

Marie Curie Research into Practice Conference 2025 Programme

Tuesday 11 February 2025.....	1
Wednesday 12 February 2025.....	4
Thursday 13 February 2025.....	7
Friday 14 February 2025.....	10

Tuesday 11 February 2025

10:00-12:00: Shaping Tomorrow's Palliative Care: Innovations and Transformations for the Future and conference prizes

Description:

Our conference kicks off with a warm welcome from Marie Curie's Chief Executive Matthew Reed. The session will start off with a presentation by Dr Sarah Scobie, Deputy Director of Research, Nuffield Trust who will give an overview of her recent work on understanding public expenditure on people in the final year of life.

This will be followed by a panel discussion focusing on where change is needed and how new innovative and collaborative services linking palliative care with hospitals, emergency services and out of hours assistance can better support people at the end of life and with that, ease system pressures.

This session will close with the awarding of Marie Curie's prestigious conference prizes.

10:00	Welcome to the 2025 Marie Curie Research into Practice Conference	Matthew Reed , Chief Executive Marie Curie
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10.05	Understanding public expenditure on people in the final year of life	Dr Sarah Scobie , Deputy Director of Research, Nuffield Trust and Lisa Cummings , Lead Health Economist, the Health Economics Unit
10:35	Panel discussion, chaired by Dr Sam Royston , Executive Director of Policy & Research, Marie Curie	Dr Sarah Scobie , Deputy Director of Research, Nuffield Trust Ed O'Brian , Professional Development Lead Frailty and End of Life Care Welsh Ambulance Services University NHS Trust Professor Patrick Vernon OBE , Chair of the Birmingham and Solihull NHS Integrated Care Board (BSol ICB) Dr Sarah Holmes , Medical Director, Marie Curie and Executive Sponsor of the REACT programme
11:30	Quick break	
11.35	Presentation of Conference Prizes	Matthew Reed , Chief Executive Marie Curie

12:30-13:30: A spotlight on: Compassionate School Communities: Strengthening Grief Education and Bereavement Support in Educational Settings

Tags – Relationships; Carers; Bereavement; Children; Qualitative research

Description:

There is a growing international movement raising awareness of childhood bereavement and the support that should be provided across different settings. This spotlight session will focus on the role of schools in supporting bereaved pupils and preparing them for this significant and inevitable life event. This session will share learning from the Marie Curie Northern Ireland Schools Bereavement programme, it will also draw on international activity in this space, including policy development opportunities in other parts of the UK.

We hope by joining this session you will be motivated and driven to share the messages and champion the need for every school to be a Compassionate Community. We also aim to demonstrate through this project the impact that can come from research evidence, policy influencing and lived experience joining forces.

Chaired by Joan McEwan, Associate Director Policy & Public Affairs Northern

Ireland, Marie Curie		
12:30	Welcome and Introductions	Joan McEwan , Associate Director Policy & Public Affairs Northern Ireland, Marie Curie
12:35	Overview of activities and learning from the Marie Curie Schools Bereavement Programme	Christine Irvine , Senior Policy Manager Northern Ireland, Marie Curie
12:45	Drawing on the Experience and Perspectives of a Panel of Experts, Closing remarks / reflections- Chair, Joan McEwan	Gail Precious , National Children's Bureau Dr Sally Paul , European Learning Network on Compassionate Schools Jacque White , Chairperson of NI Teaching Council Nick Matheson , MLA and Chairperson of the NI Assembly Education Committee
13:25	Closing remarks / reflections	Joan McEwan

14:00-15:00: A spotlight on: Partnership working between Terrence Higgins Trust, Marie Curie and people living with HIV to explore the needs of and challenges in planning for and accessing end of life care

Tags – Inequity; Coproduction; PPI; Qualitative research; Quantitative research

Description: This session highlights the partnership work that aimed to understand the potential barriers and experiences of people living long-term with HIV to planning for and receiving palliative and end of life care. We will hear from people involved in the project from Marie Curie, the Terrence Higgins Trust and people with lived experience.

Chaired by Dr Briony Hudson, Associate Director Internal Research Development, Marie Curie and UCL.

