



Care and support  
through terminal illness



# Leading the way in palliative and end of life care research

**Marie Curie annual research impact report 2015/16**

Using evidence to inform policy and practice, and to improve care for people affected by terminal illness throughout the UK



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# Welcome



Trevor Smeaton/Marie Curie

At Marie Curie, we pride ourselves on being the UK's largest charitable funder of palliative and end of life care research. In 2014, for example, we funded £1 in every £5 spent on end of life care research in the UK<sup>1</sup>.

Yet palliative and end of life care remains an underfunded area of research. And it's an area of ever more importance, particularly as people live longer and develop more complex needs. We continue to invest in research because we believe that everyone with a terminal illness has the right to high-

quality care – no matter where they live and no matter what their diagnosis or personal circumstances.

Our researchers collaborate nationally and internationally and share research findings widely to maximise their impact. Our high-quality research informs clinical practice and policy, helping us to develop the strong evidence base we need to improve care and support for those living with a terminal illness. We also work to increase capacity in palliative and end of life care research through our research funding and research lead programme at our hospices.

We are continuing to work in partnership with other organisations – for instance other charitable and governmental research funders – to make end of life care research a priority. This is vital for addressing changing demands – now and for the future.

**Dr Jane Collins**  
Chief Executive, Marie Curie

<sup>1</sup> Data taken from the UK Health Research Analysis 2014 (UK Clinical Research Collaboration, 2015).

# Foreword



Pete Jones/Marie Curie

Marie Curie-funded researchers are going from strength to strength when it comes to addressing the challenges faced by people at the end of life. As a charity we care for people living with all terminal illnesses and support research that crosses many healthcare boundaries.

Five years ago we decided to address the knowledge gap in palliative and end of life care research identified by the National End of Life Care Strategy in 2008 and the National Cancer Research Institute (NCRI) Rapid Review in 2010. We invested in three palliative care research centres at University College London, Cardiff University and the University of Liverpool. We have also invested in research leads based in our hospices to increase research activity and support evidence-based practice in our services.

Through our open and competitive funding stream, we awarded five new grants in 2015. These research projects

address some of the core issues and challenges faced by people living with terminal illnesses, their carers and families.

Our central research management team continues to oversee and arrange peer review of all our research activities. In 2015, we passed the Association of Medical Research Charities (AMRC) peer review audit. This confirms the rigour of our research management processes.

We were also pleased to award the Marie Curie Palliative Care Research Department, University College London core funding for a further five years following its independent quinquennial review.

Our Palliative and end of life care Priority Setting Partnership (PeolcPSP) with the James Lind Alliance highlighted a number of pressing questions for palliative and end of life care research. We're investing funds in strategic areas to make sure the issues identified by patients, carers and health and social care professionals are addressed.

Finally, a big thank you to all our partners and supporters, without whom we could not continue to lead the way in high-quality palliative and end of life care research.

## **Professor Bill Noble**

Executive Medical Director, Marie Curie

# Report at a glance

- We are the **largest charitable funder of palliative and end of life care research in the UK** – an area that remains significantly underfunded.
- Each year, we **invest £1 million in grants** to researchers through our open and competitive funding scheme.
- In 2015/16, we **awarded grants to five researchers** from across the UK. **See page 10**
- We established a **new research lead post at the Marie Curie Hospice, Glasgow**. We now have four research leads embedded in Marie Curie hospices across the UK, helping to engage patients, carers and staff in research. **See pages 12-13**
- Our **Marie Curie Palliative Care Research Department, University College London was successful in its bid for further funding** following an independent review. **See page 14**

## 2015/16 facts and figures

### We produce research through our...



University of Liverpool

**3**

Research centres (at University College London, Cardiff University, University of Liverpool)



Simon Rawles/Marie Curie

**£1m**

Annual funding for research project grants awarded in open competition



Pete Jones/Marie Curie

**4**

Research leads across our nine hospices

### influenced by...



Ben Gold/Marie Curie

Our group of Research Expert Voices and the results of the Palliative and end of life care Priority Setting Partnership with the James Lind Alliance



- We provide funding to our **three research centres** at University College London, Cardiff University and the University of Liverpool. **See pages 14-19**
- Over **4,000 patients, carers, staff and members of the public were recruited** to our research studies. **See page 20**
- Our funding led to **68 papers being published in peer-reviewed journals**. We made 48 (71%) freely available. **See page 21**
- Our research continues to **inform and influence policy and practice**. **See page 23**
- Marie Curie-funded researchers are involved in **collaborations in 15 countries around the globe**. **See page 26**
- We **disseminate research findings widely**. We share findings with Marie Curie staff, healthcare professionals, academics, and engage the public through the media. **See page 32**
- Marie Curie and the researchers we fund **involve patients, carers and the public in research** so it responds to the needs and wishes of the people we support. **See page 34-36**
- We **passed the AMRC five-yearly peer review audit**. This recognises the rigour of our research management processes. **See page 40**

**all of which has led to...**



**68**

Papers in peer-reviewed journals – 48 (71%) were open access



**95**

Instances of informing policy and practice



**15**

Countries around the globe where our researchers are involved in collaborations



**4,432**

People recruited to our studies



**£700k+**

Additional funding from external sources to support research in palliative and end of life care

**...together helping to influence policy and practice.**

# 1 Introduction

## 1.1 Care and support through terminal illness

**In April 2015, we simplified our name to ‘Marie Curie’ (we were previously known as Marie Curie Cancer Care), and introduced our new strapline: ‘Care and support through terminal illness’. We made this change to make clear the scope of our work – that we support people living with all terminal illnesses.**

We have taken this approach with our research for many years. Through the research we fund, our aim has been to improve care and support for people living with any terminal illness, and their

families, carers and friends. It continues to do so. For just one example, see Case study 1 – Research in non-cancer conditions: Chronic obstructive pulmonary disease.



Pete Jones/Marie Curie

- 2 Westminster Health Forum. Moving towards a national strategy for Chronic Obstructive Pulmonary Disease (COPD). Westminster Health Forum Keynote Seminar Transcript, 25 January 2011
- 3 [iph.cam.ac.uk/public-health-policy/policy-themes/endoflifecare/copd/](http://iph.cam.ac.uk/public-health-policy/policy-themes/endoflifecare/copd/)
- 4 Saunders CL, Burge P, Farquhar M, Grand-Clement S, Guthrie S, Ling T. Agreement with, and feasibility of, the emerging recommendations from the Living with Breathlessness study: findings from an online stakeholder survey. Santa Monica, CA: RAND Corporation, 2016.



## Case study 1

### Research in non-cancer conditions: Chronic obstructive pulmonary disease

**Chronic obstructive pulmonary disease (COPD) is a chronic and progressive lung condition that demands a high level of care. COPD is characterised by breathlessness, which is disabling for patients and frightening for both patients and their informal carers. In England and Wales, an estimated one person dies every 20 minutes from COPD<sup>2</sup>.**



Pete Jones/Marie Curie

**Dr Morag Farquhar** was awarded funding by Marie Curie and a Career Development Fellowship from the National Institute for Health Research (NIHR), while at the University of Cambridge. Her research focused on improving care and support for people with advanced COPD, and their carers.

