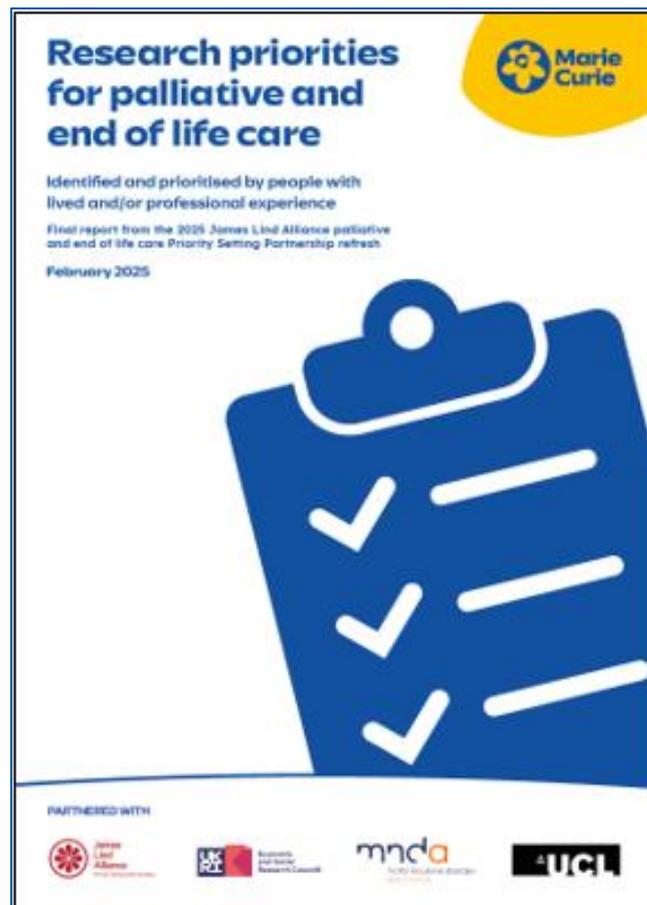


# Report of the JLA NIHR workshop session titled: Networking Workshop: From Priorities to Partnerships – NIHR JLA Rolling Call

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## Contents

Background .....	3
Workshop overview .....	3
JLA Rolling Call highlight notice overview .....	4
Key issues highlighted across discussions .....	6
Overall summary .....	6
Individual breakout room summaries .....	6
Enabling people to die well at home; what helps or hinders the delivery of care at home and what skills do staff (priority 3) and carers (priority 7) need .....	6
How can palliative and end of life care better meet the needs of people with multiple health conditions (priority 5) .....	8
Better meeting the needs of people who live alone or are socially isolated (priority 10)	10
Conclusions .....	11
Useful resources .....	12

## Background

The James Lind Alliance (JLA) is a non-profit organisation that champions the partnership of patients, carers and health and social care professionals in the setting of research priorities via Priority Setting Partnerships (PSPs).

In 2025, Marie Curie and other partners undertook a refresh of the 2015 James Lind Alliance Palliative and End of Life Care Priority Setting Partnership. This work identified 24 priorities for palliative and end of life care research that were identified through consultation with people with lived and professional experience of palliative and end of life care. The final report from the project can be accessed [here](#)

The National Institute for Health and Care Research (NIHR) is the largest funder of palliative and end of life care research in the UK. The NIHR have developed an NIHR JLA rolling call that accepts applications to any research priorities identified by JLA Priority Setting Partnerships. On occasion, they use identified research priorities in JLA Priority Setting Partnerships to develop a JLA rolling call highlight notice. The aim of the highlight notice is to enable swift signalling of priority research areas across programmes.

## Workshop overview

Marie Curie and the NIHR hosted a webinar on 26<sup>th</sup> February 2026 to highlight the current NIHR JLA rolling call and provide an opportunity for researchers to connect with each other, with a focus on knowledge sharing and networking. The session was attended by 53 people.