14:00	Background	Lynne Hughes , Head of End of Life Transformation, Marie Curie)
14.05	Building a partnership	Louisa Dreja , Community Engagement & Development Manager, Marie Curie; Marc Tweed, Centre and Service Manager, Terrence Higgins Trust
14.15	Our chosen approach: No Barriers Here®	Lynne Hughes and Louisa Dreja , Marie Curie Michael Brimacombe and Tim

	Recruiting/ involving people with HIV	Holt , Terrence Higgins Trust
14.25	On coproduction	Richard and Robert , lived experience partners
14.35	Palliative and end of life care for people living with HIV; key themes identified in the project	Jodie Crooks , Qualitative Research Manager, Marie Curie
14.45	Q&A	All

15:30-16:30: Selected abstract presentations 1

Tags – Mental health; Physical health; Inequity; Qualitative research; Digital

Description: Join us for our first session featuring three selected abstract presentations. This session will be chaired by Dr Libby Sallnow, Head of Marie Curie Palliative Care Research Department, University College London.

15:30	The Death Literacy Index-Island of Ireland (DLI-IRE)	Stephanie Crawford , Queens University Belfast
15.50	How, when, and why is video-enabled emotional support in palliative care successful?: A realist review	Michele Wood , Marie Curie
16.10	Giving voice to those with incurable head and neck cancer (HNC): understanding and identifying priorities for improving healthcare experiences	Dr Catriona Mayland , University of Sheffield and Sheffield Teaching Hospitals NHS Foundation Trust, & Dr Ada Achinanya , University of Sheffield

Wednesday 12 February 2025

10:00-12:00: Addressing inequities in palliative and end of life care

Chaired by Dr Catriona Mayland (University of Sheffield).

Tags - Inequity; Service development; PPI; Coproduction; Policy; Systematic review; Advance care planning

10:00-11:00 Description: "They aren't hard to recruit, we just need to change our approach": Practical experience from the NIHR Equitable Bereavement Care for All Ethnicities study. The first hour will focus on key insights from this study, which is the largest ethnically diverse qualitative research study in UK healthcare to date. This talk seeks to promote equitable access to healthcare research and ensure inclusivity across all communities.

10:00	"They aren't hard to recruit, we just	Dr Sabrina Bajwah , King's
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	need to change our approach"	College London
10:20	Recruiting, training and supporting community researchers	Dr Zoebia Islam and Gurpreet Santini , LOROS Hospice
10:40	Discussion with delegate engagement, including Q&A	Dr Catriona Mayland , University of Sheffield
11:05-12:00 Description: The second half of our inequity session will include two short abstract presentations and a talk on inequitable access to palliative care for people in UK prisons.		
11:00	Quick break	
11:05	What do national palliative and end-of-life care policies say we should do to address ethnic inequalities at the end-of-life and are there gaps?: a systematic review of UK policy documents 2008-2024	Dr Grace Duffy & Dr Alice Copley , Leeds Teaching Hospitals NHS Trust
11:25	Factors Influencing Advance Care Planning Implementation Among Overseas Chinese: Implications for the Chinese Ethnic Community in the UK – A Systematic Review	Lijun Xue , Queens University Belfast
11:40	Inequitable access to palliative care for people in UK prisons	Dr Mary Turner , Queens University Belfast

12:30-13:30: A Masterclass on: How can we support deaf people within palliative care?

Tags – Inequity; Carers; Qualitative research

1 in 4 adults in the UK have a hearing loss, yet their needs are often poorly understood and supported in healthcare settings. Accessible care and communication are critical in palliative care, but deaf people are often missed out leading to critical health inequalities. **Dr Natasha Wilcock**, a hospice doctor at Royal Trinity Hospice, founded IDA through her own experience as a deaf patient and doctor. IDA is an organisation aiming to improve the experience and outcomes of deaf people across healthcare settings. Join this session to explore the experiences of deaf people interacting with palliative care services, discuss real-life cases and explore how you can ensure your care is accessible to deaf people.

This session will be interpreted in British Sign Language and will have captions.

14:00-15:00: A spotlight on: Understanding Contribution and Challenges Facing Ambulance Services Attending at End of Life: Building the Evidence Base – a Masterclass

Tags – Ambulance services; Service integration; Workforce; Qualitative research; Quantitative research

Description: This session will be chaired by Mrs Jen Scott-Green (South East Coast Ambulance Service NHS Foundation Trust). Speakers will be providing expert perspectives on ambulance service provision of care at end of life in the UK, including a PPI voice, learnings from two research studies (the ParAid study and the RELIEF study) examining models of service delivery in England and Wales, and a Q&A.

