Research Impact Report

Investing in research to help deliver a better end of life for all

November 2023

Marie Curie

Foreword

I am delighted to introduce Marie Curie's latest research impact report covering the years 2021 and 2022.

Marie Curie is the largest charitable funder of palliative and end of life care (PEOLC) research in the UK and through our range of research funding programmes we play a leading role in supporting and sustaining this vital research area. But as you will see in this report, Marie Curie is so much more than just a research funder.

At Marie Curie we invest in research to provide the evidence needed to drive policy and practice changes that can help deliver a better end of life for all. **We consider the research we fund to have *impact* when it is taken up and used to benefit people affected by dying, death and bereavement.**

We work across the research ecosystem to support and enable the delivery of PEOLC research. This includes setting lived experience-led research priorities, influencing and partnering to increase PEOLC research spend, developing and sharing best practice in the management and delivery of PEOLC research, delivering our own vital programmes of research through our in-house research team, and facilitating recruitment from our clinical services to national research studies.

We also work tirelessly to help ensure that the research we fund, support and deliver has the best possible chance of leading to policy and practice changes that can improve end of life experience. This is facilitated by the powerful integration between our research and policy teams at Marie Curie, as well as the strong links with our frontline teams who provide direct care and support.

In this report, we highlight some of the key impact stories that research supported by Marie Curie has contributed to in 2021 and 2022. We also share some of the important foundational impact-enabling activities, such as targeted engagement with practitioners and policymakers, that have been delivered to help progress research along the pathway to impact.

Our investment in research and commitment to delivering impact is driving change across the UK. From research-led campaigning to amend the new Health and Care Act in England, to developing new, national public information on anticipatory care planning in Scotland, influencing the National Framework for the Delivery of Bereavement Care in Wales, and building the case for a bespoke Northern Ireland Loneliness Strategy. I hope you enjoy reading about the difference that Marie Curie is making through research and how this is supporting our vision of a better end of life for all.

Dr Sam Royston
Executive Director of Policy and Research, Marie Curie

Research at Marie Curie

Marie Curie is more than just a research funder. We're leading the way in palliative and end of life care research to help deliver a better end of life for all.

We **fund** research

Marie Curie is the largest UK charitable funder of palliative and end of life care research. We have a range of funding mechanisms to support the highest quality, most impact-driven research projects and programmes aligned to our strategic objectives, and to develop the people and capacity needed to drive this research field forward.

We **deliver** research

Our internal team of subject and methodological experts deliver strategically-aligned research projects and programmes that support the ongoing activities, and inform the future agendas, of teams across Marie Curie, including Caring Services and Policy and Public Affairs. They also successfully capture external research funding for Marie Curie projects.

We **enable** research

We enable the development and delivery of research both within Marie Curie services and the wider hospice and palliative care sector. We work in partnership with other organisations to increase the funding for palliative and end of life care research. Our Research Nurses and Leads, alongside our Research Fellows, support and undertake research activities at our hospices and in our community services.

We **involve people** to shape research

Our Research Voices Group ensures that the voices of people personally affected by dying, death and bereavement are at the heart of all our research activity. Members sit on our research decision-making panels and help shape and develop our research programmes. Our research priorities are also informed by people with lived experience through research priority setting exercises.

We use research to **drive change**

We work in partnership to engage key audiences and decision-makers so our research can inform changes to policy and practice, and improve the end of life experience for all. This is facilitated by our integrated Research and Policy teams and links to our Caring Services team. We run an annual conference to engage practitioners with the latest palliative and end of life care research and a Research Impact Fund to support implementation activities.

We support research that aligns with the four thematic priority areas highlighted within our Research, Policy and Public Affairs Strategy.

- To provide quality care and support for the **mental and physical health and wellbeing** of people affected by dying, death and bereavement.
- To end **financial insecurity at end of life** and ensure that everyone has the support they need to address their practical concerns.
- To ensure that everyone affected by death and dying – including the **family, friends and carers** of the dying person – are supported through and beyond the end of life.
- To **end inequity in end of life** experience by ensuring access to excellent standards of care and support for all.

These priority areas were informed by the themes within Marie Curie's organisational Impact Framework which reflect the areas that people with lived experience, staff and volunteers told us are most important to people's end of life experience – this is why we focus our work on them.

From research to impact

This report is divided into three sections which correspond to different stages along the pathway from research to impact.

Read about successes in capturing vital new funding for palliative and end of life care research and work to centre the voices of people affected by dying, death and bereavement in research.

Case studies

Read about research publications and activities that have been undertaken to promote the take up and use of research findings by policymakers and practitioners.

Case studies

Read about how Marie Curie-supported research has influenced changes to policy and practice that will help improve end of life experience across the UK.

Case studies

1

Making the right research happen

Funding

Marie Curie is the largest charitable funder of palliative and end of life care research in the UK(1). We currently invest around £3 million per year to support impact-focused research that contributes to our strategic goal of achieving the best possible end of life experience for everyone.

We are doing all we can to support palliative and end of life care research through our own research funding programmes, but we know that the overall investment in this vital area is simply not enough. The most recently available large-scale analysis showed that only 0.21% of health research funding in the UK goes to palliative and end of life care with Marie Curie funding a third of this research(1). That's why it's so important that we attract more funding from other health research funders, so we can build an evidence base to inform palliative and end of life care policy and practice.

Our investment in capacity building via our Centres and Fellowships gives researchers the time, space and skills to apply for and win grants for palliative and end of life care research from the major health funders, and our support for the earlier stages of research programmes enables researchers to go on to win further large scale funding with which to build on them. For example, a recent evaluation of our past portfolio of nine funded feasibility trials showed that more than half had achieved follow-on funding, with a combined total of over £3 million.

In 2021, researchers supported by Marie Curie gained £2,096,183 in additional funding to help build on and expand their research within palliative and end of life care. In 2022, this figure was £2,828,404.

These figures only include funding amounts that came directly to the Marie Curie-supported researcher at their institution; in some cases that will be less than the total amount of the grant (for example, grants where the total funding is divided across multiple different sites). The total further funding for new palliative and end of life care research which researchers supported by Marie Curie have contributved to the capture of will therefore have been significantly higher than these figures.

Further funding secured to support research into palliative and end of life care

£2.09 million

£2.83 million

Case study

A £5 million grant for end of life care research from the EU Horizon funding programme

In 2021, Professor Simon Noble from the Marie Curie Palliative Care Research Centre in Cardiff was joint lead, alongside Professor Erik Klok from Leiden University in the Netherlands, on a successful application to the EU HORIZON research funding programme. Professor Noble and team were awarded £5.17 million to carry out the SERENITY (Towards cancer patient empowerment for optimal use of antithrombotic therapy at the end of life) project. Of this funding, £861,500.00 went to the University of Cardiff to support the activities of Professor Noble, Professor Annmarie Nelson who is leading a work package on patient and public involvement for the project, and other collaborators. The project is developing and testing a clinical decision-making tool to help advanced cancer patients decide whether and when to stop anticoagulant and antiplatelet medicines in the last year of life. This significant new funding, and the collaborative work across 10 different European countries to deliver SERENITY, gives a major boost to the palliative and end of life care research field and will contribute vital new evidence to support the Cardiff Centre's vision of optimising the design and delivery of patient-focused palliative and end of life care.

Led by lived experience

At Marie Curie, we believe that putting the voices of people with lived experience at the heart of research helps ensure that the outcomes will be more relevant and useful to the people it aims to benefit. We involve people affected by dying, death and bereavement in setting priorities for research, in making decisions about which research should be funded, and in shaping and developing (and in some cases delivering, as peer researchers) our research projects and programmes.

Case study

Amplifying the voices of British Muslims – research partnership with the Muslim Council of Britain

Noura Rizk and Dr Briony Hudson from Marie Curie's internal research team, Dr Gemma Clarke (Marie Curie Senior Research Fellow, University of Leeds), and Dr Nuriye Kupeli (Marie Curie Palliative Care Research Department, University College London) worked in partnership with Mansur Safdar and Dr Shuja Shafi from the Muslim Council of Britain, to explore the experiences of British Muslims with palliative care needs during the covid-19 pandemic. The project was supported by resources from both Marie Curie and the Muslim Council of Britain, and the team also received support from a Patient and Public Involvement Bursary Fund grant from University College London.

Recognising that the best way to understand and address the challenges for people experiencing inequitable access to palliative and end of life care services is to work in partnership with people from these communities, the project adopted a "peer research" approach designed to amplify the voices of British Muslims. Peer research involves people with lived experience of an issue playing an active and integral part in the research process, from developing the questions to be answered, to collecting and analysing data, and interpreting and sharing the findings.

Left to right: Afzal Khan (MP), Karon Ornadel (Marie Curie), Zara Mohammed (Muslim Council of Britain), Briony Hudson (Marie Curie), Miqdad Asaria (London School of Economics and Political Science), Ruth Driscoll (Marie Curie) at the Parliamentary Launch of the Research.