The session was chaired by Anni Bailey (Research Programme Lead, Department of Health and Social Care) and featured presentations from the James Lind Alliance and the National Institute for Health and Care Research (NIHR). In the second half of the session breakout groups were facilitated for interested researchers to network, exchange insights, and explore ongoing and emerging research ideas that align with each priority highlighted in the NIHR rolling call.



## JLA Rolling Call highlight notice overview

Based on the top 10 priorities identified in the JLA refresh, the NIHR identified key research gaps for the following priorities:

- Enable people to die well at home; what helps or hinders the delivery of care at home and what skills do staff (priority 3) and carers (priority 7) need –**  
Supports a shift from hospital to community-based care; addresses resource gaps and inequalities in care. The NIHR funded research portfolio is currently limited to administration and management of medication
- Better meet the needs of people with multiple health conditions (priority 5) -**  
NIHR strategic priority to enable more high-quality Multiple Long Term Condition research to improve care. The research portfolio is currently limited to studies around end-of-life care for those with illnesses other than cancer
- Better meet the needs of people who live alone or are socially isolated (priority 10) -** focuses on reducing health inequalities and supports NIHR Research Inclusion Strategy. Currently the research portfolio is limited to people who are homeless and those living in rural, remote and coastal communities

The NIHR Domestic funding programme webpage with more information can be found here: [Domestic funding programmes | NIHR](#). The following research programmes are currently open for research applications and are participating in the rolling call.

Research programme	Overview of NIHR programme remits	Call open date	Call close date
<a href="#">Efficacy and Mechanism Evaluation (EME)</a>	Studies into the efficacy of new approaches to disease prevention and treatment. It supports clinical trials and other studies which test how interventions may work in practice.	3rd December 2025	1st April 2026
<a href="#">Public Health Research (PHR)</a>	Research to improve the health of the public and reduce inequalities. Research aims to generate evidence to test and	16th December 2025	21st April 2026



	inform delivery of practical, non-NHS interventions.		
<a href="#">Health Technology Assessment (HTA)</a>	Research into the clinical and cost-effectiveness of treatments and tests. Funded studies often compare a new technology's existing evidence with the current methods.	8th January 2026	6th May 2026
<a href="#">Programme Grants for Applied Research (PGfAR)</a>	A researcher-led grant programme to fund applied health and social care research. Studies seek to address health and care needs in areas other funders may not focus on.	4th February 2026	1st April 2026
<a href="#">Research Programme for Social Care (RPSC)</a>	Generates evidence to improve and strengthen the way in which adult and children's social care is provided for users of care services, carers, the social care workforce, and the UK public.	4th March 2026	17th June 2026
<a href="#">Research for Patient Benefit (RfPB)</a>	Research around the day-to-day practice of health and social care staff. Studies aim to increase the effectiveness of services, provide value for money and benefit patients and the public.	11th March 2026	8th July 2026
<a href="#">Invention for Innovation (i4i)</a>	Translational research funding scheme aimed at medical devices, in vitro diagnostic devices and digital health technologies addressing an existing or emerging health or social care need.	8th April 2026	27th May 2026

## Key issues highlighted across discussions

### *Overall summary*

People in all three breakout groups shared thoughts about the difficulties of engaging people and professionals in the design and delivery of research. Attendees recognised the importance of including people who need palliative care, and the challenges that health and social care staff may face in supporting research alongside clinical practice or other commitments due to factors such as a lack of capacity, or service funding constraints. Similarly, attendees recognised the importance of involving people with lived experience in research to ensure work is accessible and applicable, in particular people from underrepresented groups.

Breakout rooms also identified barriers and inequities to accessing care including challenges identifying deterioration or end of life care needs and identified existing training gaps for carers and professionals around palliative and end of life care (PEoLC).

Additionally, attendees in all 3 break out groups identified the need for better service models and coordination across health care including consistent data quality and measurement reporting across services so that it is easier for evidence to be gathered, and research to be conducted.

