

Mental Health and Wellbeing in Advanced Illness Network (MAIN)

Progress Report (1st January 2024 – 31st December 2025)

1. Network Overview and Aims

MAIN was launched in January 2024 and is funded by [Marie Curie](#). The network aims to provide a platform for sharing research and good practice to promote mental health and wellbeing for people impacted by advanced progressive illness. In doing so, the network seeks to connect academics, healthcare and social care professionals, psychologists, allied health professionals, policy makers, and people with lived experience.

Since its launch, MAIN has focused on building a strong and diverse membership base, delivering accessible and relevant evidence sharing events, and fostering meaningful engagement across disciplines and stakeholder groups. MAIN’s vision, values, and priorities are outlined in its [Position Statement](#).

2. Network Growth and Reach

MAIN has grown steadily since its launch. As of 31 December 2025, it has 455 members. Our membership includes individuals based across the UK, as well as a growing number of international members (approximately 7% of the membership), reflecting the network’s widening reach and relevance beyond a national context.

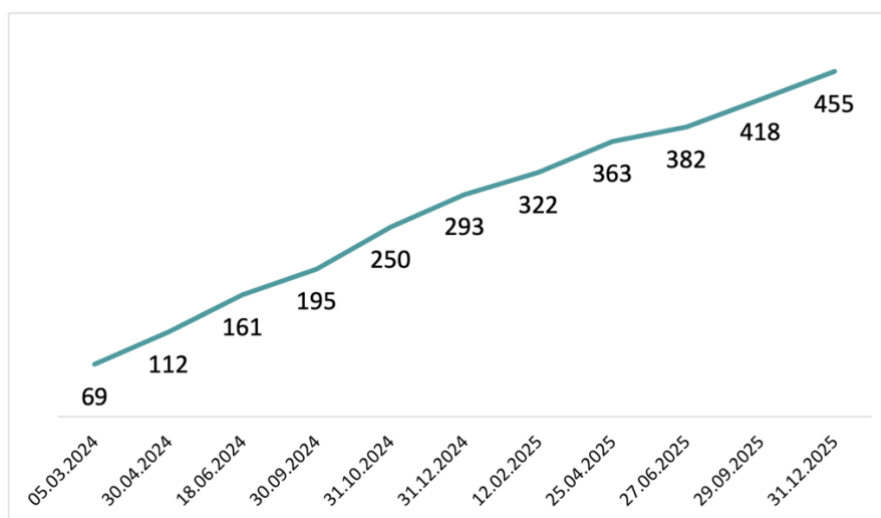


Figure 1 Cumulative MAIN membership numbers

Members represent a wide range of backgrounds, including psychologists, researchers, healthcare professionals, social workers, service managers, policy stakeholders, and members of the public. This diversity reflects strong cross-sector interest and engagement.

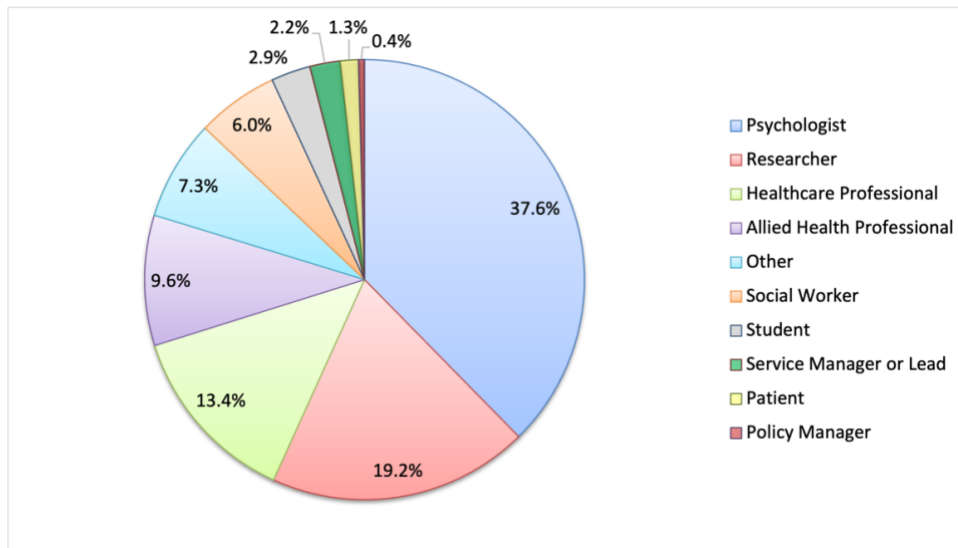


Figure 2 Member composition by primary role (n = 449).