The research team identified, recruited, and trained people from the British Muslim community to act as peer researchers in this project. They also provided training in qualitative research methods to the peer researchers and supported them to carry out telephone interviews with people from the British Muslim community with palliative care needs, and their families, using a co-designed topic guide. As a key part of the research team, the peer researchers were also involved in the qualitative analysis of the data collected and the shaping of the recommendations in the project report(2). These were practical recommendations with the potential to improve support for British Muslims with palliative care needs and their families in the UK.

The research findings highlighted the ways in which covid-19 impacted the physical and mental health of British Muslims with palliative and end of life care needs and their families. They showed that, for people interviewed as part of the study, families were often pivotal in providing support to loved ones and took on extra caring responsibilities. Older people with additional health and social needs faced language barriers and communication challenges, digital exclusion, and challenges adjusting to telephone and video consultations. Participants also reported experiencing uncertainty around how to access information and a sense of exclusion from public health messaging and government policies during the pandemic.

As well as the practical recommendations laid out in the report, the research team also produced a thought-provoking video(3) capturing the challenging real-life experiences that people had faced in supporting their loved ones towards the end of their lives. The video has featured in anti-racism workshops attended by colleagues across Marie Curie.

The report and video were launched at a well-attended parliamentary event in Westminster, providing an opportunity for decision-makers such as parliamentarians and representatives from Integrated Care Boards to engage with the research and its recommendations.

To continue their successful and collaborative partnership, the team on this project were recently awarded further funding for a PhD joint-funded by the Economic and Social Research Council's White Rose Doctoral Training Partnership and Marie Curie, for team member Noura Rizk. Noura's PhD will be based at the University of Leeds and her project will explore the influence of ethnic background, culture and faith on attitudes around advance care planning conversations with the British Muslim community.

The researchers we fund share our commitment to putting the voices of people with lived experience at the heart of their research. The quality of plans to involve people with lived experience is a key factor in decisions about which applications for research funding we support and is assessed by the lived experience members of our decision-making panels.

Marie Curie Research Voices Group

The Marie Curie Research Voices Group was set up in 2013 to facilitate the involvement of people with personal experience of living with a life limiting illness, caring for someone, or bereavement, in our research activities.

> "The best research on end of life care always keeps the lived experience of people affected by dying, death and bereavement at its very heart – at Marie Curie we are so privileged that the Research Voices Group is there to help us do just that."
>
> *Sam Royston, Director of Policy and Research at Marie Curie*

Members come from all four nations of the UK and share a common passion for using their own experiences to help shape and improve the end of life experience for others.

> "It is undoubtedly therapeutic after my wife's traumatic illness and death. […] Everything I do is in Wendy's memory."
>
> *Peter Buckle, on why he is a member of Marie Curie's Research Voices Group*

In 2022, Marie Curie committed to expanding our work involving people with lived experience, by creating a role in the research team for a Public Involvement and Engagement Manager to directly support the Research Voices Group. A process was begun to increase and diversify the membership of the group and to extend its remit beyond research to involvement in our policy and impact work.

If you have would like more information on the Marie Curie Research Voices, or would like an informal chat about potentially joining the group, please email research.info@mariecurie.org.uk

Researchers at the Marie Curie Palliative Care Research Centre at the University of Cardiff have developed the **Public Involvement in Research Impact Toolkit (PIRIT)**(4). This free resource has been designed to support the planning of effective and meaningful public involvement in research in line with the UK Standards for Public Involvement, and to help track activity and showcase the impact that public members have on research.

PIRIT
Public Involvement in Research
Impact Toolkit

Case study

Putting families at the heart of children and young people's advance care planning research

Children and Young People's Advance Care Planning (CYPACP) is important because children with life-limiting conditions and their families do not always have the opportunity to talk about the care they would like to receive as their illness progresses. As a result, the care provided to them may not reflect their wishes. For example, most children will die in intensive care in hospitals, despite families preferring for their child to be at home(5).

Dr Karen Shaw, Research Fellow at the Institute of Applied Health Research, University of Birmingham, led a team that received funding from Marie Curie to carry out research into the experiences and impact of CYPACP. The aim of the project was to understand how families, health professionals and organisations can work together to deliver the best care for children and young people with life-limiting conditions. The researchers evaluated the effectiveness of the existing CYPACP – a standardised tool used across the UK to help families and healthcare professionals discuss, agree and document plans for a range of possible scenarios.

Involving people with lived experience at every stage of this research project, was a key driver of the success of the project. This included having a project steering group made up of parents, carers and members of the public to ensure that the research contributed to meaningful change.

Effective public and patient involvement within this project ensured that the research was done in partnership. Not just for families, but with families. Members of the public provided advice to the research team and shared equal power in decision-making throughout the research project following a co-production model. Their involvement ranged from co-designing research materials, such as interview schedules, to planning the project dissemination strategy. The latter ensured that dissemination events focused on the issues that mattered most to families and enabled their voices to be heard. Several parents from the steering group were keynote speakers and co-facilitated interactive workshops with professionals, which encouraged clinical and academic professionals to engage with the research findings and develop more family-centred practices.

Co-production is an approach whereby researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge(6).

Parent Emma Murphy was a member of the project's steering group and played a crucial role from the early stages of the project:

> "There is a sense of achievement – I'm so pleased to have been involved, and that what I have done has helped shape a project that will make a difference to people's lives for many years to come."

- Emma Murphy, Patient and Public Involvement (PPI) representative

> "[Emma's] strong involvement allowed us to be confident that we were producing information and materials that would be appropriate for the people who need it most."

- Dr Shaw

The involvement of people with lived experience contributed to the successful uptake of the project's findings and recommendations to improve advance care planning for children and young people in the UK. This has included informing the latest iteration of the CYPACP (Version 5), as well as the development of more practical guidance around making, sharing, reviewing and using plans. This supplementary guidance will sit alongside the CYPACP and will include information about how to initiate conversations with children, parents and other professionals, and how to complete and implement the CYPACP in a family-centred manner. It is being developed by the CYPACP Working Group with funding from Marie Curie's Research Impact Fund. The research has also informed the Children's Palliative Care Education Standard Framework(7) for Advanced Care Planning, which provides new guidance to help organisations, health professionals and educators coordinate and quality assure their teaching and learning around advance care planning.

Dr Karen Shaw, Research Fellow at the Institute of Applied Health Research, University of Birmingham

2

Laying the foundations for impact

Publication

Publishing in peer reviewed journals ensures that research findings are publicly available for others to access and use, and that their quality has been validated by independent researchers. Publishing open access means that the findings are accessible to all for free, so that everyone can benefit from reading and using the research.

At Marie Curie, we are committed to ensuring that the findings from the research we fund are accessible to all, to maximise the chance of them being accessed and used to deliver change for people affected by dying, death and bereavement. Our open access publication policy and provision of funding for open access fees for research that we support is helping to make this happen.

In 2021, Marie Curie-supported researchers published 112 papers in peer-reviewed journals and 90% were published with open access. In 2022, the equivalent figures were 111 papers and 84% open access.

2021

112 papers

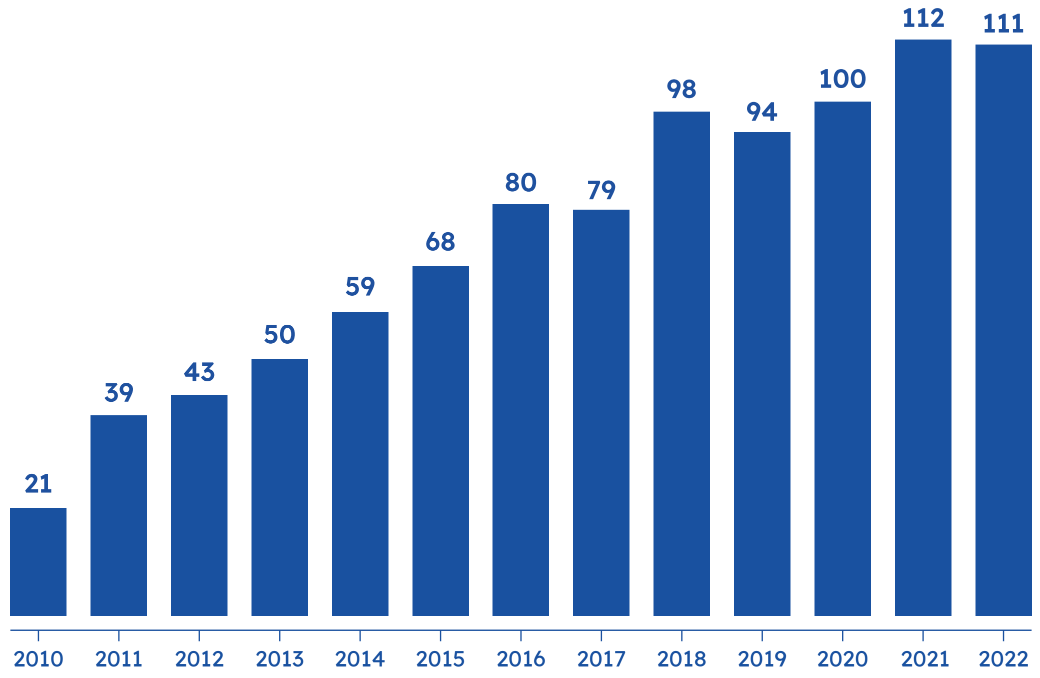
in peer reviewed journals
- **90%** were open access

2022

111 papers

in peer reviewed journals
- **84%** were open access

Overall publication figures since 2010



Engagement activities

Activities that engage wider audiences beyond academia, such as practitioners or policymakers, with the findings of research, are an important way of promoting the take up those findings by individuals who can use them to make a difference to the lives of people affected by dying, death and bereavement. Engagement activities with these audiences earlier on in the research project lifecycle are also a powerful way of helping ensure that the research and its outputs are maximally useful and used.