Dr Farquhar and her team conducted interviews and surveys with over 500 patients, carers and health care professionals. The findings highlighted different preferences for care and support among those living with COPD. It also emphasised that the needs of patients and carers are often unmet.

As well as showing that the burden of caring goes beyond purely physical demands, Dr Farquhar's research found

that patients and carers face a range of barriers to getting the information and support they need.

The study's findings have been used to develop recommendations for improving the care and support available to people living with COPD. The recommendations are underpinned by action points<sup>3</sup> which emphasise the need to deliver more person-centred care, improve the ways in which people's needs for support are identified, and raise awareness and understanding of COPD across society.

#### Improving care and support in clinical practice

Dr Farquhar has presented the findings widely. At a meeting led by the Canadian Foundation for Healthcare Improvement in Vancouver, she led workshops to assist clinicians with supporting carers as they adopt new models of care for COPD across Canada. The study team also conducted a stakeholder workshop in London in autumn 2015, and a UK stakeholder survey. Stakeholders broadly supported the recommendations of the research, but had different views on how easy they would be to implement<sup>4</sup>.

## 1.2 New research projects in 2015/16

**In 2015, we awarded five new grants through our open and competitive research call. From investigating ways to improve care for adults and young people with terminal or life-limiting illnesses, to examining ways to better support friends and families after bereavement – Marie Curie-funded research projects are addressing gaps in palliative and end of life care research.**

Dr Peter O'Halloran from **Queen's University Belfast** was awarded funding to investigate the acceptability and usefulness of 'My Healthcare Passport' to young people with life-limiting conditions in Northern Ireland.

Dr Emily Harrop from **Cardiff University** was awarded funding for her systematic review of evidence on support for people bereaved through advanced illness. These findings will be used to develop a core outcome set for bereavement research in palliative care.

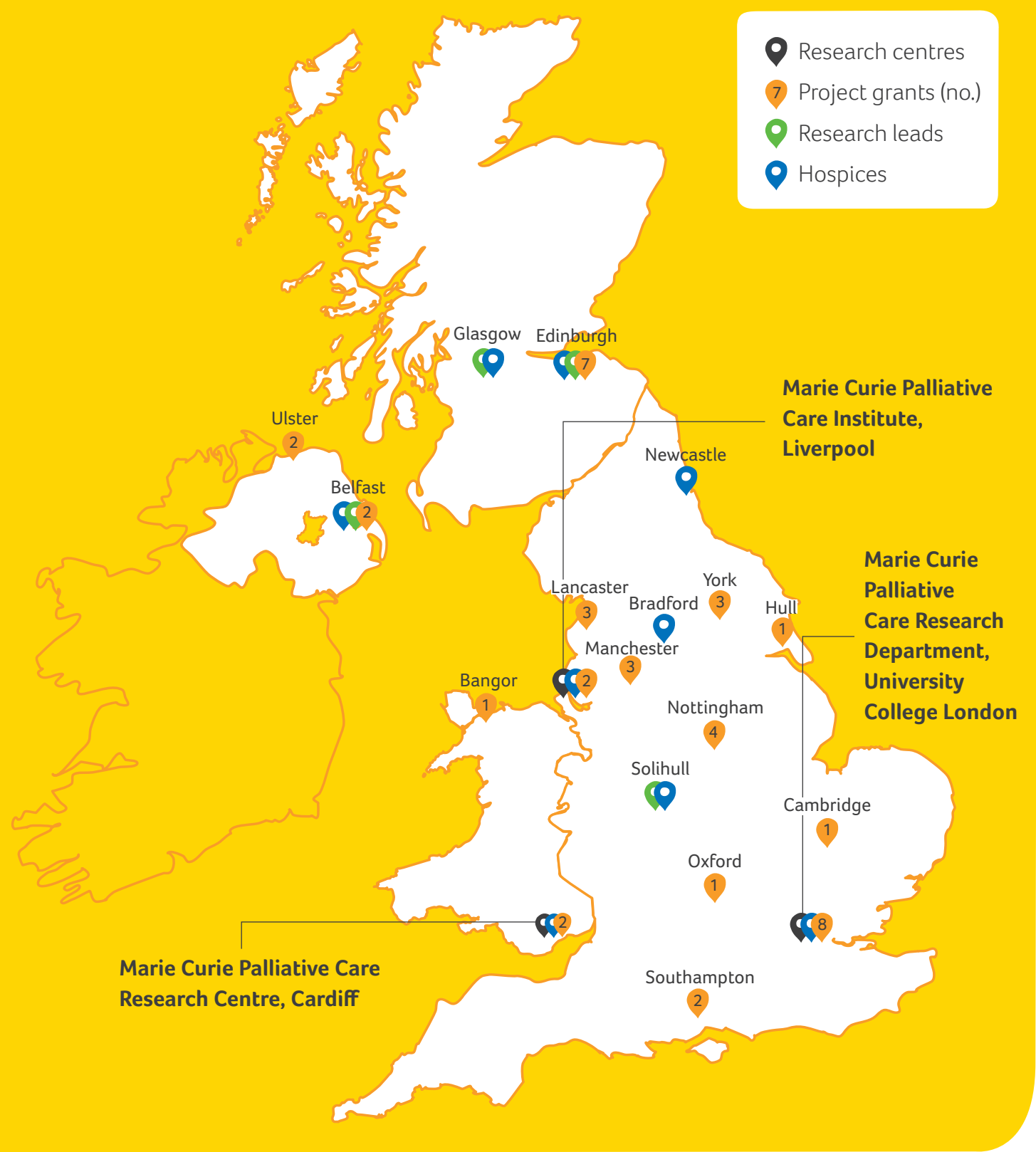
Professor Marie Fallon from the **University of Edinburgh** is leading a clinical trial, developed by the late Professor Kenneth Fearon, with joint funding from Marie Curie, the Rising Tide Foundation for Clinical Cancer Research and Pancreatic Cancer UK.

The MENAC Trial is a randomised, open-label trial of a Multimodal intervention (Exercise, Nutrition and Anti-inflammatory medication) plus standard care versus standard care alone, to prevent/attenuate Cachexia in patients with advanced cancer undergoing chemotherapy.

Dr Sorrel Burden from the **University of Manchester** is investigating the role of parenteral nutrition in women with advanced ovarian cancer to understand the views and experiences of patients, carers and staff.

Professor Sonja McIlpatrick from **Ulster University** is using her funding to develop and evaluate an educational intervention for the management of constipation in people with advanced cancer.

### Marie Curie research activities since 2010, by location



## 1.3 New research lead post

A new research lead post was created at the Marie Curie Hospice, Glasgow in 2015, taken up by Dr Emma Carduff, former Interim Lead at the Marie Curie Hospice, Edinburgh. Dr Kathy Armour (West Midlands), Dr Emma Carduff (Glasgow), Dr Anne Finucane (Edinburgh) and Dr Lisa Graham-Wisener (Belfast) are all

helping to increase patient, carer and staff engagement with research and establish relations with academic and health service organisations to improve the care and support for patients overall. Dr Emma Carduff explains what her average working day looks like in Box 1.