14:00	Ambulance attendance at end of life: the lived experience	Mr Ian Dickerson , Patient and Public Involvement (PPI) Representative
14.15	Ambulance service delivery at end of life (context, practice and service developments): the ParAid study	Dr Natasha Campling , Associate Professor Palliative and End of Life Care, University of Southampton
14.30	The Welsh ambulance 'just-in-case' service initiative: the RELIEF study	Dr Chris Moore , Welsh Ambulance Services NHS University Trust and Swansea University
14.45	Delegate questions and discussion of the benefits, or otherwise, of service developments and potential for wider adoption into practice	Mrs Jen Scott-Green , South East Coast Ambulance Service NHS Foundation Trust

15:30-16:30: A spotlight on: Research Priorities for Palliative and End of Life Care

Tags - Research Priorities; Qualitative research; Quantitative research

Description: Marie Curie have partnered with organisations including the James Lind Alliance, Open University, University of Edinburgh, MND association, University of Warwick and ESRC, to produce the latest priorities in end of life care research. Defined in a robust process by those with lived experience, including patients, their families, carers, and healthcare professionals, these ranked priorities serve as a framework of where to place research efforts and funding. Join us as we launch these new priorities and discuss their influence.

Chaired by Professor Erica Borgstrom, Professor of Medical Anthropology, Open University

15:30	Welcome	
15.35	The refreshed top 10 end user research priorities for palliative and end of life care	Dr Briony Hudson , Associate Director Internal Research Development, Marie Curie & Dr Sabine Best , Associate Director Research Management & Impact, Marie Curie

15.50	Mental health and wellbeing research priorities in palliative and end of life care	Dr Anne Finucane , Senior Research Fellow, University of Edinburgh and Marie Curie Scotland
16.05	Secondary Analysis of JLA Data to Identify Research Areas in Palliative and End of Life Care for Social Science and Humanities	Professor Erica Borgstrom , Professor of Medical Anthropology, Open University & Dr John MacArtney , Marie Curie Associate Professor, University of Warwick and Marie Curie Hospice West Midlands.
16.20	Q&A	All

Thursday 13 February 2025

10:00-12:00: Physical Health and Wellbeing – Improving Symptom Management Tags – Physical health; Medication; Carers; Service integration; Coproduction		
<p>10:00-11:00 Description: Building bridges from research to practice: launch of evidence-based tools applied in a multi-centre impact project to improve medication management</p> <p>Launch of the Getting Palliative Medications Right Toolkit, followed by sharing of supporting evidence, highlighting possibilities to improve medication management systems in practice. Evidence to support the toolkit comes from observing more than 120 hours of everyday practice and informal conversations at home, in hospital and in hospice. We spoke to 83 patients, informal carers, and professionals, mapping out who does what and when.</p> <p>Led by Dr Sally-Anne Francis, Senior Research Fellow & Dr Sarah Yardley, Associate Professor of Palliative Medicine on behalf of the ‘Getting palliative prescription medications right at home, in hospital & hospice’ study team (co-investigators: Dean Franklin, Ogden, Kajamaa, Mattick) Chaired by Natasha Bradley, Marie Curie Senior Research Fellow</p>		
10:00	At the end of this session you will have a good understanding of: <ul style="list-style-type: none"> - Evidence to improve palliative medicines management at home, in hospital, in hospice and when people move between these settings - Hot spots and cold spots (things we need to attend to more) to 	Dr Sally-Anne Francis , Senior Research Fellow & Dr Sarah Yardley , Associate Professor of Palliative Medicine, Marie Curie Palliative Care Research Department, University College London with representatives from the Joint

	<p>improve</p> <ul style="list-style-type: none"> - What the toolkit can offer organisations, policymakers, educators and clinicians to help them improve palliative medicines management, including how to self-assess priorities for change - How the toolkit has been used in four Marie Curie Places to drive locally important quality improvement projects - The benefits of working with patients and carers in quality improvement activities 	<p>Impact Team: Marie Curie Bradford, Glasgow, and West Midlands.</p>
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Toolkit contents:

- [Summary report](#)
- [Interactive pictorial model](#)
- [Research infographic](#)
- [Top tips for patients and carers](#)
- [Top tips for health care professionals](#)
- [System Quality Indicators for commissioners and policy makers](#)

Additional resources including “palliative postcards” for educational use can be found [here](#) as well as further information about the research.

11:00 Quick break

11:05-12:00 Description: Delirium assessment and management towards end-of-life.

11:05-12:00: The second half of our Physical Health and Wellbeing session will look at delirium assessment and management towards end-of-life. Chaired by Dr Juliet Spiller, Consultant in Palliative Medicine, Marie Curie Hospice Edinburgh and include talks from her, Dr Anne Finucane, Senior Research Fellow (University of Edinburgh and Marie Curie Scotland) and Hilary Nailon, Research Nurse (Marie Curie Scotland).