Engaging public audiences with the findings of research offers an opportunity to raise awareness and share learnings directly with people who are, or will be at some stage, directly affected by dying, death and bereavement.

Marie Curie-supported researchers carried out hundreds of engagement activities over the course of 2021 and 2022, both in the UK and internationally, with audiences including policymakers, practitioners, patients and carers, and the general public. These activities included presentations, workshops or other events targeted at key audiences for the research, sitting on formal working groups or expert panels, participating in print or broadcast media activity about the research, and producing online content such as websites, blogs or for social media.

Many of these activities were delivered in collaboration with Marie Curie's Research, Policy and Public Affairs teams, drawing on their engagement expertise, networks and knowledge to maximise the chance of reaching the right audiences with the right messages in the most effective way.

Case study

Loneliness among people at the end of life and their carers in Northern Ireland – engaging policymakers with new research

In 2021, Dr Tracey McConnell, Marie Curie Senior Research Fellow in Northern Ireland, led a successful application to the Marie Curie Internal Small Research Grants Scheme and was awarded funding for a research project to explore the experiences and impact of loneliness among those with a terminal illness and their carers in Northern Ireland. This important research was carried out in partnership with Professor Joanne Reid of Queen's University Belfast, as well as Marie Curie's Northern Ireland Policy team, and provided the first dedicated examination of loneliness among people living with a terminal illness, and their carers, that has ever been carried out in Northern Ireland.

Findings from the study indicated that there is an extremely high prevalence of loneliness among people with a terminal illness and their carers. Of the Marie Curie frontline staff surveyed, 93% said they had supported patients who were lonely and 87% had supported carers who were lonely. Alongside the statistics from the survey, the report(8). also included many powerful quotes from staff describing the loneliness that patients and carers had faced – one staff member was told by a patient: "you're the first person who's sat on that sofa in 12 months"(8).

To accompany the launch of the report, the Marie Curie Northern Ireland Policy team convened a webinar that took place in February 2022, with the aim of engaging key audiences with the findings of the research. The webinar was chaired by Sinéad Bradley, a member of the Legislative Assembly (MLA) of Northern Ireland and comprised a presentation of the study's findings, as well as the perspective of Majella Brogan, a Marie Curie Registered Nurse. The audience was varied and wide-reaching, with over 90 attendees from health and social care, the community and voluntary sector, policymakers, elected representatives and more.

Tracey McConnell, Marie Curie Senior Research Fellow in Northern Ireland

Since chairing the event, Sinéad Bradley has submitted two Written Questions to the Department of Health based on the findings of the report. One on expanding day care provision for those at the end of life, and the other on Health and Social Care training to identify loneliness. Additionally, Claire Sugden MLA has responded to the report by publicly backing the recommendation for a bespoke Northern Ireland Loneliness Strategy.

Following the success of this engagement activity in growing public support among policymakers for action, the team are now progressing with the next steps on the pathway to impact for this research to help ensure that it contributes to real change for people with a terminal illness, and their carers, experiencing loneliness in Northern Ireland.

> **There will be a range of upcoming opportunities to promote the research and to influence policy and practice, this will include informing a Loneliness Framework for Health and Social Care set up by Department of Health and working with partners across the sector to highlight shared calls to Government during Loneliness Awareness Week. We are also members of the All-Party Parliamentary Group on Loneliness and sit on the Action on Loneliness Policy Forum.**
>
> **Tracey McConnell, Marie Curie Senior Research Fellow in Northern Ireland**

Case study

The UK Commission on Bereavement – evidence-led engagement and influencing to ensure bereaved people are properly supported after the death of a loved one

The covid-19 pandemic, an unprecedented time of mass bereavement, threw a spotlight on bereavement care and support. Marie Curie initiated and supported the UK Commission on Bereavement (UKCB) alongside Independent Age, Cruse, Childhood Bereavement Network, National Bereavement Alliance, Sue Ryder, Centre for Mental Health and MacIntyre, in order to better understand the needs of bereaved people, the support they were receiving, and the improvements that could be made to deliver a better experience for them.

The Commission led one of the largest ever consultations on bereavement support undertaken in the UK, which included over 1,000 adult and 100 child respondents to their surveys, and submission of evidence from over 130 organisations. Research to analyse the experiences of those bereaved in the last five years, was undertaken by Marie Curie's internal research team in partnership with Dr Emily Harrop from Cardiff University's Marie Curie Palliative Care Research Centre, Dr Lucy Selman from the University of Bristol, and other steering group partners. They found that there were 750,000 excess bereavements during the pandemic, a figure which was regularly quoted in many high-profile discussions on covid-19. Key wider findings pointed to the need for greater support beyond covid-19: 46% of bereaved people had no support from friends and 28% had no support from their family, 40% were unable to access the professional support they would have liked, and 61% had difficulties with at least one practical or administrative task following bereavement.

Marie Curie also funded a further in-depth analysis of the UKCB's survey data with a focus on access to, and infrastructure around, bereavement support. This secondary analysis was funded by Marie Curie's Internal Small Research Grants scheme and led by Marie Curie's Senior Research Fellow, Associate Professor John MacArtney, and Dr Catherine Grimley, both based at the University of Warwick. Their report(9) describes how age, gender, ethnicity, or sexual orientation impact many people's access to formal and informal bereavement support, as well as their satisfaction with, and effectiveness and delivery of, bereavement services. It includes several recommendations on how to reduce inequalities in accessing effective bereavement support which further strengthen and expand on recommendations made by the UKCB.

In October 2022, the UKCB launched their final report *Bereavement is Everyone's Business*(10), which included eight principles for change and 26 evidence-led recommendations to transform bereavement support for people in the UK. The report was launched at an event in Westminster which brought together academics, policymakers including Ministers and senior civil servants, influencers, and operational and regulatory partners, to explore and hear for the first time the principles and policy recommendations of the UK Commission on Bereavement and to start to plan collaborative work to address them.

The UKCB's 2022 report *Bereavement is Everyone's Business*

The event was hosted by the Chair of the Commission, The Right Reverend and Right Honourable Dame Sarah Mullally DBE, and was attended by over 200 people, either in person or virtually. Video messages at the event from Scottish, Welsh and Northern Irish Health Ministers, alongside the director with policy responsibility for bereavement in the Department for Health and Social Care (DHSC), cemented a four nations commitment to listening and responding to the findings and recommendations of the UKCB.

> "The pandemic has challenged and changed all our lives. For those whose loved ones have died during this time life has changed the most. With hundreds of thousands more people facing bereavement, covid-19 has had a profound impact on how those affected have experienced grief."
>
> *Chair of the UKCB, the Rt Revd and Rt Hon Dame Sarah Mullally DBE, speaking at the report launch*

Since the launch of the UKCB report, Marie Curie's Policy and Public Affairs team has been working tirelessly, along with other members of the UKCB, to engage with and influence decision-makers to drive forward progress on the principles and recommendations outlined in the report. This has included building relationships with the DHSC bereavement team and with relevant civil servants and minsters across the four nations of the UK, the establishment of new cross-departmental bereavement working group, engagement with Local Authorities on UKCB recommendations and running fringe events at the Labour, Conservative, SNP and Plaid Cymru party conferences.

Progress is already being observed, including the recent review and updating of the UK Government webpages on bereavement by Government Digital Services, in consultation with Marie Curie and other UKCB partners, to incorporate new signposting to emotional support for people who have been bereaved.

The report's launch event hosted by the Chair of the Commission, The Right Reverend and Right Honourable Dame Sarah Mullally DBE.