### Box 1

#### Dr Emma Carduff, Research Lead, Marie Curie Hospice, Glasgow

**I begin my day in the office** with a strong coffee and some writing. I often have academic publications, reports, grant applications or presentations to write, and learnt while writing my PhD that I am at my most productive early in the morning.

**I'm responsible for leading, facilitating and governing research** at the Marie Curie Hospice, Glasgow. With a team of colleagues, I am currently developing work on access to and experience of palliative care for those living in social deprivation and how we can best support bereaved children. Everyone should have the right to high-quality palliative care when they have a terminal illness, regardless of where they live or their personal circumstances. Research in this area can

help us understand the needs of these groups, and identify the best ways to meet those needs.

**We also have a number of studies in the pipeline** with academic partners and Marie Curie colleagues, which will mean recruiting patients and staff at the hospice to be involved in research. This is important to make sure we're always providing the best possible care and support for people living with a terminal illness and their families.

**My typical day includes** discussions with colleagues at the hospice about potential project ideas and ways we can disseminate their research. I support undergraduate and postgraduate research students at the hospice to conduct and disseminate small projects

Richard Dyson



“I believe working with partners towards a common goal is vital to improve patient care. My academic collaborations in Edinburgh and Glasgow bring me great satisfaction.”

during their time with us. I also sit on a number of committees to extend our work beyond the hospice. I work closely with our policy and public affairs team to ensure the work I do is impactful beyond academic journals and that evidence is used to help influence policy and clinical practice.

**What I enjoy the most** is being able to encourage and empower staff to generate ideas about potential projects. I originally trained as a nurse

and recognise the value of evidence-based practice. Secondly, I believe working with partners towards a common goal is vital to improve patient care. My academic collaborations in Edinburgh and Glasgow bring me great satisfaction.

**I am very fortunate to have** a network of fellow Research Leads based at Marie Curie hospices throughout the UK, whom I know I can pick up the phone for a chat with at a moment's notice.

## 1.4 Focus on our research centres

**Our palliative care research centres at University College London (UCL), Cardiff University and the University of Liverpool are developing ways to improve the care of people with terminal illnesses.**

### Marie Curie Palliative Care Research Department, UCL

The Marie Curie Palliative Care Research Department, University College London is recognised for its work in end of life care research, the evaluation of interventions in palliative care and end of life care in non-cancer conditions, in particular dementia. In 2015, it was successful in its bid for further funding following an independent review. This

confirmed the high quality and merit of the UCL research centre's work, and it was awarded a further five-year grant. This will be used to embark on an ambitious programme exploring end of life care relating to prognostication and sedation, palliative care for the homeless as well as people with dementia and advanced liver disease.

#### Baillie Marie Curie PhD fellowship

Marie Curie received a generous donation in December 2015 from Sir Adrian Baillie and The Gawaine Stamp Fund to support the Baillie Marie Curie PhD fellowship, hosted by our UCL research centre. Anna-Maria

Krooupa was successful in obtaining the fellowship. Her PhD forms part of the UCL research centre's wider work on sedation monitoring to improve care and the quality of life for people at the end of life (see Case study 2 on page 15).

#### Celebration of outgoing Head of Centre, Dr Louise Jones



Marie Curie celebrated the career of **Dr Louise Jones** as she stepped down from her post as Head of the UCL research centre. Her work was celebrated at the Royal Society of Medicine in London on 19 January 2015 and Dr Jones retired on 5 April 2016 after almost 10 years building up and leading the team, and 23 years with Marie Curie.



## Case study 2

### **Improving care, assessment, communication and training at the end of life (I-CAN-CARE)**

**Identifying when patients are entering the last few days, weeks or months of life can be a challenge for doctors. But it's vital for ensuring people living with a terminal illness – and their families – get timely access to the care and support they need. I-CAN-CARE is a programme that looks at how doctors identify terminal illness, how their prognostic skills can be improved and how end of life care can be enhanced.**



Aubrey Wade

**Professor Paddy Stone**, Marie Curie Chair of Palliative and End of Life Care at the Marie Curie Palliative Care Research Department, University College London is leading the I-CAN-CARE research programme. The team is examining the use of sedatives in palliative care and their impact on quality of life. Their work looks at the potential benefits of using clinical observation scales and other more technical approaches to monitor sedation. Improved monitoring, combined with clinical management advice, could help to optimise the dosage of sedatives that patients receive.

The team is also investigating how doctors make judgements about life expectancy, and how this is communicated to patients and families.

“Delivering the most appropriate care and treatments for those with terminal illnesses is often dependent on doctors making an accurate prognosis. Knowing how much time is left can also better equip patients and their carers to make more informed choices about their care.”

**Professor Paddy Stone**

Marie Curie Palliative Care Research Department,  
University College London

The aim is to help doctors make more accurate predictions about prognosis and to achieve more consistency across staff. These findings could help to inform training of medical students and junior doctors, both in the UK and overseas.

# Marie Curie Palliative Care Research Centre, Cardiff

The Marie Curie Palliative Care Research Centre, Cardiff specialises in three key areas: patient and carer experience, palliative rehabilitation and cancer-associated thrombosis.



Matthew Horwood

“We are pleased to be part of the Wales Cancer Research Centre, one of only five integrated research centres funded by Health and Care Research Wales. This is helping to draw together research expertise across the spectrum of preclinical, translational and clinical care. It is also enabling us to focus on prioritised areas of cancer patient and carer needs.”

Dr Anthony Byrne

Marie Curie Palliative Care Research Centre, Cardiff

**In 2015, Health and Care Research Wales invested £300,000 in the palliative and supportive care research infrastructure at the Cardiff research centre over three years.**

The funding was awarded to **Dr Anthony Byrne** (above), **Dr Annmarie Nelson** (opposite) and **Professor Simon Noble** (right) to support their work at the new Welsh Government-funded Wales Cancer Research Centre (WCRC).

Dr Anthony Byrne, Clinical Director of the Cardiff research centre, is an executive member of the WCRC and leads the community theme, one of

four research themes. Dr Annmarie Nelson, Scientific Director of our Cardiff research centre leads on palliative and supportive care.



## Communicating patient experience in research



As part of her work in patient and carer experience, Dr Nelson seeks to understand how patients experience clinical trials. For example, before a treatment is tested through a clinical trial, researchers must be sure that one

treatment is not better than another otherwise a doctor would have a duty to prescribe that treatment. This concept, known as “equipoise”, relates to the need to achieve a balance between risk and benefit in clinical trials. Patients often have questions about equipoise and the perceived issues.

To improve understanding of this issue, Dr Nelson delivered an online tutorial on the concept of equipoise in clinical trials as part of a Massive Open Online Course (MOOC) in 2015. More than 8,000 participants have joined this recurring course to date.