Chaired by Dr Juliet Spiller, Consultant in Palliative Medicine, Marie Curie Hospice Edinburgh

11:05	Delirium in palliative care - prevalence, assessment and management	Dr Juliet Spiller , Consultant in Palliative Medicine, Marie Curie Hospice Edinburgh
11:20	Development of a multicomponent intervention to improve delirium assessment and management in hospice inpatient settings	Dr Anne Finucane , Senior Research Fellow, University of Edinburgh and Marie Curie
11:35	Co-designing audiovisual resources for families and professionals to support delirium assessment and management	Hilary Nailon , Research Nurse, Marie Curie
11:50	Q&A	All

12:30-13:30: A spotlight on: The timebomb of multiple long-term conditions: how do we diffuse it? An interactive workshop

Tags: Multimorbidity; Inequity; Qualitative research

Description: Increasing numbers of people are living with and dying from multiple long-term conditions. However, people with multiple long-term conditions are less likely to have access to palliative and end of life care services. This session will explore research projects across two institutions, funded by NIHR and the Wellcome Trust, to understand how palliative and end of life care services can identify those with multiple long-term conditions who are approaching the end of life and what services are currently available. Finally, an interactive focus group will be held inviting participants to reflect on what they and their service can do to meet the needs of the growing population of people with multiple long-term conditions.

12:30	Identifying those with multiple long-term conditions towards the end of life	Dr Sarah Bowers, Multimorbidity PhD Fellow, University of St Andrews
12:50	Palliative care services for those with multiple long-term conditions	Dr Felicity Dewhurst, Honorary Clinical Senior Lecturer, Newcastle University
13:10	Interactive session: Is your service ready for the timebomb of multiple long-term conditions?	Dr Sarah Bowers & Dr Felicity Dewhurst

14:00-15:00: A spotlight on: Communicating about an uncertain future: a state of the science masterclass

Tags – Physical health; Multimorbidity; Prognostication; Systematic review; Qualitative research

Description: We will be bringing together the latest interdisciplinary evidence on communicating unpredictable outcomes in palliative care. The session will share insights from three research projects, each of which spotlights a different element:

1. Realist review of communicating prognostic uncertainty;
2. Conversation analysis - Exploring uncertainty in decision-making conversations in advanced renal disease;
3. Co-design of a toolkit for communicating uncertainty in multimorbidity.

This session is chaired by Dr Simon Noah Etkind (University of Cambridge and Cambridge University Hospitals NHS Foundation Trust).

14:00	Introduction	Dr Simon Noah Etkind, Assistant Professor of Palliative Care, University of Cambridge and Cambridge University Hospitals NHS Foundation Trust
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14.05	Improving communication of prognostic uncertainty in palliative and end of life care contexts: Early findings from a realist literature review	Dr Katharine Weetman , Assistant Professor in Clinical Communication, University of Birmingham
14.20	Communicating uncertainty and risk during treatment decision-making conversations with older people with advanced kidney disease	Dr Chloe Shaw , Senior Research Associate, University of Bristol
14.35	Developing a toolkit to support conversations about future uncertainties in multimorbidity	Dr Rosanna Fennessy , Research Associate, University of Cambridge
14.50	Discussion of common themes	Dr Simon Noah Etkind

15:30-16:30: Selected abstract presentations 2

Tags – Carers; Workforce; Mental Health; Service Development

Description: This session will be chaired by Professor Nathan Davies, Professor of Ageing and Applied Health and Care Research (Queen Mary, University of London). Join us for another engaging session featuring three selected abstract presentations.

15:30	What support do care home staff need when supporting residents at the end of life?	Dr Isabelle Latham , Hallmark Care Homes & University of Worcester & Charli Morgan Henley Manor Care Homes, Hallmark Care Homes
15:50	Screening for Depression and Anxiety in Palliative Care Inpatients: A Quality Improvement Project	Dr Juliette Murphy , St Joseph's Hospice
16:10	Addressing depression in care home residents: a collaborative approach to working with care home Activity Coordinators to improve identification and management	Lynne Partington , The End of Life Partnership
16:30	Close	

Friday 14 February 2025

10:00-12:00: Financial insecurity at the end of life.

Chaired by Helen Barnard, Director of Policy, Research & Impact at Trussell with a focus on financial insecurity at end of life.