Media coverage of the report

Case study

Partnering with artists – innovative perspectives on academic research to engage new audiences

Dr John MacArtney, Marie Curie Associate Professor at the University of Warwick, collaborated with artist Emily Warner to create the piece *Things Change, Things Changed*(11) as part of the Coventry Creates project which commissioned local artists to work with researchers, to bring new perspectives and new audiences to academic work.

Emily and John worked together to produce an artistic expression of John's ESRC-funded (Economic and Social Research Council) research programme that explored the impact and implications of covid-19 on experiences of hospice care in the West Midlands (the ICOH study) (12).

Using initial findings from John's study, Emily interpreted the climate and conditions that local hospices and hospice users faced during the pandemic and worked with producer Marley Butler to create a "deep listening" experience – an audio response to the research along with an accompanying film featuring a crop of plants affected by weedkiller, slowly breathing in and out of focus, articulating the complexities of the pandemic and of dying.

> "Presenting the research in new formats provokes curiosity and interest. The piece brought to light the more human side of the work that people can resonate with as well as creating an opportunity to access the work that may not be easily accessible in a non-conventional way."
>
> *Emily Warner*

Things Change, Things Changed, a title selected for the piece as a direct quote from a participant in the ICOH study, was launched online as part of a digital exhibition of 30 artist responses to research funded through Coventry Creates.

> "This process enabled me to see my own research and the field I'm working in a different light – it is quite a powerful thing to see what you're doing in a different way. Also connecting with different audiences which I think is such an interesting and important activity to be doing with our research."
>
> *Dr John MacArtney*

The findings of the ICOH study offer important lessons to inform current government plans for people with life-limiting illnesses to 'live with covid', and future plans for hospice care as part of the wider health and care system. In addition to the public engagement work described above, John has been leading a programme of targeted engagement activity, in partnership with the Marie Curie Policy team, to raise awareness of the evidence from the ICOH study among key decision-makers. This included a parliamentary briefing on the research sent to all MPs in the West Midlands region, as well as submission of evidence from the ICOH study to the UK Commission on Bereavement and the All-Party Parliamentary Group (APPG) for Hospices and End of Life Care's review on the lasting impact of covid-19 on death, dying and bereavement. The evidence submitted from the ICOH study to the APPG has been cited extensively in their recently published APPG's *The Lasting Impact of COVID-19 on Death, Dying and Bereavement* report(13).

Case study

Research-led Dying in Poverty campaign – engagement activities to drive policy change

In 2021 Marie Curie commissioned Dr Juliet Stone and Professor Donald Hirsch at the Centre for Research in Social Policy at Loughborough University to conduct research into the risk and prevalence of poverty in the last year of life across the UK.

This research provided ground-breaking evidence to show that 90,000 people die in poverty in the UK each year(14), and initiated our campaign to end people dying in poverty.

The researchers found that certain sub-groups of the population were at particular risk of dying in poverty, including working age people, women, people from minoritised ethnic groups and parents with dependent children. Those living in deprived, urban areas were also found to be at increased risk of poverty at the end of life.

In response to these research findings, the Dying in Poverty campaign(15) is calling for government support to enable all dying people, regardless of age, to access their State Pension, to protect them from soaring energy bills, and to support them with childcare costs. These recommendations aim to ensure that nobody living with a terminal illness has to face financial insecurity at what is already one of the most difficult times in their life.

Further research(16) conducted by Dr Stone and Professor Hirsch has quantified the potential impact and cost to the UK Government of implementing the core ask of the campaign – early access to the State Pension for dying people. This cost-benefit analysis modelled several different options for implementing the potential policy and

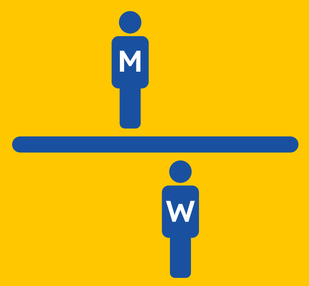
Key stats from the Dying in Poverty report

90,000

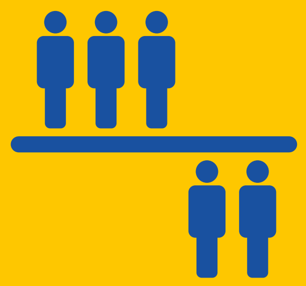
90,000 people die in poverty every year in the UK.

1 in 4 terminally ill people of working age spend the last year of their lives in poverty.

Working age people at the end of life are twice as likely to be in poverty than those of pension age.



Women are more likely to fall below the poverty line at the end of life than men.



2 in 5 working age people from minority ethnic groups die below the poverty line.

1 in 4 pensioners are below the poverty line at the end of life.

Working age people with children are more likely than any other group to fall below the poverty line at the end of life.

People living in London, the North West and the North East of England have the highest risk of dying in poverty.

estimated how many people would be lifted out of poverty as a result. The findings supported the State Pension ask as a highly effective policy to reduce the risk of people dying in poverty, with the potential to lift thousands out of poverty at the end of life, and with relatively low cost to the state in the context of the overall welfare budget.

> “People approaching the end of their lives should be able to spend the last months and years of life focusing on what really matters – making memories with their families and loved ones, living as well as they can for as long as they are able.
>
> **Matthew Reed,**
> **Chief Executive, Marie Curie**

Additional evidence to support the Dying in Poverty campaign came from a Marie Curie-led survey of our Caring Services staff, conducted to better understand how the cost of living crisis impacted families affected by terminal illness over the course of 2022.

The cost of living survey results(17) found that in 2022, clinical staff had witnessed a sharp increase in the number of patients struggling financially as the cost of living had risen – with significant impacts not only on their ability to make ends meet and pay for daily essentials like food and utility bills, but also on their health and wellbeing. More than four in five staff had witnessed patients struggling to pay their energy bills – a particular concern given the vulnerability of people living with a terminal illness to fuel poverty, and the vital importance for them of staying warm, especially over winter.

The findings of this survey emphasised the need for further, targeted support to be made available to people living with a terminal illness, and those close to them, to help them manage the added costs and financial impacts they face due to their illness. Across Marie Curie, we are seeing the strain on people affected by terminal illness, with one in five calls to our Support Line relating to financial insecurity in 2022, a 38% increase from 2021.

The Dying in Poverty campaign has been Marie Curie's largest campaign to date. The research led by Dr Stone and Professor Hirsch has been integral to the campaign and has played a foundational role in supporting the engagement activities led by the Marie Curie Policy and Public Affairs team to drive policy change in this area. This has included forming the basis of a briefing given to MPs at the launch of the Dying in Poverty campaign in Parliament in September 2022 attended by more than 60 MPs from all parties, as well as of submissions to inquiries by the House of Commons Work & Pensions Committee, Energy Security & Net Zero Committee and consultations by the Department for Work and Pensions, Department for Energy Security and Net Zero, and the Cabinet Office.

The campaign has had significant public support and media coverage and a campaign petition garnered 166,240 signatures from members of the public. The petition, asking the Government to enact the campaign's policy recommendations, was handed in at Downing Street by ex-footballer and TV presenter Chris Kamara and campaign supporters Tammy and Cheryl, who have been pivotal to the campaign, sharing their own experiences of financial insecurity at the end of life.

Tammy sadly passed away in May 2023 but the major contributions she made to driving forward engagement with the campaign from both the public and politicians were hugely appreciated and continue to be felt. This included featuring in a front cover story in the Daily Mirror in August 2022, as well as being invited by Sir Keir Starmer to attend Prime Minister's Questions later that year and to meet with him afterwards to discuss her experiences and the Dying in Poverty campaign.

As we enter an election year, the campaign continues apace. Marie Curie has also made significant additional investments recently in research to help support our policy and influencing activity in this area and to drive forward progress towards our vision of no one in the UK dying in poverty.

3

Informing policy and practice change

Informing changes to policy and practice is a fundamental part of how research we support can benefit people affected by dying, death and bereavement. At Marie Curie, we work tirelessly to ensure that the research we fund, support and deliver has the best possible chance of leading to policy and practice changes that improve end of life experience. Our funded researchers share our ambition to see their research contribute to meaningful change and a commitment to helping deliver that change.

Over the course of 2021 and 2022, Marie Curie-supported researchers have reported numerous instances of their research informing policy or practice both in the UK and internationally. Data from Overton, the online platform that links policy documents with the research cited within them, also shows citations of Marie Curie research in policy documents from around the world during this time period.

Dr Jeff Round carried out his PhD based at the Marie Curie Palliative Care Research Department at UCL, with the assistance of Marie Curie funding. As part of his programme of PhD research he looked into the vital issue of the cost of caring for people with a range of cancers and published a seminal paper in the journal Palliative Medicine in 2015, *Estimating the cost of caring for people with cancer at the end of life: A modelling study*, which showed significant costs to society, with a high proportion being borne by unpaid carers. Overton data shows that this paper has been cited within 35 new NICE clinical guidelines in the last five years, including 10 in 2021 and 6 in 2022.