## Influencing practice

An estimated 17,000 people with cancer will receive pelvic radiotherapy. Of these, 40% will experience changes in their bowel function. Due to the sensitive nature of these symptoms, patients may not report them and, as a result, they are under-recognised by doctors.

In 2015, researchers from Cardiff University and the Cardiff research centre received additional funding from Tenovus Cancer Care to develop and test a tool to help doctors screen patients for gastrointestinal symptoms

and provide the appropriate treatment. The tool is a short questionnaire to be used in routine clinical practice. The team is working with several NHS trusts and cancer charities to increase its use by health professionals in practice.

The questionnaire has since been used in a research study among people who received pelvic radiotherapy for prostate cancer. Led by the Cardiff research centre, with substantial funding from Prostate Cancer UK, it is helping to improve the care offered to men and their partners and families.

# Marie Curie Palliative Care Institute, Liverpool

**As well as its research activities, the Marie Curie Palliative Care Institute, Liverpool, headed by Professor John Ellershaw, specialises in education, learning and teaching, policy and practice.**

The research team secured a seed award from the Wellcome Trust in 2015/16 to carry out research in the Biology of the Dying. **Dr Seamus Coyle** and **Professor John Ellershaw** (right) from the Liverpool research centre are working with colleagues to investigate the presence of biomarkers. By understanding the changing physiology of the body at the end of life, this can help prompt the development of novel techniques to both assess and improve the care and support of patients at the end of life.



## Leading the development of palliative care medical education



**Dr Stephen Mason** (above), Head of Research and Development at the Liverpool research centre, and Professor Ellershaw coordinate task forces from the European Association of Palliative Care Steering Group on Medical Education and Training.

They are working with colleagues to develop curricula for undergraduate and post-graduate medical education in palliative care.

As part of this, the Liverpool research centre is taking the lead on the Global IMEP Initiative (International assessment of Medical Education in Palliative care). This involves developing a body of research to establish national assessment programmes to evaluate undergraduate medical training. The programme supports the aim to make palliative care a mandatory part of all undergraduate medical curricula across Europe.

## Training for teachers

The Liverpool research centre also works with palliative care health professionals to develop their teaching skills. In July 2015, Professor Ellershaw and Dr Ruthmarijke Smeding together with Dr Ednin Hamzah, Chief Executive

of Hospis Malaysia, a charitable palliative care organisation, led a teaching course in Kuala Lumpur. The course shared learnings on effective teaching and delivery skills and is also run annually in Liverpool.

“Developing curricula for both undergraduate and postgraduate medical education is fundamental to the overall effort to drive up quality of palliative and end of life care globally. It not only benefits those entering into the field of palliative medicine but also fosters the broader understanding that all doctors should have in order to support compassionate clinical care for patients and families.”

Professor John Ellershaw, Marie Curie Palliative Care Institute, Liverpool

## Influencing policy

Care of the Dying Evaluation (CODE) is a validated post-bereavement questionnaire developed by **Dr Catriona Mayland**, Consultant in Palliative Medicine and Honorary Senior Clinical Lecturer at our Liverpool research centre, that looks at care of the patient and relatives in the last 48 hours of life and immediate post-bereavement period.

In 2015, the Cheshire and Merseyside Palliative and End of Life Care Strategic Clinical Network commissioned a network-wide survey of bereaved relatives using CODE. This included benchmarking and looking at ways to improve services.



The CODE questionnaire is currently the focus of a European/Latin American research bid in collaboration with Professor Dagny Faksvag Hagen at Helse Bergen University Hospital, Norway. This looks at developing an international version of CODE, as well as national translations, to benchmark the quality of care for the dying at an international level.



## 2 Research outputs and impact

This section highlights the research outputs for 2015/16 from our:

- three research centres
- four research leads
- nine hospices
- 40 past and present research projects from our various funding mechanisms.

The data was gathered from the annual reports of the research centres and research leads. Research project grant information was also collected from 36 principal investigators across 17 institutions through the online reporting tool Researchfish.

The results are categorised according to:

- the number of patients, carers, staff and members of the public that are involved in research studies
- research publications
- the influence of research on policy and practice
- research funding awarded to Marie Curie research grant holders from the government and other charities
- national and international collaborations
- how research findings are shared with various audiences.

### 2.1 Recruiting to research studies

Marie Curie-funded research gives people with a terminal illness, carers, healthcare staff and members of the public the opportunity to take part in research studies to improve palliative and end of life care. A total of 4,432 people were recruited to research studies funded by Marie Curie or

carried out by Marie Curie researchers in 2015/16 (see Table 1). Of these people, 195 were recruited to studies at Marie Curie Hospices, up from 172 in 2014/15. In addition, at least 80 health records have helped to inform palliative and end of life care research projects in 2015/16.

Table 1: Study recruitment from 1 April 2015 to 31 March 2016 for Marie Curie-funded research





## 2.2 Publications

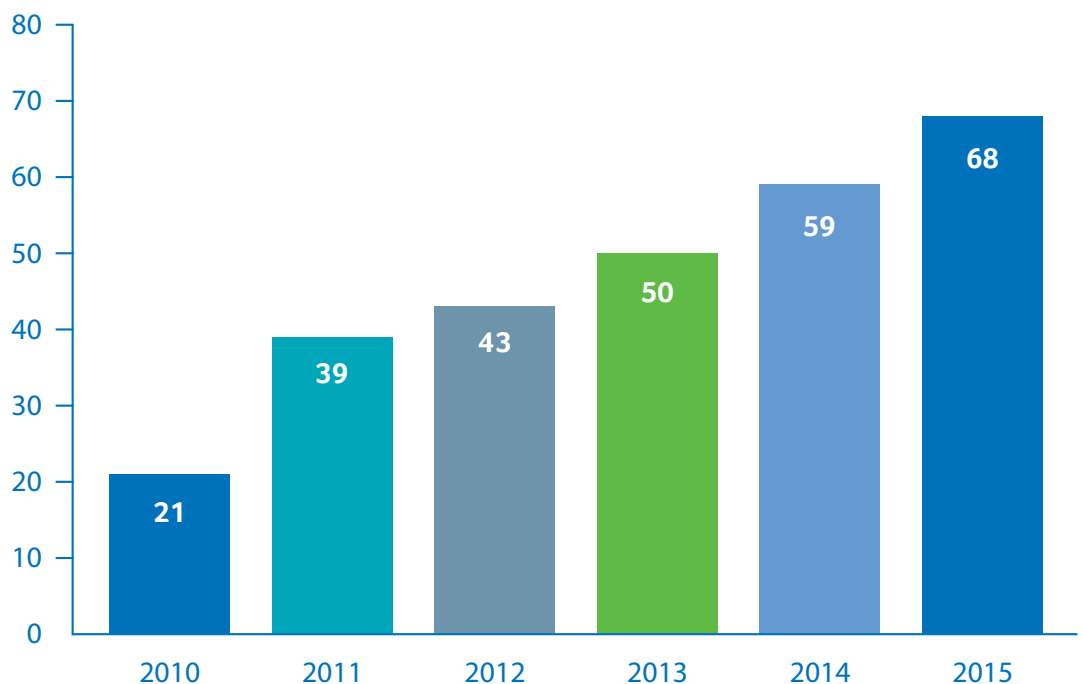
The number of publications has been increasing steadily since the charity scaled up its investment in research in 2010. In 2015, Marie Curie researchers published 68 papers in peer-reviewed journals. Of these, 20 were qualitative studies, 11 systematic reviews, 13 used mixed methods and seven reported on clinical trials or feasibility studies, reflecting the diversity of the research being undertaken. The remaining 17 were a mixture of quantitative research, commentaries or letters.

