AIIHPC on palliative care research funding from 2019-2023.
10. UK Health Research Analysis 2022 (UK Clinical Research Collaboration, 2023) **https://hrcsonline.net/reports/analysis-reports/uk-health-research-analysis-2022/**
11. Bush J, Crooks J, Dawson A. et al. Reflections on the impact of the Lived Experience Group in the James Lind Alliance Palliative and End-of-life care Priority Setting Partnership Refresh. Res Involv Engagem. 2025;11:133. **https://doi.org/10.1186/s40900-025-00774-4**
12. Priority Setting Partnership with the James Lind Alliance. Palliative and End-of-life care Priority Setting Partnership (PeolcPSP).
13. Cowan K. The James Lind Alliance Guidebook. 2021. **https://www.jla.nihr.ac.uk/jla-guidebook**

Appendix 1: All Ireland Palliative Care Research Prioritisation Workshop Agenda

Thursday 16 October 2025 10am – 4pm
Venue: Education and Research Centre in Our Lady's Hospice & Care Services, Dublin

Time	Session
10:00	Registration and refreshments
10:20	**Welcome and introduction to the workshop** (main room) • Overview of the James Lind Alliance and the priority setting workshop. *Maryrose Tarpey JLA Chair* • About the All Ireland Palliative Care Research Priorities *Mary Rabbitte Project Lead (AIIHPC)* • Questions from people taking part in the workshop
10:50	**Small group session 1 – comparing priorities** (breakout rooms) • Participants divided into three small groups to discuss and reflect on their top priorities from the list of questions for research
11:50	Refreshment break *(20 mins)*
12:10	**Small group session 2 – first round of prioritisation** (breakout rooms) • In the same small groups, participants rank the questions in order of priority
13:10	Lunch break *(45 mins)*
13:55	**Welcome back – progress review** (main room) • Overview of the current ranking, based on all three groups' priorities.
14:10	**Small group session 3 – new groups, review the priorities** (breakout rooms) • Participants divided into three new small groups to discuss and potentially revise the order of the priorities
15:05	Refreshment break *(20 mins)*
15:25	**Final priority setting session** (main room) • Overall ranking presented *JLA Chair* • Final ranking discussed and top 10 priorities for future research agreed
15:45	**Summing up, next steps and thank you** (main room) • JLA Chair & Mary Rabbitte Project Lead
16:00	Workshop ends

Appendix 2:
Workshop Participant Worksheet

Ref	Question	Your ranking (1-24)	Notes
A	What are **the best ways to provide support to children** (e.g. psychological and social support) when someone important to them is dying, or has died?		
B	How can **communication and care co-ordination** be improved across the teams of health and social care professionals caring for people with any serious life-limiting illness?		
C	What kinds of palliative and end-of-life care and support need to be in place **to enable people to die well at home?** What skills do staff need? What helps or hinders the delivery of care at home?		
D	How can palliative and end-of-life care **better meet the needs of people who live alone**, or are socially isolated?		
E	What are the **best ways to provide palliative and end-of-life care, support and advice at all hours** (24/7 or out of hours)?		
F	What are the **best ways to provide personalised palliative and end-of-life care** that meets all the physical, mental, practical, social and spiritual needs of a person with a serious life-limiting illness?		
G	What **stops people's wishes from being acted upon** (e.g. with future or advance care plans)? How can any barriers be overcome?		
H	How can it be ensured that everyone has **access to the palliative and end-of-life care** they want or need?		

I	How can palliative and end-of-life care better meet the needs of people who have **communication difficulties** (e.g. people with learning disabilities, or people who have lost their speech or language)?		
J	How can **health, social services and charities work more collaboratively to provide joined-up care** that better meets the needs of people with a serious life-limiting illness and their friends and families?		
K	What are the best ways to ensure **adequate pain relief** for people with a serious life-limiting illness?		
L	How can the **quality of palliative and end-of-life care in hospital be improved**? What helps or hinders improvement?		
M	How can palliative and end-of-life care better meet the **complex needs** of people with multiple health needs?		
N	What are the **best ways to train and support staff who provide care** at the end of life - either at home, in care homes or nursing homes?		
O	When and how can people with a serious life-limiting illness best be supported to **make decisions about their future care,** e.g. advance care planning?		
P	What are the best ways to manage people who are **restless, agitated or experience sudden confusion** (delirium) at the end of life?		
Q	What are the **best ways to provide emotional and psychological support** to people with a serious life-limiting illness, from diagnosis through to end of life?		
R	How can **symptoms at the end of life be managed** in a timely way, including by rapid access to medicines?		