NICE guidelines are evidence-based recommendations for health and care in England with wide reach, designed to help health and social care professionals, commissioners, patients and carers make informed decisions on appropriate treatment and care.

Estimates from Marie Curie, covering the financial year 2021-2022, indicate that our research, policy and public affairs work has driven changes to policy and practice which could benefit more than six hundred thousand people affected by dying, death and bereavement.

Case study

Closing the gap – driving transformative change to end of life care provision through research-informed campaigning to amend the new Health and Care Act.

The Health and Care Act 2022 is a UK law that has reformed the organisation and delivery of health and care services in England. It was introduced with the aim of improving health outcomes and tackling health inequalities.

However, when it was first drafted as a bill, there was no direct reference made to the provision of care and support for people living with a terminal illness. This would have left palliative and end of life care in the continuing, unenviable position of being the only aspect of healthcare in England funded primarily by charities. With no legal duty to ensure the provision of palliative and end of life care services, the existing postcode lottery in terms of the care people receive at the end of life would have continued.

> "We cannot carry on with the lack of action and the continued jumble sales, cake sales and everything else."
>
> *Baroness Finlay of Llandaff, on the reliance on charity funding at a Health and Care Bill debate at the House of Lords in January 2022*(18)

In response to this fundamental omission in the initial draft of the bill, Marie Curie led a campaign to introduce an amendment to the Health and Care Bill that would mean that, for the first time in NHS history, health commissioners would be required to commission palliative care services in every part of England. This Make End of Life Care Fair campaign was supported by Baroness Finlay, a cross-party group of MPs and Peers, and leading charities including Hospice UK, Sue Ryder, Together for Short Lives and Alzheimer's Society.

The campaign drew heavily on evidence from Marie Curie-funded research to make the case for the need for the amendment. This included findings from the Public Attitudes to Death and Dying survey of over 8,000 people from across the UK, led by Professor Annmarie Nelson at the Marie Curie Palliative Care Research Centre in Cardiff, which showed that three-quarters of people think that end of life care should be given equal priority in the NHS as care for people in any other stage of life. Another key piece of evidence came from the Better End of Life Program – a three-year collaborative project between Marie Curie, King's College London, Hull York Medical School at the University of Hull, and the University of Cambridge. Analysis of the inclusion of palliative and end of life care in Integrated Care System (ICS) strategies, led by Professor Katherine Sleeman at King's College London, showed that only six of England's 42 ICSs had a published strategy which included palliative care as either a priority, an area of focus or an ambition.

These and other findings collated by Marie Curie's Policy and Campaigns team to support the campaign were frequently quoted in Parliament when amendments to the bill were debated, including in the House of Lords on 18 January 2022:

The commissioned services we campaigned for will include:

- Providing support in every setting including private homes, care homes, hospitals and hospices
- Making specialist palliative care advice available on a 24/7 basis
- Ensuring the right, skilled workforce is available to deliver this care
- Supporting advance care planning development in all services to ensure patients are able to have open conversations about their needs and concerns and more.

> "[...] a compelling body of evidence has been provided by Marie Curie, the end of life charity, which has been mentioned several times already in this debate. Building on that evidence, this amendment will not only prevent many people with a terminal illness dying in pain but deliver significant cost savings to the NHS by reducing unnecessary hospital admissions."
>
> *The Lord Bishop of Carlisle* (18)

> **The impact of this legal requirement to provide appropriate care to dying people could be transformative – it is one of the biggest developments in end of life care since the inception of the NHS.**
>
> **Matthew Reed, Chief Executive, Marie Curie**

Marie Curie also created over 427 million media opportunities for people to see and engage with the campaign, capitalising on high-profile media coverage, public campaigning actions, social media engagement and storytelling from people with lived experience to influence change.

As a result of this evidence-led campaign to Make End of Life Care Fair, the Government accepted the crucial amendment to the Health and Care Bill to introduce a requirement for palliative care services to be commissioned in every part of England. This could result in up to 490,000 people a year in England benefitting from improved access to better quality palliative care near them.

The amended Health and Care Bill becoming law in April 2022 was not the end of the campaign. Marie Curie's Policy team in England are leading a significant programme of work to ensure that the Integrated Care Boards (ICB) which are responsible for planning and funding most local NHS services, are acting on their new legal duty to commission palliative and end of life care services for their local communities.

This continued engagement work with the ICBs serves a further, crucial purpose: tackling entrenched inequities in access to and experience of palliative and end of life care. As it stands, marginalised communities experiencing wider societal disadvantage are disproportionately represented among the one in four dying people across the UK unable to access the palliative and end of life care they need.

By ensuring that all ICBs are meeting their legal duty to not only commission high quality palliative care services that are tailored to their local populations' specific needs, but also improve equity of access and outcomes, we hope to see these persistent inequalities lessen. We will continue to work collaboratively with ICBs to ensure this hope becomes a reality.

Case study

Promoting meaningful conversations about Anticipatory Care Planning across Scotland

Dr Kirsty Boyd, Reader in Palliative Care, Primary Palliative Care Research Group, The University of Edinburgh

Anticipatory Care Planning (ACP) in Scotland is a person-centred approach that encourages people living with serious illness, certain disabilities, declining health or frailty in older age to think ahead and plan for future changes in their health and care. Having a plan helps people get better coordinated care in a future emergency, not just when they are very unwell and approaching the end of life. This approach to future care planning aims to support people and those close to them to talk about what is important to them, between each other and with key professionals. People share values and priorities that shape how they would like to be cared for and any treatment they do not want. These are recorded alongside clinical recommendations for treatment and care that accept the inherent uncertainties of declining health. ACP in Scotland is offered to people of all ages and includes those who do not have full decisional capacity, so differs from other parts of the UK to some extent.

In 2020, Dr Kirsty Boyd received funding from Marie Curie for a research project that aimed to implement and evaluate an intervention to improve ACP in the community for people living at home or in a care home (the 4ACP project). As part of this project, Dr Boyd and her team carried out public consultations, a scoping literature review, and a review of public facing ACP websites across the UK and internationally.

Working in partnership with the team at NHS Inform, using the results of these scoping activities, they developed new, national public information on ACP in Scotland that included a short video explaining how future care planning can help anyone who would like to think ahead and make plans for changes in their health and care.

This content was peer reviewed by PPI representatives, members of the public from patient support charities and professionals, before being approved by the Scottish Government. Since February 2022, it has been freely accessible on NHS Inform, Scotland's public health information website (19).

The 4ACP research study is now looking at how these resources for staff, patients and families are being used in primary care across Scotland, as part of the ACP intervention.

The 4ACP project is just one part of a substantial programme of work led by Dr Boyd to support and promote meaningful conversations about ACP across Scotland and beyond, which has been supported by Healthcare Improvement Scotland, Scottish Government, Scottish Partnership for Palliative Care, Macmillan Cancer Support and Scottish charity PATCH (Palliation and the Caring Hospital), in addition to Marie Curie. This has included the development and distribution of freely available, evidence-informed ACP prompt cards and a video(20) developed with the Royal College of Physicians and Surgeons of Glasgow to support health and care staff to have guided conversations with patients and families about care planning.

> **“This approach to future care planning aims to support people and those close to them to talk about what is important to them, between each other and with key professionals.**

Case study

Research into practice – improving palliative care and support for people experiencing homelessness

People experiencing homelessness have higher rates of long-term illness[21] and a median age of death that is approximately 20 years younger than that of the general population[22]. Due to a range of factors, health needs aren't always recognised and so people experiencing homelessness face barriers in accessing support from health and social care services. Support from palliative and end of life care (PEoLC) services remains rare, and so many deaths are often unexpected and unsupported.

Dr Briony Hudson is Associate Director for Internal Research Development at Marie Curie and in collaboration with Dr Caroline Shulman, Senior Clinical Research Fellow at Pathway, she leads a programme of research identifying challenges to palliative care access for people experiencing homelessness, and exploring new models of care. Through a series of research grants from a range of research funders, Dr Hudson has developed significant expertise in this research area and delivered a programme of work which has produced innovative models for improving care and support for people experiencing homelessness and those supporting them.

Dr Briony Hudson, Associate Director for Internal Research Development at Marie Curie

As part of her programme of research, Dr Hudson was awarded a grant from the National Institute for Health and Care Research (NIHR) to build a network of professionals to come together to improve access to palliative care for people experiencing homelessness. There had previously been no central place for experts in this area to come together to share learnings, challenges, and best practice. The first National Palliative Care and Homelessness ECHO Network was held in June 2022 and now attracts attendees from a wide variety of backgrounds, including homelessness staff, palliative care staff, inclusion health staff, prison staff and people from local councils.