The outputs of our funding continue to increase each year, up from 59

publications in 2014 and 50 in 2013 (see Figure 1). Alongside this, we are working to ensure publications arising from Marie Curie investment are openly accessible to all. Of the total 68 papers published in 2015, 48 (71%) were openly available.

An additional 72 national and international conference proceedings or abstracts were published by Marie Curie-funded researchers. A further four publications were in book chapters (see Box 2: End of life care for prisoners).

**Figure 1: Publications in peer-reviewed journals from Marie Curie-funded research, by year<sup>1</sup>**



<sup>1</sup> The publications figures presented in this report have been re-calculated to exclude e-publication dates and only refer to print dates (where possible), and therefore differ from figures presented in the Marie Curie research impact report for 2014/15.

Box 2

## End of life care for prisoners

**Dr Mary Turner**, from Lancaster University, carried out research on improving end of life care for older prisoners from 2013 to 2016. Her study entitled 'Both sides of the fence: using action research to improve end of life care for prisoners' aims to improve palliative care for prisoners in the UK. In 2015, Dr Turner contributed a chapter entitled 'Palliative care for prisoners,' to the book *Palliative Care Nursing at a Glance*.



“Older prisoners have multiple, complex health and social care needs. They also have high levels of frailty, vulnerability and fears for the future. Prisons are often poorly equipped to provide high-quality palliative care, and research in this area is needed to ensure prisoners receive the right care without risking the safety and security of others. I am impressed by Marie Curie’s vision in funding research in this important area.”

Dr Mary Turner, Lancaster University

Her chapter highlighted how, in the UK, the number of prisoners is growing steadily, with an increasing proportion aged over 50. As a result, there is a growing need for palliative care among older prisoners. The Department of Health and Ministry of Justice recognise that prisoners should be entitled to the same quality of care they would receive outside prison; however the challenges to achieving this are complex.

## 2.3 Influencing policy and practice

Researchers funded by Marie Curie are encouraged to engage with policy makers and practitioners as well as work with the Marie Curie policy and public affairs teams in England, Scotland, Wales and Northern Ireland to maximise the impact of their research findings on policy. Our researchers influenced policy and practice in 95 instances in 2015, up from 78 in 2014.

Figure 2 shows the different ways researchers used their influence, including participating in advisory committees and giving evidence for government reviews. A significant number (84%) provided training to practitioners or fellow researchers.

**Figure 2: Influence on policy and practice by type in 2015**

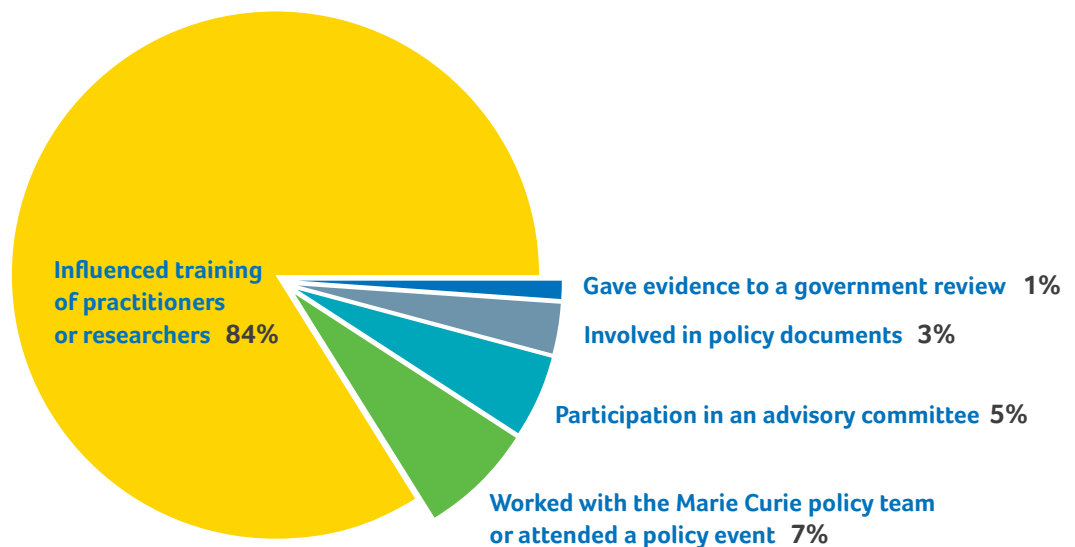
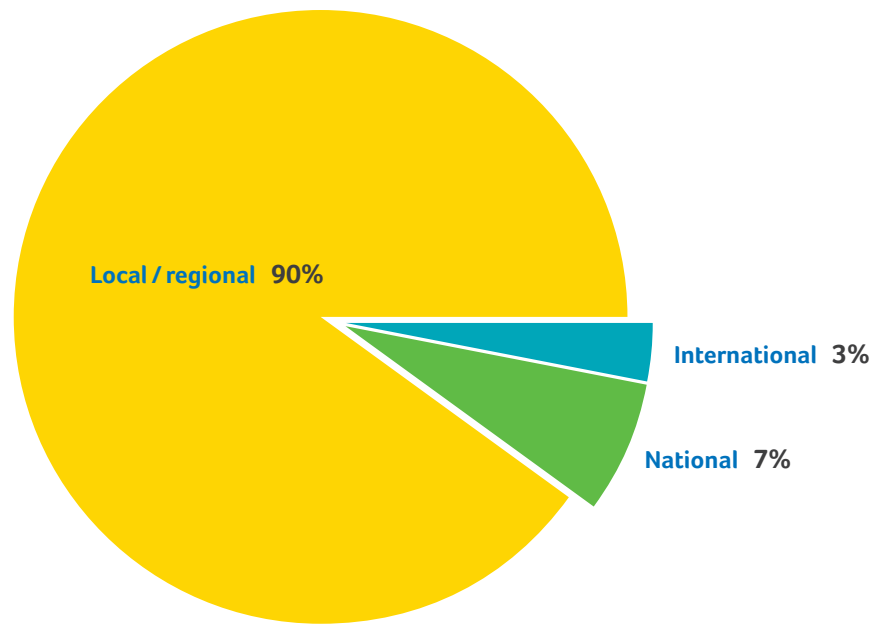


Figure 3 overleaf shows the number of policy and practice influences in 2015 by location. The majority (90%) took place locally or regionally, due to the fact that training of practitioners and researchers often took place locally. Seven per cent took place at a national level and 3% internationally. Marie

Curie is also working to ensure research findings are used to inform clinical practice to improve care and support for people with terminal illnesses, their carers, friends and families (see Case study 3: End of life care for people with dementia).