Tags: Quantitative research; Inequity; Poverty; Policy; Financial security

10:00-11:00 Description: The first half of the session will have talks looking at end of life poverty in the UK, fuel poverty and the financial and employment impacts on end of life carers.		
10:00	Welcome	
10:05	Dying in Poverty: Updated Insights on End-of-Life Poverty in the UK, including New Findings on Fuel Poverty	Dr Juliet Stone , Research Fellow, University of Loughborough & Elaine Robinson , Research Associate, University of Loughborough
10:30	The financial and employment impacts of end of life family caregiving	Professor Clare Gardiner , Professor of Palliative Care, University of Sheffield & Dr Edward Webb , Senior Research Fellow, University of Leeds
11:00	Quick break	
<p>11:05-12:00 Description: The second half of the session will explore evidence and practice on improving benefit take-up for people living with life-limiting illness. The session will cover understanding the role of clinicians in completing applications for benefits under the 'Special Rules', including the recent changes from the DS1500 to the new SR1 form.</p> <p>Speakers will provide evidence on the level of take-up of benefits for people in the last year of life and explore the facilitators and barriers to making benefit claims under the 'Special Rules', drawing on evidence from the current Marie Curie funded 'Take-up Project'</p> <p>The session will provide an opportunity for delegates to ask questions, seek clarification, gain confidence in discussing with patients and highlight challenges with helping people to access benefits.</p>		
11:05	Introduction	Dr Steve Marshall , Palliative Care Social Worker, King's College Hospital and Honorary Senior Lecturer, King's College London
11:10	Presentation of quantitative data evidence from the 'Take-up' Study	Dr Joanna Davies , Research Fellow, King's College London
11:20	Presentation of qualitative data evidence from the 'Take-up' Study	Dr Steve Marshall
11:30	The perspective of the Department of Work and Pensions	Dr Emily Pikeft , Clinical Lead for Special Rules for End of Life, Department for Work and Pensions, UK
11:40	Panel discussion with time for questions from delegates	All

12:30-13:30: Selected abstract presentations 3 - inequities in end of life care

Tags - Financial security; Inequity; Systematic review

Description: This session will be chaired by Dr Tracey McConnell, Lecturer in Palliative and End of Life Care, Queen's University Belfast. Join us for this engaging session featuring three selected abstract presentations.

12:30	Financial insecurity for terminally ill migrants in the UK: double jeopardy at the end of life	Professor Liz Forbat , University of Stirling
12:50	Community researchers in end-of-life care research addressing intersectional inequalities: A rapid realist review and evaluation of the why, the how, for whom and in what circumstances	Dr Jamilla Hussain , Bradford Teaching Hospitals NHS Foundation Trust
13:10	Understanding the scale of exclusion for people unable to consent to research towards the end of life: A Scoping Review	Dr Caroline Barry , Norfolk and Norwich University Hospital NHS Foundation Trust and University of East Anglia

14:00 -15:00: Selected abstract presentations 4 - Care outside the Hospice

Tags – Workforce; Service development; Service integration

Description: This session will be chaired by Professor Cara Bailey, Professor of End-of-Life Care (University of Birmingham). Join us for this engaging session featuring three selected abstract presentations. The full lineup of speakers and topics will be announced soon – stay tuned for more details!

14:00	"It's a lot more in-depth for us than it was before": A multi-methods study of community nurses' extended roles in palliative care	Dr Ben Bowers , University of Cambridge
14:20	Findings from the Phase 1 evaluation of Marie Curie's Lothian Enhanced Hospice Care at Home service	Dr Hannah Leach , Marie Curie
14:40	The impact and value of Marie Curie Health Care Assistants in the Emergency Department at University Hospitals Plymouth	Dr Susannah Baines & Jenny Evans , Marie Curie
15:00	Close	

15:30-16:30: Selected abstract presentations 5 - children, young people and families

Tags – Inequity, Bereavement, Relationships, Carers, Children, PPI, Coproduction

Description: This session will be chaired by Katie Tallwin (Head of Education and Professional Development, Together for Short Lives). Join us for our final session featuring three selected abstract presentations.

15:30	Inequity in access to bereavement care for families whose child dies unexpectedly: pioneering care from a children's hospice	Sarah Hodkinson , Shooting Star Children's Hospices & University of Southampton & Lisa Dennis , Shooting Star Children's Hospices
15:50	Assessing grief in bereaved children and young people: Validating the Children's Attitude to Grief Scale (CAG)	Dr Noreen Hopewell , Marie Curie Palliative Care Research Centre, Cardiff University
16:10	Embedding PPIE within a study that co-designed a psycho-therapeutic intervention for young people with life limiting conditions	Professor Joanna Smith , Sheffield Children's NHS Foundation Trust /Sheffield Hallam University & Dr Alison Rodriguez , University of Leeds
16:30	Close	