As well as the national network, in 2022 the team developed a free online platform with resources to help people set up communities of practice in their local area. This is known as the Intervention to optiMise Palliative caRe for peOple with liVed Experience of homelessness (IMPROVE). They partnered with Pathway, UCL, NHS England and the Oak Foundation to build the platform, and it contains information and videos about a range of topics related to homelessness, health, and palliative care. Within each community of practice, frontline homelessness staff, together with primary care, palliative care, addiction support, psychologists, social care staff and others, meet virtually to learn, share, and work together. They access online sessions that can be used to develop actions for challenging situations and support each other. The topics covered are wide-ranging, including the relationships between homelessness, health and palliative care, life in a hostel, complex trauma, frailty, care act assessments, mental capacity, and bereavement.

> “Working in partnership with people who have experienced homelessness will be key in developing research that can most effectively change practice and improve end of life care and support for people experiencing homelessness.

Dr Hudson's research has also influenced practice by informing a new NICE (National Institute for Health and Care Excellence) guideline[23] on integrated health and social care for people experiencing homelessness. NICE guidelines are evidence-based recommendations for health and care in England with wide reach, designed to help health and social care professionals, commissioners, patients and carers make informed decisions on appropriate treatment and care. Research by Dr Hudson and other colleagues from Pathway and the Marie Curie Palliative Care Research Department at UCL was cited within the evidence review that informed the guideline, and supported its recommendations around considering, discussing, and responding to palliative care needs for people experiencing homelessness.

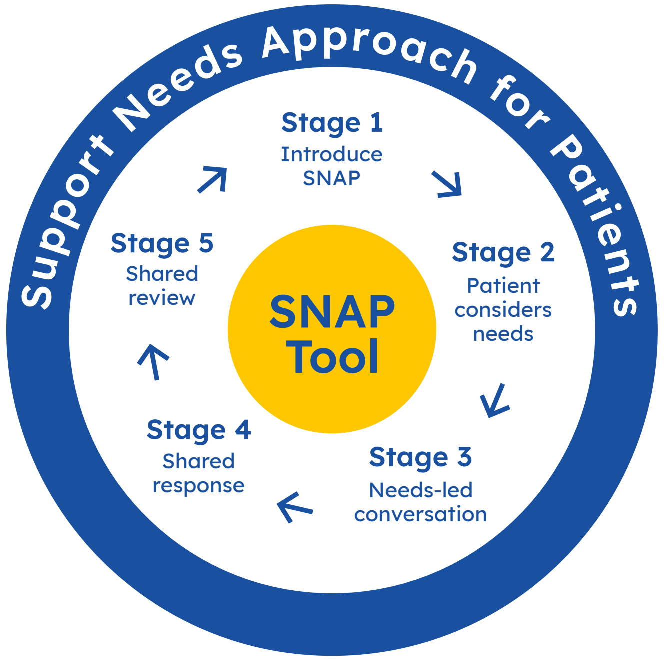
Dr Hudson's ambition to ensure people experiencing homelessness have access to the palliative care and support they need continues to be supported by the latest phases of her research programme. Her previous research uncovered the shocking finding that homeless hostel residents, with a mean age of 55, had frailty scores equivalent to those of 89-year-olds in the general population[24]. To understand this issue further, Dr Hudson has recently been awarded new research funding via the Marie Curie Internal Small Grants Scheme to look at how frailty can be better identified and improvements can be made to the support offered for this group towards the end of life. Dr Hudson is currently working on guidance on how best to involve people with lived experience of homelessness in palliative and end of life care research. Working in partnership with people who have experienced homelessness will be key in developing research that can most effectively change practice and improve end of life care and support for people experiencing homelessness.

Case study

An intervention to support person-centred care for patients with chronic or progressive conditions

For patients with chronic or progressive conditions, such as chronic obstructive pulmonary disease (COPD), person-centred care is key to improving their outcomes and experience. However, the provision of person-centred care relies on healthcare professionals having a good understanding of a patient's support needs so that they can work with them to meet them in an individualised way. This is something that has traditionally been challenging in practice, as demonstrated by the *Living with Breathlessness* (*LwB*) study (2013-2015) (25), jointly funded by Marie Curie and the NIHR, and led by Professor Morag Farquhar, Professor of Palliative Care Research, University of East Anglia. The *LwB* study aimed to identify ways to improve care and support in advanced COPD. It showed the unmet support needs experienced by patients with advanced COPD, as well as the difficulty they had in articulating those support needs spontaneously to healthcare professionals.

Research funding from both Marie Curie and the NIHR over a number of years subsequently supported Professor Farquhar to lead a team developing, validating and implementing the Support Needs Approach for Patients (SNAP) intervention. Initially developed to support people living with advanced COPD in response to the findings from the *LwB* study, but now in use across a range of chronic progressive conditions, SNAP is a five-stage intervention, underpinned by the 15 question SNAP tool. It has been designed to make it easier for patients to tell healthcare professionals about their support needs and for healthcare professionals to help address those needs.



SNAP tool stages

By helping patients and professionals work together to proactively identify and address patients' care and support needs, SNAP has the potential to bring about real improvements in the care provided for people living with a range of chronic progressive conditions as well as COPD, such as heart failure, strokes, neurological conditions, cancer, and Parkinson's Disease. It can be delivered by any SNAP-trained clinician and in multiple settings.

Professor Morag Farquhar, Professor of Palliative Care Research, University of East Anglia

SNAP is free to use for healthcare professionals from non-commercial organisations but is licensed to ensure appropriate and supported use. Licences have so far been issued across primary care, secondary care, community care and hospice settings. In each of these settings, SNAP is being delivered by a range of clinicians, including nurses, occupational therapists, and physiotherapists, to people living with a range of chronic progressive conditions. There have been many recorded improvements in the overall experience for clinicians to identify and meet the needs of patients:

> "SNAP has really enabled me to have conversations with patients that really are patient focused that really address the things that are important to them"

Deirdre Siddaway, Respiratory Nurse Specialist (26)

> "Using SNAP has the benefit that it helps focus your conversation with a patient during a consultation and it also gives patients permission to identify their own needs, it empowers them to help identify their needs and work out what it is they need in order to live well and live well with their condition"

Nicola Zolnhofer, Respiratory Nurse (26)

In 2021, the SNAP team received further funding from the Abbeyfield Research Foundation to pilot the intervention within district nursing to facilitate whole person care for older people living in the community. The research team also received further funding from the National Institute for Health and Care Research (NIHR) Applied Research Collaboration East of England to adapt and operationalise SNAP for mental health.

There is also a clear appetite for this intervention globally, with the tool licence being issued for research use in Sweden and the USA, as well as being translated into Swedish, Portuguese and traditional Chinese.

“

There is a clear appetite for this intervention globally, with the tool licence being issued for research use in Sweden and the USA, as well as being translated into Swedish, Portuguese and traditional Chinese.

Case study

Bereavement research shapes policy and practice to improve people's bereavement experience

Since 2010, Marie Curie has funded the Palliative Care Research Centre at Cardiff University to deliver research that improves the care and experience of people living with a terminal illness and those who support them. Dr Emily Harrop is a Research Fellow at the Centre and Marie Curie funding has enabled her to conduct research and develop specialist knowledge in bereavement care and experience. This stemmed from an initial piece of work analysing the bereavement experiences and needs described by people who took part in the 2015 Palliative and End of Life Care Research Priority Setting Partnership(27).

Millions of people across the UK faced bereavement in unprecedented circumstances during the covid-19 pandemic. In response, Dr Harrop drew on her existing bereavement research expertise to undertake research to develop an understanding of grief experiences during that time and identify real-time implications, to help improve bereavement support available to people.

Dr Harrop's national study Bereavement During Covid-19(28) was co-led with Dr Lucy Selman at the University of Bristol, with funding from the Economic and Social Research Council as part of UK Research and Innovation's (UKRI) rapid response to covid-19. The research involved a UK-wide survey investigating the experiences and support needs of people bereaved during the pandemic in the UK.

Key findings(29) of the study included:

- Two thirds (**67%**) of survey respondents reported that they experienced social isolation and loneliness after a bereavement.
- Those bereaved due to covid-19 were less likely to be involved in care decisions and to be well supported by healthcare professionals after the death.
- Almost half (**48%**) of survey respondents reported that they had not been provided with information about bereavement support services.
- Around three quarters (**74%**) of bereaved people with high or severe vulnerability were not accessing formal bereavement services or mental health support.

Dr Emily Harrop is a Research Fellow at the Palliative Care Research Centre, Cardiff University

Influencing policy and practice

Findings from the research received considerable media coverage which served to raise public awareness of the challenges of bereavement during the pandemic. In response to the findings, the former Health Minister responsible for bereavement Nadine Dorries MP issued a public statement committing to address the gaps and challenges identified in the study:

> "We must ensure that those who are bereaved have access to support, should they need it, when they need it."
>
> *Nadine Dorries MP (30).*

The findings were also directly cited in key documents seeking to influence change and improve bereavement experiences such as the National Framework for the Delivery of Bereavement Care(31) from the Welsh Government. Dr Harrop sat as a member of their Core Oversight group helping to shape the national framework as it was developed, enabling real-time consideration of her research findings at Welsh policy level. She continues to be involved with this group which is now focused on overseeing the implementation of the framework.