Note. Role categories are based on the first role selected. Where multiple roles were indicated, only the first selected role was used for classification.

In parallel, MAIN has established a growing social media presence. The MAIN LinkedIn page, launched on 26 June 2025, has expanded rapidly, reaching over 500 followers by 31 December 2025. Posts related to network activities and events attract consistent engagement, further extending the network’s visibility and reach.

3. Activities and Events

The network has delivered a range of activities designed to be inclusive, accessible, and responsive to member interests including webinars and a grant writing workshop.

3.1 Online Webinars

Between January 2024 and December 2025, ten webinars were delivered, addressing key topics in mental health and wellbeing in advanced illness. Across the ten webinars, nearly 1,200 live attendances were recorded, with many revisiting our [webinar archive](#) where we store the webinar recordings, presentations slides, and other resources shared during the

webinar sessions. There were high levels of engagement during live sessions and follow-up requests for recordings and resources. We also provided certificates of attendance to encourage people to attend webinars in real time.

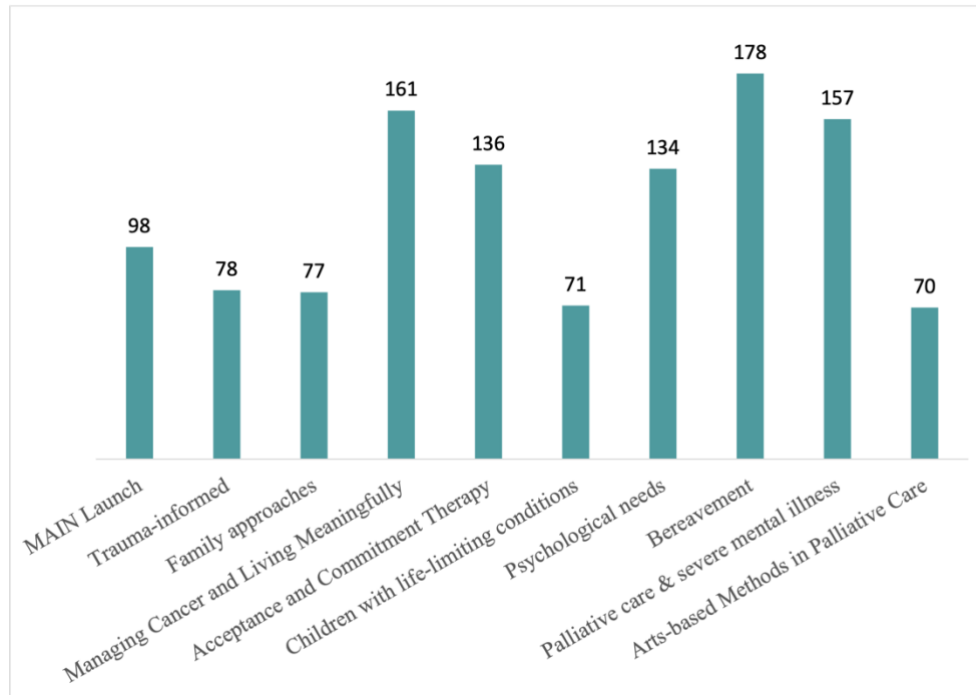


Figure 3 Live attendance for MAIN webinars by topic

3.2 In-person Research Grant Planning Event

An in-person Grant Planning and Networking Day took place on 8 May 2025, bringing together 25 participants, including researchers, healthcare professionals, and PhD students. The event combined structured collaborative group work to develop research ideas and funding plans with practical guidance on preparing competitive grant applications. To widen access and support attendance, two £300 bursaries were offered to early career researchers, helping to reduce financial barriers and enable broader participation.

Participant feedback was highly positive, with attendees describing the event as supportive, encouraging, and well-structured. Many highlighted the value of practical grant-writing advice and the opportunity to refine ideas through multidisciplinary discussion.

The event facilitated the development of new collaborations. For example, a group of clinicians and academics identified a shared interest in clinical conversations about death and dying during the workshop; these early discussions have since evolved into an ongoing

multidisciplinary *research collaboration*. In addition, two bursary recipients later contributed *blog posts* reflecting on their experience, further demonstrating the impact of the event.