Figure 3: Policy and practice influence by location



“Although a lot has been written about shortcomings in the care of people with dementia, there is little evidence-based research on how it can improve. Our Marie Curie-funded COMPASSION programme has allowed us to carry out three years of qualitative and quantitative testing, to inform the development of an intervention to improve end of life care for people with dementia.

“Our research has highlighted that care home staff may not have the skills to recognise when someone with dementia is in the later stages of the condition or at the end of their life. These findings helped us to develop and implement an intervention to improve end of life care for people with advanced dementia in care homes.

“This research highlights the reality of care for people with advanced dementia in the UK and why investing in this area is so important.”

Dr Liz Sampson

Marie Curie Palliative Care Research Department, University College London

### Case Study 3: End of life care for people with dementia



Marie Curie funds **Dr Liz Sampson**, Clinical Reader at the Marie Curie Palliative Care Research Department, University College London. Dr Sampson is an expert in palliative and end of life care for people with advanced

dementia and received a joint grant from Alzheimer's Society and the BUPA Foundation to carry out research on the link between pain and behavioural symptoms in people with dementia in hospitals.

People with dementia often struggle to express themselves, which can make it difficult to identify and treat any pain they experience. Hospitals can also be challenging places for people with dementia, where the unfamiliarity of their surroundings can cause further distress and confusion.

#### Top cited article in journal *PAIN*

Over a period of 12 months, Dr Sampson and her team carried out an observational study of 230 people with dementia in two UK hospitals. This is the first study of its kind in a general hospital setting. Findings showed that over half (57%) of people with dementia

experienced pain, but fewer than 40% were able to report it due to the nature of their condition. The paper, published in the journal *PAIN*, was one of the 'top 25 cited articles' of all those published in the journal in 2015.

#### Influencing policy

Dr Sampson's work on dementia, looking at ways to improve care for people with dementia, influenced policy in a number of ways in 2015.

As well as being a member of the National Council for Palliative Care Dementia Working Group, Dr Sampson worked on the Royal College of Physicians (RCP) National Care of the

Dying Audit of Hospitals. This national clinical audit, commissioned by the Healthcare Quality Improvement Partnership, was run by the RCP with additional funding from Marie Curie. In January 2015, Dr Sampson was invited to speak at an event organised by the German government about end of life care and the German national dementia policy.

## 2.4 Research funding from the government and other charities

In 2015, researchers funded by Marie Curie received an additional £727,187 to support their work in palliative and end of life care from other funders. Of this, more than 90% came from public or government funders, such as the

National Institute for Health Research and Health Education England (see page 16, our Cardiff research centre, for examples of further funding from charity sources in 2015). The remainder came from other charities or donors.

## 2.5 Collaborations

In 2015, Marie Curie researchers worked with colleagues in academic, charity and public sectors in 15 countries worldwide. This amounted to over 74 collaborations between the UK and other countries, including Australia (see Figure 4: Marie Curie international collaborations in 2015).

For instance, Professor Simon Noble from the Cardiff research centre leads on research on cancer-associated thrombosis (CAT), the clotting of blood in the circulatory system. His qualitative research looks at how CAT affects people with cancer as the disease progresses and people's experiences of

Figure 4: Marie Curie international collaborations in 2015 by country





living with the condition. This is with the aim of finding ways to improve quality of life for people with cancer.

Professor Noble is working with colleagues at universities in France

and New Zealand in this international study and presented his work at six international conferences in 2015. The results will be used to inform clinical guidelines in the management of CAT.

## 2.6 Engagement activities

Engaging with a wide range of audiences is a key requirement of Marie Curie research funding. Sharing findings widely promotes partnerships and helps inform research, policy and practice.

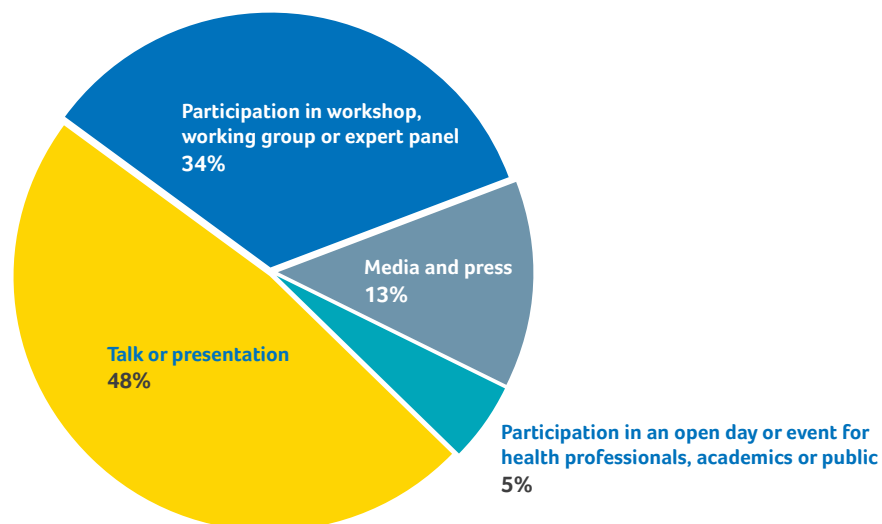
### Types of engagement

In 2015, our researchers were involved in a range of engagement activities including working groups, expert panels, presentations and media activities. Of the 121 instances reported, the most common forms of

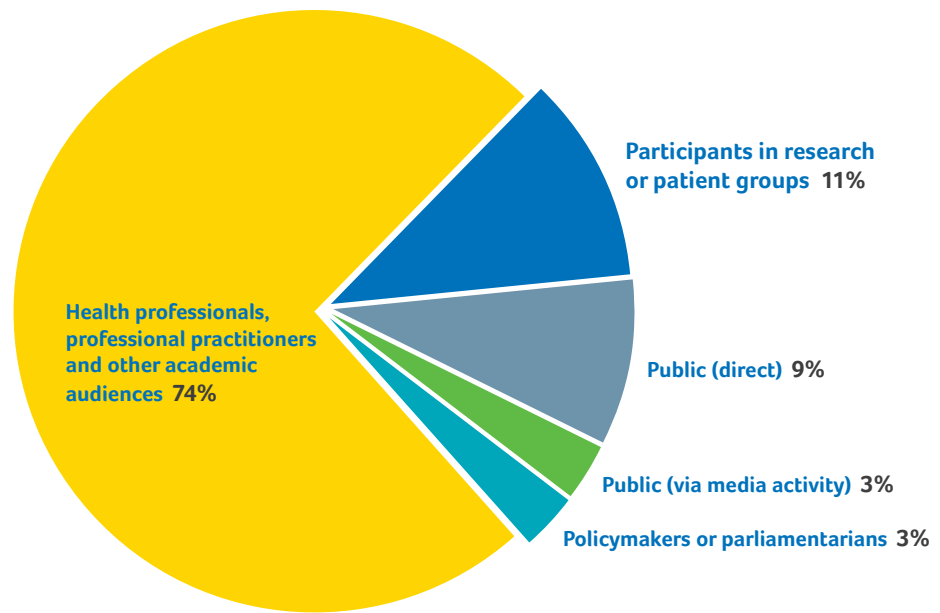
engagement were a talk or presentation (48%) or participation in a workshop, working group or expert panel (34%). Our researchers reported engagement through open days or events at their institutions (5%) (see Figure 5: Research engagement activities by type in 2015).