> "The high-profile nature of the study and the commitment from other stakeholders to learning from the study results has really helped to maximise the potential for rapid policy impact from the study."
>
> *Dr Emily Harrop*

Findings from the study also played a crucial role in shaping the UK Commission on Bereavement(32) which was established in 2021 to explore issues around bereavement and make recommendations on how to better support bereaved people. Dr Harrop presented the findings at the launch of the Commission in June 2021 and provided her expertise to the Commission throughout as part of their evidence sub-group. She helped design and oversaw the Commission's call for evidence, as well as submitting written and oral evidence drawing on relevant findings from across her portfolio of bereavement studies. The Commission published its report(10) in October 2022 and is now working to progress the key recommendations identified.

Dr Harrop's involvement on multiple steering groups, because of her expertise in bereavement, enables insights from her research to have direct influence over UK-wide policy, exploring the concerns of those who have been bereaved, and proposing suggestions to improve the support they receive. Dr Harrop and her team have also presented their results to a wide range of policy and practitioner audiences over the last two years, including the Bereavement and Funerals Cross Party Group (Wales) and Public Health England, and attended monthly meetings with the Department of Health and Social Care. Their extensive engagement with professional and practitioner audiences raised awareness of the challenges faced by people bereaved at this time and changes that could be made to improve people's bereavement experiences pre- and post-death.

Dr Harrop's work in this area continues apace. She was awarded a Small Research Grant from Marie Curie in 2022 to conduct a fourth survey looking at long-term grief experiences and support needs of people bereaved during the covid-19 pandemic. This has enabled Dr Harrop, Dr Selman and the team to follow up with their original study participants two years post bereavement to see whether and how their grief is still affecting them, the type of support they have received so far, and critically, the support that they still need. This project has recently completed and will help inform the planning, design, and delivery of relevant bereavement support services in these later stages beyond the pandemic.

Additionally, the team have also recently been awarded an impact grant by the University of Cardiff ESRC Impact Fund to develop an evidence-based resource which, using their research findings, will help bereaved people to find the type of support that is right for them. This impact work is being delivered in partnership with Marie Curie, the National Bereavement Alliance, Compassionate Cymru and the Good Grief Festival.

Case study

Research findings reported in landmark paper trigger a change to NICE guidelines

In February 2021, a landmark paper(33) reporting the findings of the NIHR-funded *ROCS (Radiotherapy after Oesophageal Cancer Stenting)* study, co-led by Professor Anthony Byrne at the Marie Curie Palliative Care Research Centre in Cardiff, was published in the Lancet Gastroenterology and Hepatology. In August 2022, NICE published a surveillance report detailing planned updates to their guideline on oesophago-gastric cancer assessment and management in direct response to the findings reported in this paper.

For those with advanced oesophageal cancer, swallowing difficulties are very common and often addressed by insertion of an expandable stent to overcome tumour obstruction. However, the effectiveness of the stent may wane after about three months, worsening quality of life and resulting in hospital admissions towards the end of life. The *ROCS* study examined the effects of giving a small dose of radiotherapy alongside insertion of the stent to see if it would reduce those burdens in this vulnerable population by maintaining swallow for longer. The study found that radiotherapy did not achieve improvements and did not improve survival, with patients often finding the radiotherapy burdensome. The researchers concluded that radiotherapy should not be routinely offered to this patient group.

Professor Anthony Byrne, Marie Curie Palliative Care Research Centre, Cardiff

On the basis of these findings, the NICE guideline will be changed to remove the recommendation to “Consider external beam radiotherapy after stenting for people with oesophageal and gastro-oesophageal junctional cancer, for long-term disease control”, guiding doctors to not routinely give radiotherapy in this situation. Marie Curie estimate, based on data from the National Oesophago-Gastric Cancer Audit (NOGCA), that over 3,000 patients per year in England and Wales could benefit from the changes made to this guidance and the implications it has for improved quality of life at the end of their lives.

> **Over 3,000 patients per year in England and Wales could benefit from the changes made to this guidance and the implications it has for improved quality of life at the end of their lives.**

Case study

Influencing the Heart Disease Action Plan in Scotland to prioritise palliative care

Electronic palliative care coordination systems enable the creation of electronic records containing key information about an individual’s preferences and the plans for their end of life care, which can be shared with those delivering care across different healthcare settings (such as GP practices, hospices, care homes, ambulance services and emergency departments).

The Key Information Summary (KIS) was introduced in Scotland in 2013 as an electronic care coordination system for anyone who might be likely to need urgent or out of hours care, including those living with an advanced progressive illness.

Research(34) led by Dr Finucane estimated the proportion of people in Scotland living with an advanced progressive illness who have a KIS by the time they die. They found that people with organ failure, including those with heart failure, were much less likely to have a KIS compared to people with other types of advanced progressive illness such as cancer or dementia.

Dr Anne Finucane, Research Lead at the Marie Curie Hospice, Edinburgh

This work was cited in the Scottish Heart Disease Action Plan(35) published in 2021, to make the point that people with heart failure are less likely to be considered for a palliative approach or palliative care when they would benefit from it. In response, the Action Plan commits to including access to palliative care as a core part of nationally agreed pathways of care for heart disease, and to include access to palliative care as an indicator within data collection and quality improvement work.

This should mean that more people living with heart disease in Scotland get the care and support that they need at the end of their lives.