S	How can palliative and end-of-life care better **meet the needs of people with illnesses other than cancer** e.g. chronic obstructive pulmonary disease (COPD), pulmonary fibrosis, organ failure, motor neuron disease (MND) or chronic fatigue syndrome (CFS)?		
T	What are the best ways to meet the palliative and end-of-life care **needs of teenagers/ young adults moving into adult services?**		
U	**How do people with dementia experience end of life**? How can palliative and end-of-life care better meet their needs and those of their carers, friends and families?		
V	How can **discharge from hospital** be improved for people with any serious life-limiting illness?		
W	What are the **best ways to identify that a person is dying or is near to death** (in their last year, months, weeks, days of life)? How can health professionals better recognise these stages in people with any serious life-limiting illness?		
X	What **skills, training and information do carers, friends and family members need** to be able to care for someone who is dying at home (e.g. giving medicines safely by injection, managing incontinence, moving people)? What is the impact (pros and cons) of upskilling the people giving care?		

Appendix 3:
Final Workshop Ranking

1	**F**	What are the **best ways to provide personalised palliative and end-of-life care** that meets all the physical, mental, practical, social and spiritual needs of a person with a serious life-limiting illness?	**1**	**6**	**1**
2	**B**	How can **communication and care co-ordination** be improved across the teams of health and social care professionals caring for people with any serious life-limiting illness?	**8**	**1**	**4**
3	**Q**	What are the **best ways to provide emotional and psychological support** to people with a serious life-limiting illness, from diagnosis through to end of life?	**4**	**2**	**7**
4	**C**	What kinds of palliative and end-of-life care and support need to be in place **to enable people to die well at home?** What skills do staff need? What helps or hinders the delivery of care at home?	**7**	**8**	**3**
5	**A**	What are **the best ways to provide support to children** (e.g. psychological and social support) when someone important to them is dying, or has died?	**5**	**9**	**9**
6	**N**	What are the **best ways to train and support staff who provide care** at the end of life - either at home, in care homes or nursing homes?	**13**	**4**	**6**
7	**H**	How can it be ensured that everyone has **access to the palliative and end-of-life care** they want or need?	**2**	**5**	**19**
8	**O**	When and how can people with a serious life-limiting illness best be supported to **make decisions about their future care,** e.g. advance care planning?	**3**	**19**	**8**
9	**S**	How can palliative and end-of-life care better **meet the needs of people with illnesses other than cancer** e.g. chronic obstructive pulmonary disease (COPD), pulmonary fibrosis, organ failure, motor neuron disease (MND)?	**12**	**11**	**11**
10	**L**	How can the **quality of palliative and end-of-life care in hospital be improved**? What helps or hinders improvement?	**14**	**7**	**14**

11	**I**	How can palliative and end-of-life care better meet the needs of people who have **communication difficulties** (e.g. people with learning disabilities, or people who have lost their speech or language)?	**6**	**15**	**15**
12	**U**	**How do people with dementia experience end of life**? How can palliative and end-of-life care better meet their needs and those of their carers, friends and families?	**9**	**12**	**16**
13	**X**	What **skills, training and information do carers, friends and family members need** to be able to care for someone who is dying at home (e.g. giving medicines safely by injection, managing incontinence, moving people)? What is the impact (pros and cons) of upskilling the people giving care?	**11**	**3**	**23**
14	**D**	How can palliative and end-of-life care **better meet the needs of people who live alone**, or are socially isolated?	**17**	**13**	**13**
15	**E**	What are the **best ways to provide palliative and end-of-life care, support and advice at all hours** (24/7 or out of hours)?	**16**	**17**	**10**
16	**M**	How can palliative and end-of-life care better meet the **complex needs** of people with multiple health needs	**19**	**22**	**2**
17	**R**	How can **symptoms at the end of life be managed** in a timely way, including by rapid access to medicines?	**21**	**18**	**5**
18	**J**	How can **health, social services and charities work more collaboratively to provide joined-up care** that better meets the needs of people with a serious life-limiting illness and their friends and families?	**10**	**20**	**20**
19	**K**	What are the best ways to ensure **adequate pain relief** for people with a serious life-limiting illness?	**15**	**23**	**12**
20	**G**	What **stops people's wishes from being acted upon** (e.g. with future or advance care plans)? How can any barriers be overcome?	**20**	**10**	**21**
21	**T**	What are the best ways to meet the palliative and end-of-life care **needs of teenagers/ young adults moving into adult services?**	**18**	**16**	**17**

22	**P**	What are the best ways to manage people who are **restless, agitated or experience sudden confusion** (delirium) at the end of life?	**23**	**14**	**22**
23	**W**	What are the **best ways to identify that a person is dying or is near to death** (in their last year, months, weeks, days of life)? How can health professionals better recognise these stages in people with any serious life-limiting illness?	**24**	**24**	**18**
24	**V**	How can **discharge from hospital** be improved for people with any serious life-limiting illness?	**22**	**21**	**24**

Notes

AIIHPC

All Ireland Institute of
Hospice and Palliative Care

AIIHPC, Education Centre,
Our Lady's Hospice & Care Services,
Harold's Cross, Dublin D6W EV82

www.aiihpc.org | info@aiihpc.org

Company Registration No: 744467
Charity Registration No: 20206781 | CHY 23287