### Individual breakout room summaries

#### *Enabling people to die well at home; what helps or hinders the delivery of care at home and what skills do staff (priority 3) and carers (priority 7) need*

**The research questions that attendees discussed for these priorities included:**

- What skills do domiciliary carers have and need at end-of-life?
- How are staff training needs identified and how is the quality of training and care managed and funded?
- What is the effectiveness of online training courses for carers at the end of life.

- How can family carers be better trained to identify the dying process to prevent avoidable emergency service contact and protect trained carer time, and to ensure that their loved ones are able to be cared for at home if that is their wish?
- What role does the ambulance service play at the end of life?
- How can carers prevent and/or manage delirium at the end of life at home?
- How can the impact on family carers be measured to identify the quality of death/dying experiences that their loved ones had?

**Challenges identified conducting research in this area include:**

- This is a complex topic for research. Establishing the right team and getting clinicians and front-line workers involved in research is very difficult. Closer working with multi-disciplinary teams in General Practice is needed.
- There is a need to understand the specific needs of patients, carers and healthcare professionals to allow someone to stay at home. There is a need to capture both positive and negative experiences around what works well to inform practice.
- Translating a clinical intervention into a multi-component intervention as part of a research trial to bridge the gap between clinical care and research can be challenging.
- Certain staff groups, for example care home staff or paramedics may not have adequate training about palliative and end-of-life care and therefore may not know what to expect or how to identify or respond to people reaching the end of life.
- Use of data. Coding in medical records can be inconsistent across services as the documentation of advanced care plans is not incentivised in the GP contract.
- Inequalities in dying well at home should be considered in future research e.g. dying well, deprivation and poverty.
- Attendees highlighted the evidence that already exists in this area. Research that builds on, or implements findings from existing evidence would be beneficial.

- The evidence base around delirium at end-of-life is minimal. Delirium can be managed at home, but this is often challenging.

**Key stakeholders and end users of this research were discussed and include:**

- This group recognised the impact research in this area could have on family and friends as they could benefit from knowing what to expect when somebody is dying and to increase their confidence in recognising the signs that someone is dying, so as to prevent unnecessary emergency service calls.
- Health and social care staff were identified as there are gaps in health and social care staff knowledge and capacity leading to inadequate support

***How can palliative and end of life care better meet the needs of people with multiple health conditions (priority 5)***

**The research questions that attendees discussed relating to this priority included:**

- What effective ways of engaging and raising awareness of how to identify people in the last year of life for those with, or caring for, people with multiple health conditions (such as the EARLY tool).
- Given that advanced care planning was highlighted in the top 10 JLA PEoLC PSP priorities in 2015 and 2025 – where are the remaining evidence gaps relating to advance care planning.
- How can we develop guidance for clinicians and informal carers to better support people living with multiple health conditions regarding polypharmacy and the management of medication as their conditions develop.
- How can we adapt and implement innovations around community pharmacy medication reviews for people with multiple health conditions receiving PEoLC.
- How to better support shared decision-making and improve outcomes for people with multiple health conditions, including prescribing and deprescribing medication.

- What are the specific needs of a paediatric population regarding palliative and end of life care. Is there a need for a paediatric Palliative and End of Life Care James Lind Alliance Priority Setting Partnership.
- The experiences and needs of young adults (18-25) were also highlighted as an evidence gap, in particular developing outcome measurement tools for this population.
- What are the best ways that research can be developed to better include and support people with multiple health conditions? Including consideration of how their condition may change over time and how to support families with admin post-death such as disposal of medications and the emotional impact this can have.
- How can we develop an understanding of the needs and experiences of young people who are experiencing homelessness to improve safe practices and practical guidance for clinicians.