Figure 4 Attendees of Grant Planning & Networking Day

4. MAIN e-Newsletters

Since September 2025, MAIN has produced a monthly newsletter, with four issues circulated to all registered members. Each issue features MAIN events, new publications, partner activities, and relevant policy updates. Engagement has grown steadily, with members praising the newsletter’s clarity, relevance, and usefulness in signposting opportunities, resources, and developments in the field. While the newsletter provides a curated overview, the *News Site* on our website continues to provide timely updates and complementary content.

5. Research Outputs

The network commissioned a research project to identify priority areas for future research on mental wellbeing for people impacted by an advanced progressive illness. This project involved researchers, healthcare professionals, and other stakeholders, ensuring that the resulting priorities reflect a wide range of perspectives and expertise. Through this process,

we identified ten key areas that now provide a shared direction for collaborative research development and funding applications across the network. These priorities have been presented at two major conferences (*Marie Curie Annual Conference 2025* and *European Association for Palliative Care 2025*), helping to stimulate discussion and inform future collaborative research activity.

MENTAL HEALTH AND WELLBEING IN ADVANCED ILLNESS: A MIXED METHODS STUDY TO IDENTIFY AND PRIORITISE KEY RESEARCH QUESTIONS

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Introduction

Optimising wellbeing through psychological, social and spiritual support is an essential component of palliative care.

However evidence on mental health and wellbeing for people with a life-limiting illness is fragmented and lacks visibility. Priority areas for future research need to be identified to inform research efforts.

Aim

We sought to identify priority areas for research focused on mental health and wellbeing for people impacted by advanced life-limiting illness.

Methods

- A mixed-methods study consisting of a secondary data analysis and four focus groups.
- We analysed data from the 2024 James Lind Alliance Palliative and End-of-life Care Research Priorities Project survey (1,032 respondents).
- Focus groups were conducted with people with experience of life-limiting illness (n=6), health care professionals (n=7), advocates and third sector representatives (n=7) and researchers (n=9).
- Data from both the James Lind Alliance dataset and focus groups were imported into NVivo 14 and analysed thematically.

Results

We identified ten **key** priority areas for future research.

 <p>LIVING WELL: What are the best ways to support people to live well with a serious life-limiting illness?</p>	 <p>CAREGIVERS: What are the best ways to support caregivers experiencing stress, distress and exhaustion?</p>
 <p>COMMUNICATION: What are the best ways to enable open, timely and sensitive conversations about living with serious life-limiting illness?</p>	 <p>BEREAVEMENT: What are the best ways to provide culturally sensitive and timely bereavement support?</p>
 <p>ANXIETY & PSYCHOLOGICAL DISTRESS MANAGEMENT: What are the best ways to prevent and treat anxiety and psychological distress for people with a serious life-limiting illness?</p>	 <p>INTERVENTION DELIVERY: What are the best ways to deliver and implement mental wellbeing support?</p>
 <p>SOCIAL CONNECTION: What are the best ways to support people with a serious life-limiting illness to remain connected to others?</p>	 <p>ACCESS: How can it be ensured that everyone with a serious life-limiting illness has access to mental wellbeing support should they need it?</p>
 <p>SPIRITUAL CARE: What are the best ways to provide spiritual support to people with a life-limiting illness?</p>	 <p>WORKFORCE: What approaches are best to upskill a broader range of professionals to provide mental wellbeing support for people impacted by serious life-limiting illness, and what are the best ways to sustain workforce wellbeing?</p>

Conclusion

People affected by life-limiting illness and health and social care professionals identified several areas where evidence is needed to support mental wellbeing towards end-of-life. Our findings will help guide researchers and funders when making decisions regarding future research activities and resource allocation.



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For future information on mental health in advanced illness see: <https://www.mainexchange.org.uk/>

Figure 5 Poster presenting the ten research priorities identified through our collaborative priority-setting exercise

6. Research Library

As part of MAIN's knowledge exchange commitment, we have developed an online [*research library*](#) to store and share research reviews relevant to mental wellbeing in the context of advanced illness. The library provides a curated, accessible resource to support researchers and practitioners, and is regularly updated to reflect the latest evidence, ensuring that it continues to serve as a valuable resource for the network and the wider community.

