

Routes to impact: influencing wider palliative and end of life care research funding



Care and support
through terminal illness

In 2017, Marie Curie published a report outlining the gaps in palliative and end of life care research¹. This report mapped UK-wide health research activity against the 83 questions identified by the Palliative and end of life care Priority Setting Partnership (PeolcPSP), which was initiated by Marie Curie and supported by the James Lind Alliance and a number of other organisations².

In 2018, this grant mapping report influenced a themed research call of the National Institute for Health Research (NIHR)³. The NIHR is the largest national clinical research funder in Europe, spending around £1 billion a year on health research. It was established in 2006 as part of the UK government's health research strategy 'Best Research for Best Health' and is funded by the Department of Health and Social Care.

The NIHR launched their end of life care research call in 2018, to increase the evidence base for support health and care services to support people at the end of their lives. This research could include the impact on patients, carers and/or health and social care professionals, and take place within a range of different settings, such as services, care homes and hospices.

The NIHR funding programmes involved in the end of life care call are:

- Health Services and Delivery Research – for research aiming to improve the accessibility and organisation of health and social care services.
- Health Technology Assessment – for research about the clinical and cost effectiveness and broader implications of treatments and tests, which are compared to the current standard intervention.
- Public Health Research – for research to generate evidence to inform the delivery of non-NHS

interventions intended to improve the health of the public and reduce inequalities in health.

- Efficacy and Mechanism Evaluation – for research evaluating interventions with potential to make a step-change in the promotion of health, treatment of disease and improvement of rehabilitation or long-term care.

The NIHR grant call across these programmes outlined specific areas of research, which were informed by the Marie Curie grant mapping report:

- Referral and transition across health and social care services and continuity of care
- Managing symptoms at the end of life
- End of life care for infants, children and young people
- Time and place of access to services
- Bereavement support
- Reducing health inequalities in end of life care
- Workforce and skills issues

By publishing and implementing their findings, the projects funded by the NIHR have the potential for significant impact on individuals, society and the economy, by expanding our knowledge in the field, and ultimately leading to better care and support for people

living with a terminal illness and their families. Research investment by government funding organisations is promising for the future.

1. Does current palliative and end of life care research match the priorities of patients, carers and clinicians? A grant mapping analysis of the UK Clinical Research Collaboration's Health Research Classification System dataset 2014 (2017). Available at: mariecurie.org.uk/globalassets/media/documents/research/publications/grant-mapping-report.pdf
2. James Lind Alliance Palliative and end of life care Priority Setting Partnership (PeolcPSP) (2015). Available at: palliativecarepsp.files.wordpress.com/2015/01/peolcsp_final_report.pdf
3. New End of Life Research Funding Calls from NIHR (2018). Available at: enrich.nihr.ac.uk/news/new-end-of-life-research-funding-calls-from-nihr

Marie Curie is the largest charitable funder of palliative and end of life care research. The charity invests nearly £3 million each year into research to help inform better quality of care for people with any terminal illness, and the people who care for them.

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