Engagement through the media and press was up from 7% in 2014 to 13% in 2015. The Marie Curie public relations team continues to work closely with researchers to help their findings reach a wider audience (see Case study 4).

**Figure 5: Research engagement activities by type in 2015**



**Figure 6: Research engagement activities by audience in 2015**

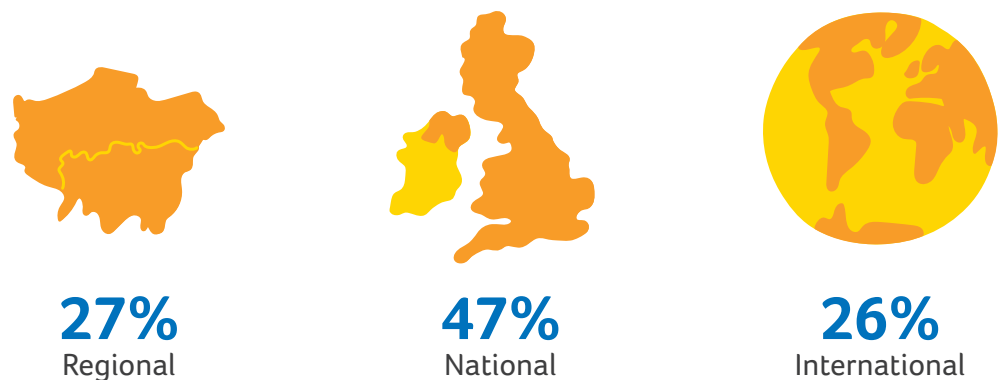


### Audiences and location

Health professionals, specialist practitioners and other academics made up the largest share of our audience in 2015 (see Figure 6: Research engagement activities by audience in 2015).

The majority of engagement activities (74%) reported by researchers took place throughout the UK. The rest (26%) occurred internationally, up from 18% in 2014 (see Figure 7: Research engagement activities by location).

**Figure 7: Research engagement activities by location in 2015**



## Case Study 4: Public engagement with the press



**Dr Jeff Round** undertook his PhD at the Marie Curie Palliative Care Research Department, University College London focusing on the economics of care for people at the end of their life. Dr Round investigated the cost of providing care to people with lung, breast, colorectal and prostate cancers, using a modelling-based approach to calculate the costs of caring to the NHS and society. It is the first study of its kind to consider the costs of unpaid carers. The findings of his research showed significant costs to society, with a high proportion being borne by unpaid carers.

Dr Round published part of his work in the journal *Palliative Medicine* in 2015. He also worked with the Marie Curie public relations team to produce a press release, which received significant media coverage. The story appeared in 29 national and regional newspapers.

Commenting on the findings, Dr Round was struck by the limited availability of data on the health and social care needs of people as they near the end of life. This highlights the need for good data to inform policy and practice.

He said: “Without good data it becomes hard for everyone to plan services in a way that meets the needs of both those who are dying and those who provide such valuable unpaid care.”

The study received further acclaim, with Dr Round being awarded Research Paper of the Year in the journal *Palliative Medicine* (pictured), in recognition of the contribution of his research to the field. His study was selected from all papers published in the journal’s print editions in 2015. Dr Round is now a lecturer in Health Economics at the University of Bristol.





## 2.7 Awards and recognition

**In 2015, Marie Curie-funded researchers were awarded at least 55 measures of esteem. As in 2014, the majority of these involved researchers being personally invited to be a keynote speaker at a conference.**

### Research prizes

Dr Kathryn Almack and Professor Jane Seymour, while at the University of Nottingham, were awarded a Best Paper prize by the Royal College of Nursing at their Annual International Nursing Research Conference and Exhibition

in April 2015. Their paper, 'I have no wish to be at the tender mercies of a homophobic carer/service,' explores the end of life experiences and care needs of older lesbian, gay, bisexual and transgender (LGBT) people.

### Susie Wilkinson award

The Susie Wilkinson award was established in recognition of Dr Susie Wilkinson, and her contribution to Marie Curie research. Dr Wilkinson (pictured inset left) set up the original Marie Curie Palliative Care Research Department, London at the Royal Free Hospital in 1999.

In 2015, the award was presented to **Kerry McGrillen**, (pictured left and inset right), from the Marie Curie Hospice, Belfast, in recognition of the significant personal progress she has made with research.

Alongside her role as physiotherapist at the hospice, Kerry developed an outpatient rehabilitation and exercise programme for people with palliative care needs. The programme focused on improving physical function and overall quality of life for people with a terminal illness, recruiting patients from the



Trevor Smeaton/Marie Curie

Marie Curie Hospice, Belfast. Her paper, published in the journal *Progress in Palliative Care*, showed aerobic exercise, strength training and balance-related exercises made a significant difference to a person's physical ability, reduced their feelings of tiredness and boosted their self-esteem and confidence.

Kerry has since coordinated a wellbeing clinic for patients at the hospice with the support of Sport Northern Ireland. She has presented her findings to other health professionals both regionally and nationally. Kerry continues to focus on high-level rehabilitation to meet the needs of those she is looking after.

## 3 Advancing research

Marie Curie works to ensure its research goes beyond academic outputs. We do this by supporting our researchers to communicate their findings widely to audiences within and outside the organisation. We identify gaps in palliative and end of life care in urgent need of further research in the areas that matter most to the people we support. We also encourage the involvement of the public in research and our related activities.

### 3.1 Disseminating research findings

#### The annual Marie Curie Palliative Care Research Conference



Trevor Smeaton/Marie Curie

The tenth annual Marie Curie Palliative Care Research Conference, held jointly with the Palliative Care Section of the Royal Society of Medicine, took place in London in March 2015. The theme of the conference was: 'The future of palliative care'. It covered topics including clinical outcome measures, the role of social media in palliative care and priorities for research.

Dr Laura Green from the University of Bradford and Dr Fliss Murtagh (left) from King's College London were invited to speak at the conference. Dr Green presented her work on social media in palliative care education and research. Dr Murtagh spoke about the need to adopt meaningful outcome measures in palliative care, to capture the difference healthcare makes for patients and their families.

Other speakers included Dr Sabine Best from Marie Curie, Dr Alastair Canaway from the University of Birmingham, Dr Emma Carduff from the Marie Curie Hospice, Edinburgh and Professor Scott Murray from the University of Edinburgh.



## 3.2 Identifying priorities for research

Marie Curie launched its top 10 priorities for future research in palliative and end of life care in January 2015, based on the results of the Palliative end of life care Priority Setting Partnership (PeolcPSP). This was a partnership effort with the James Lind Alliance and 10 co-funders.