7. Involvement of People with Lived Experience of Advanced Illness

Our MAIN Advisory Panel was established to support meaningful patient and public involvement. The panel currently consists of seven members (three patients and four carers). Members were recruited through an open call advertised via LinkedIn, the network newsletter, and the news section of the MAIN website. The first advisory panel meeting took place in December 2025. The group is expected to play an important role in shaping future network activities, priorities, and approaches to dissemination, ensuring that the network remains grounded in the context of living with and caring for someone with advanced illness.

8. Policy Engagement

MAIN has begun to contribute collectively to policy-related activity. To date, this includes a [*coordinated response to the Scottish Parliament's pre-budget consultation on mental health spending*](#), as well as written input to Members of the Scottish Parliament regarding the need to specially mention the need for access to psychological support in the Assisted Dying for Terminally Ill Adults (Scotland) Bill.

9. Emerging Impact

Although still at an early stage, several areas of impact and emerging value are evident. The network has created new connections across disciplines and sectors, increased visibility of mental health and wellbeing within advanced illness contexts and supported early-stage collaboration that is beginning to translate into concrete research and practice activity.

Informal feedback from members consistently highlights the value of the network as a supportive, inclusive, and focused space for discussion and collaboration. The Network continues to act as a platform for relationship-building and future research development, aligning closely with the funder's strategic priorities.

10. Priorities for the Coming Year

As the network continues to grow, our focus over the coming period will be on further strengthening engagement, collaboration, and impact across the community. Key priorities include expanding MAIN membership and increasing the visibility of the network through a more developed social media and communications strategy. We also plan to build on the success of our current activities by developing and expanding the webinar programme and establishing the [blog site](#) as a space for sharing diverse experiences and perspectives from across the network.

Alongside these activities, we aim to support greater collaboration and research development by creating further opportunities for networking and by facilitating grant development among members. We will also continue gathering data to evaluate the reach and impact of the network's activities, which will help inform future planning. Finally, we hope to strengthen engagement with funders and policy makers to ensure that the network's work contributes meaningfully to wider conversations around mental health and wellbeing in advanced illness.

We are continuing to develop our Advisory Panel to further embed patient and public involvement across the network. This includes creating opportunities for members to provide feedback on relevant research proposals and contribute to ongoing and future research activities.

11. Network Steering Group

The steering group plays a key role in guiding the direction and activities of the network. Comprising researchers, clinicians, and professionals with expertise in mental health and wellbeing in the context of advanced illness and end-of-life care, the group provides strategic advice, supports collaboration and engagement across the network, and helps shape key activities and priorities.

Below we acknowledge and thank the members of the Steering Group for their valuable contributions to the network:

- *Anne Finucane* (Network Lead; Senior Research Fellow in Clinical Psychology at the University of Edinburgh; Honorary Research Lead at Marie Curie Hospice Edinburgh)
- *David Gillanders* (Network Lead; Senior Lecturer in Clinical Psychology at the University of Edinburgh)
- *Yingna Li* (Network Administrator; PhD Student in Clinical Psychology at the University of Edinburgh)
- *Anne Canny* (Research Fellow in Clinical Psychology at the University of Edinburgh)
- *Emily Harrop* (Senior Research Fellow at the Marie Curie Research Centre, Cardiff University)
- *Ivor Williams* (Honorary Practice Fellow at Imperial College London's Institute of Global Health Innovation; Design leader specialising in healthcare innovation)
- *Juliet Spiller* (Consultant in Palliative Medicine at Marie Curie Hospice Edinburgh)
- *Kasia Patynowska* (Doctoral Research Fellow at Ulster University; Research Nurse at Marie Curie Hospice Belfast)
- *Kate Maitland* (Research Utilisation Manager and Innovation Lead at Marie Curie)
- *Liz Forbat* (Allied Health Manager at Marie Curie Hospice Edinburgh, Honorary Professor at the University of Stirling; Family Psychotherapist in independent practice)
- *Naomi Richards* (Senior Lecturer in Social Science and Director of the End-of-Life Studies Group at the University of Glasgow)
- *Phillippa Ashcroft* (Senior Research and Policy Manager for Health and Wellbeing at Marie Curie)
- *Sarah Yardley* (Associate Professor of Palliative Medicine at University College London)
- *Tracey McConnell* (Lecturer in Palliative and End of Life Care at Queen's University Belfast; Honorary Marie Curie Research Fellow)