References

1. Marie Curie and NIHR (2023). Marie Curie and National Institute for Health and Care Research (NIHR) palliative and end of life care research portfolio snapshot (2011 – 2018/19).
2. Hudson, B., Clarke, G., Kupeli , N., Rizk, N., Safdar, M. and Shafi, S. (2023). Muslim Voices: The palliative care needs of British Muslims during the Covid-19 pandemic and beyond. [online] Marie Curie. Available at: https://www.mariecurie.org.uk/globalassets/media/documents/research/mcb-report/j437-muslim-council-report_en.pdf.
3. Marie Curie (2023). Muslim Voices: Inequities in access to palliative and end of life care (English subtitles). [online] www.youtube.com. Available at: https://www.youtube.com/watch?v=WsKNLZ5Y7ew [Accessed 1 Sep. 2023].
4. Marie Curie Research Centre Cardiff University (n.d.). Public Involvement in Research Impact Toolkit (PIRIT). [online] Cardiff University. Available at: https://www.cardiff.ac.uk/marie-curie-research-centre/patient-and-public-involvement/public-involvement-in-research-impact-toolkit-pirit [Accessed 12 Oct. 2023].
5. Winger, A., Kvarme, L.G., Løyland, B., Kristiansen, C., Helseth, S. and Ravn, I.H. (2020). Family experiences with palliative care for children at home: a systematic literature review. BMC Palliative Care, [online] 19(1). doi: https://doi.org/10.1186/s12904-020-00672-4.
6. Hickey, G., Brearley, S., Coldham, T., Denegri, S., Green, G., Staniszewska, S., Tembo, D., Torok, K., and Turner, K. (2018) Guidance on co-producing a research project. Southampton: INVOLVE.
7. International Children's Palliative Care Network (n.d.). Children's Palliative Care Education Standard Framework and Self-Audit Tool. [online] ICPCN. Available at: https://icpcn.org/resources/education-framework-self-audit-tool/ [Accessed 16 Oct. 2023].
8. McConnell, T., Finucane, A.M. and Hanna, J. (2023). You're the first person who's sat on that sofa in 12 months" Experiences of loneliness among people at the end of life and their carers in Northern Ireland. [online] Marie Curie. Available at: https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2022/experiences-of-loneliness-among-people-at-the-end-of-life-and-their-carers-in-northern-ireland.pdf [Accessed 16 Oct. 2023].
9. Grimley, C., Hudson, B., Warren, R., Harrop, E., Murray, J., Hilleard, G., Goodburn, L., Matheson, A. and MacArtney, J. (2023). The perceived value of bereavement support and the impact of inequalities on availability and access: Accessing bereavement support. [online] University of Warwick. doi: https://doi.org/10.31273/978-1-911675-11-2.
10. 1The UK Commission on Bereavement (2022). Bereavement is everyone's business. [online] Bereavement Commission. Available at: https://bereavementcommission.org.uk/ukcb-findings/.
11. 1Coventry Creates (2021). Things Change, Things Changed. [online] coventrycreates.co.uk. Available at: https://coventrycreates.co.uk/project/things-change-things-changed/ [Accessed 10 Jul. 2023].
12. MacArtney, J., Eccles, A., Fleming, J., Grimley, C., Dale, J., Almack, K., Mayland, C., Mitchell, S., Driscoll, R., Hammond, R., Tatnell, L. and Roberts, L. (2021). What do we know about the impact of the Covid-19 pandemic on hospices? A collaborative multi-stakeholder knowledge synthesis. AMRC open research, 3(23), doi: https://doi.org/10.12688/amrcopenres.13023.1.
13. 1All-Party Parliamentary Group for Hospice and End of Life Care (2023). The Lasting Impact of COVID-19 on Death, Dying and Bereavement. [online] Hospice UK. Available at: https://hukstage-new-bucket.s3.eu-west-2.amazonaws.com/s3fs-public/2023-02/Final%20APPG%20report.pdf?VersionId=nIC3UxdxrAtZ2g8ak.ZjcMwmS5rTGN6K.
14. Stone, J. and Hirsch, D. (2022). Poverty at the end of life in the UK. [online] Marie Curie. Available at: https://www.mariecurie.org.uk/globalassets/media/documents/policy/dying-in-poverty/h420-poverty-at-the-end-of-life-in-the-uk-2nd-pp.pdf.
15. Marie Curie (2022). Dying in poverty: Exploring poverty at the end of life in the UK. [online] Available at: https://www.mariecurie.org.uk/globalassets/media/documents/policy/dying-in-poverty/h420-dying-in-poverty-5th-pp.pdf.
16. Stone, J. (2022). Policy interventions to alleviate poverty at the end of life – a cost/benefit analysis. [online] Available at: https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2022/policy-interventions-to-alleviate-poverty-at-the-end-of-life.pdf.
17. Marie Curie (2023). Marie Curie data briefing: The Cost of Living: A survey of Marie Curie Caring Services Staff. [online] Available at: https://www.mariecurie.org.uk/globalassets/media/documents/policy/briefings-consultations/uk-consultations/report-on-key-findings-from-the-cost-of-living-survey-.pdf.
18. House of Lords Hansard (2022). Health and Care Bill Volume 817. [online] UK Parliament. Available at: https://hansard.parliament.uk/lords/2022-01-18/debates/33979D37-BB91-408C-B5DB-4DFE3FBD70BB/HealthAndCareBill [Accessed 20 Aug. 2023].
19. NHS Inform (2022). Future care planning. [online] www.nhsinform.scot. Available at: https://www.nhsinform.scot/acp [Accessed 10 Oct. 2023]Future care planning. [online] www.nhsinform.scot. Available at: https://www.nhsinform.scot/acp [Accessed 10 Oct. 2023]
20. Royal College of Physicians and Surgeons of Glasgow (2023). REDMAP. [online] www.youtube.com. Available at: https://www.youtube.com/watch?v=bLWeQua8ZV0 [Accessed 20 Oct. 2023].
21. Aldridge, R.W., Story, A., Hwang, S.W., Nordentoft, M., Luchenski, S.A., Hartwell, G., Tweed, E.J., Lewer, D., Vittal Katikireddi, S. and Hayward, A.C. (2018). Morbidity and mortality in homeless individuals, prisoners, sex workers, and individuals with substance use disorders in high-income countries: a systematic review and meta-analysis. The Lancet, [online] 391(10117), pp.241–250. doi: https://doi.org/10.1016/s0140-6736(17)31869-x.
22. Aldridge, R.W., Menezes, D., Lewer, D., Cornes, M., Evans, H., Blackburn, R.M., Byng, R., Clark, M., Denaxas, S., Fuller, J., Hewett, N., Kilmister, A., Luchenski, S., Manthorpe, J., McKee, M., Neale, J., Story, A., Tinelli, M., Whiteford, M. and Wurie, F. (2019). Causes of death among homeless people: a population-based cross-sectional study of linked hospitalisation and mortality data in England. Wellcome Open Research, [online] 4(49), p.49. doi: https://doi.org/10.12688/wellcomeopenres.15151.1.
23. National Institute for Health and Care Excellence (2022). Integrated health and social care for people experiencing homelessness: NICE guideline [NG214] [online] Available at: https://www.nice.org.uk/guidance/ng214.
24. Rogans-Watson, R., Shulman, C., Lewer, D., Armstrong, M. and Hudson, B. (2020). Premature frailty, geriatric conditions and multimorbidity among people experiencing homelessness: a cross-sectional observational study in a London hostel. Housing, Care and Support, 23(3/4), pp.77–91. doi: https://doi.org/10.1108/hcs-05-2020-0007.
25. University of Cambridge (n.d.). Living with Breathlessness Study. [online] Available at: https://www.phpc.cam.ac.uk/pcu/research/research-projects-list/living-with-breathlessness-study/ [Accessed 15 Oct. 2023].
26. SNAP (n.d.). 'Clinicians often ask…'. Available at: https://thesnap.org.uk/use-snap/training/ [Accessed 10 Oct. 2023].
27. Harrop, E., Morgan, F., Byrne, A. and Nelson, A. (2016). 'It still haunts me whether we did the right thing': a qualitative analysis of free text survey data on the bereavement experiences and support needs of family caregivers. BMC Palliative Care, 15(1). doi: https://doi.org/10.1186/s12904-016-0165-9.
28. Harrop, E et al (2021). Support needs and barriers to accessing support: Baseline results of a mixed-methods national survey of people bereaved during the COVID-19 pandemic. Palliative Medicine, 35(10), pp.1985–1997. doi: https://doi.org/10.1177/02692163211043372.
29. Marie Curie (2021). New research shows impact of grief during the pandemic as two thirds of people report experiencing social isolation and loneliness. Available at: https://www.mariecurie.org.uk/media/press-releases/uk-commission-on-bereavement-new-research/316796 [Accessed 26 Sep. 2023].
30. Clarke, N. (2021). Government committed to plugging gaps in support for grieving families. [online] Evening Standard. Available at: https://www.standard.co.uk/news/uk/nadine-dorries-government-gps-university-of-bristol-uk-parliament-b940794.html [Accessed 1 Aug. 2023].
31. Welsh Government (2021). National framework for the delivery of bereavement care. [online] Available at: https://www.gov.wales/national-framework-delivery-bereavement-care [Accessed 12 Sep. 2023].
32. The UK Commission on Bereavement (2022). Bereavement is everyone's business. [online] Bereavement Commission. Available at: https://bereavementcommission.org.uk/ukcb-findings/.
33. Adamson, D., Byrne, A., Porter, C., Blazeby, J., Griffiths, G., Nelson, A., Sewell, B., Jones, M., Svobodova, M., Fitzsimmons, D., Nixon, L., Fitzgibbon, J., Thomas, S., Millin, A., Crosby, T., Staffurth, J. and Hurt, C. (2021). Palliative radiotherapy after oesophageal cancer stenting (ROCS): a multicentre, open-label, phase 3 randomised controlled trial. The Lancet Gastroenterology & Hepatology, 6(4), pp.292–303. doi: https://doi.org/10.1016/s2468-1253(21)00004-2.
34. Finucane, A.M., Davydaitis, D., Horseman, Z., Carduff, E., Baughan, P., Tapsfield, J., Spiller, J.A., Meade, R., Lydon, B., Thompson, I.M., Boyd, K.J. and Murray, S.A. (2019). Electronic care coordination systems for people with advanced progressive illness: a mixed-methods evaluation in Scottish primary care. British Journal of General Practice, 70(690), pp.e20–e28. doi: https://doi.org/10.3399/bjgp19x707117.
35. The Scottish Government (2021). Heart Disease Action Plan 2021. [online] Available at: https://www.gov.scot/publications/heart-disease-action-plan/.

The data underlying this report were submitted through Researchfish by Marie Curie-supported researchers and by Marie Curie internal staff. Case studies were developed in partnership with the individuals or teams who feature in them and we are very grateful for their time and support to make these possible. We thank the many Marie Curie colleagues who have contributed to the review and production of this report. Finally, our thanks go to our Research Funding Committee, Research and Policy Committee, and Marie Curie Research Voices, and to all those who make research at Marie Curie possible through their donations and support.

Marie Curie is there for anyone with an illness they're likely to die from, and those close to them. Whatever the illness, wherever you are, Marie Curie is with you to the end.

The charity brings 75 years of experience and leading research to the care they provide at home, in their hospices and over the phone. And they push for a better end of life for all by campaigning and sharing research to change the system.

Authors

Izzie Baverstock-Poppy
Sabine Best
Lydia Dent
Sam Royston
Hannah Thomas

Our offices

Registered office
One Embassy Gardens
8 Viaduct Gardens
Nine Elms
London SW11 7BW

Scotland
14 Links Place
Edinburgh EH6 7EB

Northern Ireland
60 Knock Road
Belfast BT5 6LQ

Wales
Bridgeman Rd
Penarth CF64 3YR

Thank you to everyone who supports us and makes our work possible.

mariecurie.org.uk

mariecurieuk

Charity reg no. 207994 (England & Wales), SC038731 (Scotland) J441

Registered with FUNDRAISING REGULATOR