**Challenges discussed relating to conducting research in this area included:**

- It can be difficult for clinical settings to engage in research due to capacity.
- People in the last 1–2 years of life would like to be included in medication reviews, but clinicians often do not know what to do when the person is receiving palliative care.
- Researchers need to do more to understand the barriers to people with multiple health conditions being included in research and tailor support specifically for them.
- Transition between children and adult services can be fragmented and may struggle with funding to collaborate with people with academic expertise.
- Can be difficult to engage with people experiencing homelessness living with multiple health conditions.

## **Better meeting the needs of people who live alone or are socially isolated (priority 10)**

### **The research questions that attendees came up with for these priorities include:**

- How are new service models used, and are they offering equitable care for people who are living alone?
- How are service models able to identify deterioration of an older person requiring PEOLC who lives alone or is socially isolated?
- An evaluation of the effectiveness of how Compassionate Communities approaches care
- How can clinical and practical support be provided and prioritised for people who live alone, who may not know how to seek support and do not have anyone to advocate for support for them?
- Exploration of digital interventions to allow people living alone to self-identify support needs, or easily view existing support information online.
- Effectiveness of the implementation of virtual wards for people who live alone requiring PEoLC.

### **Challenges identified conducting research in this area include:**

- Challenges in measuring effectiveness of research.
- Mistrust of people can be a barrier to accessing support.
- People experience barriers to receiving support alongside social isolation. It would be important to consider the intersection of difficulties e.g. language barriers.
- For people that are more socially isolated, and may not be engaging with services, the ways in which people are approached to take part in research and the way that research is described, would be important factors to consider.

### **Key stakeholders and end users of this research were discussed and include:**

- Engaging people early and ensuring the research is accessible.



- Working alongside people with lived experience to ensure co-production and accessibility.
- Involving healthcare professionals e.g. social care providers or areas that may have community groups.
- Linking in with organisations that have similar interests, for example Aging Without Children (AWOC).

## Conclusions

This webinar provided an opportunity for researchers to connect around the four priorities from the 2025 Palliative and End of Life Care Priority Setting Partnership that were highlighted in the latest NIHR rolling call.

Potential challenges to research and possible research questions were discussed in breakout groups and are shared here, for the benefit of those that could not attend the session.

We hope that this report provides a useful insight into the discussions held on the day, and encourages the development of collaborative, interdisciplinary research projects to address these priorities for palliative and end of life care research.

## Useful resources

### Final report from the 2025 JLA Palliative and End of Life Care Priority Setting Partnership

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 Res 2025, 7:2 (document) (<https://doi.org/10.21955/healthopenres.1115018.1>)

### Peer reviewed papers from the 2025 JLA Palliative and End of Life Care Priority Setting Partnership

[Hudson BF, Ashcroft P, Bedford J, et al. Setting research priorities for palliative and end-of-life care: a James Lind Alliance Priority Setting Partnership Refresh. BMJ Open 2026;16:e108910. doi: 10.1136/bmjopen-2025-108910](#)

[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 11, 133 \(2025\). <https://doi.org/10.1186/s40900-025-00774-4>](#)

### To Know Dying Report

A secondary analysis of data from survey 1, to generate research areas for the social sciences and humanities.

Greenfield M, Borgstrom E, Hudson B and MacArtney JI. "To Know Dying" Identifying research areas in palliative and end of life care for the social sciences and humanities [version 1; not peer reviewed]. Health Open Res 2025, 7:1 (document) (<https://doi.org/10.21955/healthopenres.1115017.1>)

### Exploring research priorities for mental wellbeing

A poster outlining the results of a secondary analysis to identify priority areas for future research on mental wellbeing for people impacted by an advanced progressive illness can be found in this report from the Mental Health and Wellbeing in Advanced Illness Network Report.

[\\_Mental\\_Health\\_and\\_Wellbeing\\_in\\_Advanced\\_Illness\\_Network\\_\(MAIN\)\\_Progress\\_Report\\_\(1st\\_January\\_2024\\_-\\_31st\\_December\\_2025\).pdf](#)