Following public consultation, 1,403 respondents, including people likely to be within the last years of their life, carers and health and social care professionals submitted their unanswered research questions. These formed a full list of 83 questions, which were prioritised to a top 28 in a prioritisation survey, and a top 10 in a workshop of carers, patients and professionals.

Marie Curie has used the 83 questions to guide its own call for research in 2015. In partnership with the Motor Neurone Disease Association and Chief Scientist Office, Scotland, both of which supported the PeolcPSP, we launched our largest call for research ever. Together, we made £1,425,000 available for research projects that addressed one of the 83 questions (see Appendix 2 for the full list).



## 3.3 Involving people in research

Marie Curie supports the involvement of people with terminal illnesses, their carers, friends and families to ensure their views are represented in all areas of research we fund. This is often described as research that is done ‘with’ or ‘by’ the public, rather than ‘to’, ‘for’ or ‘about’ them. It can benefit from the unique personal experiences and

knowledge of those it aims to benefit. We also do this through our Research Expert Voices Group who help us to identify our research priorities, ensure we allocate funding efficiently and disseminate our results widely. For an example of patient involvement in research see Case study 5: Putting patients at the centre of research.

### Case study 5: Putting patients at the centre of research



Tom Davill/Marie Curie

Involving patients, carers and the public in research can strengthen its quality and help make sure studies reflect the needs of the most important people – those with terminal illnesses and their carers, families and friends. **Dr Debra Howell**, from the University of York, is an advocate of involving patients in research and recognises the difference it can make.

Dr Howell has been investigating the preferred and actual place of care and death for people with blood cancers (eg leukaemia, lymphoma and myeloma). Understanding this is

important in enabling people to stay in their preferred place at the end of life, whenever possible. Dr Howell’s work is set within the Haematological Malignancies Research Network (HMRN). This ongoing study in Yorkshire and Humberside registers and collects information on around 2,200 people newly diagnosed with blood cancers each year for research purposes. Around 800 patients and their families are members of HMRN’s Patients Partnership group. Through this, they can contribute to a number of research activities, including taking part in discussion groups and interviews, completing questionnaires and joining study advisory panels.

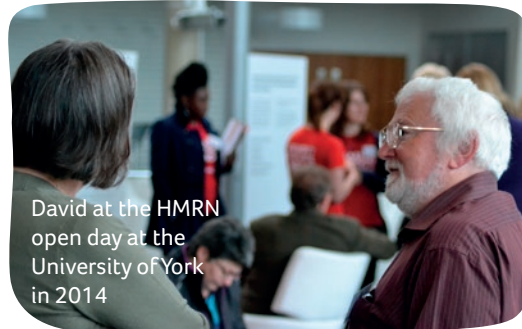
**David Brown** is a blood cancer patient and a member of the project’s advisory group. He has been influential in bringing the patient’s perspective to the project from the study outset.





## Here, Debra and David explain what patient involvement in research means to them:

### David



#### What made you want to be involved in this research study?

I felt it was important to study end of life care in blood cancers so that some of the mystery could be removed from this issue and further support for patients and their families could be provided if need be. I was diagnosed with a blood cancer in 2005 and feel that patients can really help to improve care in the NHS by feeding back about their experiences.

#### What have you enjoyed the most?

I have really enjoyed feeling that my contribution may help to make the experiences of patients and their families and friends better in the future. Although background skills aren't needed to be involved in research projects, I enjoyed the

therapeutic mental stimulation that came with being part of the group and being able to draw on my past work in research and project analysis.

#### For anyone out there who would like to help, what advice would you give?

If you are affected by any of the issues being studied, then do get involved. People can provide valuable input based on their own experiences and it's important to "have your voice heard". Your views will not only help the research team but also other patients by making sure reports are readable and useable. The group were sensitive when discussing issues relating to end of life care.

#### How can researchers encourage service users to be involved in research?

They could make sure their studies are well publicised and also make their findings more widely available to patients. If they let service users know how their involvement can improve things for others, I think this would encourage more people to get involved.



## Debra



### What difference has David's involvement made to your research?

In any HMRN project we always try to see things from the perspective of the patient and their family. David really helped us to do that, not only sharing his own experiences and views, but also those of people he'd talked to at the local blood cancer support group he attends and at other research meetings. This helped us plan our study and decide which areas to focus on.

### What were the biggest challenges to including patients and how did you overcome them?

We were conscious that talking about end of life issues can be emotionally challenging. To prepare David, we discussed his feelings about this before he joined the team. Although difficult issues were not avoided during study

meetings, members of the advisory group were sensitive to David's feelings. David managed the situation well, making valuable contributions throughout.

We also asked relatives what it was like to care for their loved one at the end of their lives, so that we could understand more about their experiences. This was obviously a sensitive area. These stories were hugely valuable, however, as they allowed us to find out what was important, what was done well, and where improvements could be made.

### What advice would you give other researchers looking to involve service users in a similar project?

- Identify the most appropriate way of finding people who might want to be involved, such as via support groups, patient conferences, or links with clinical staff.
- Make it more than a box-ticking exercise by supporting and training the people you work with, listening to them and ensuring they know their opinions are important and valid.
- Factor the costs of patient involvement into your study proposal.

## 4 Looking ahead

**Investment in research is crucial to improving the care and support delivered to people at the end of their life. Since scaling up our investment in this area in 2010, we have made strides in strengthening the limited evidence base. Our research is helping to shape policy and inform clinical practice. Our work with other funders, researchers and organisations has helped guide our investment to ensure funds are used to address the gaps in research.**

**We continue to invest in research to support people with terminal illness, their carers, friends and families by:**

- Investing in our palliative care research centres, research leads and projects to increase the evidence base for palliative and end of life care research and build capacity to support the next generation of researchers.
- Supporting our researchers to communicate their findings widely to maximise the impact of research on practice.
- Striving to make all research funded by Marie Curie openly accessible to everyone, not just researchers.
- Working with Marie Curie policy and public affairs teams to identify opportunities for research findings to inform UK health policy.
- Increasing research activity in our hospices through our research lead programme.



Kieran Dodds/Marie Curie





Simon Rawles/Marie Curie

**We know there is still more to be done. This is why we are:**

- Laying the foundations to design and develop new and innovative models of care that will take account of the complex care needs of our ageing population, through the Marie Curie Design to Care programme.
- Listening to the personal and professional experiences of patients, families and health care professionals in palliative and end of life care and the questions which have the potential to be addressed by social science research.
- Working to address the issues that matter most to the people we support, by identifying which of the 83 questions of our PeolcPSP are being answered through current and ongoing research.
- Working in partnership with other research funders to increase the funds available for palliative and end of life care research and encourage researchers to address the questions raised by patients, carers and clinicians in the PeolcPSP.
- Funding research that aims to improve care and support through terminal illness for everyone – regardless of who they are, their personal circumstances or background. For example, projects on the end of life experiences of older LGBT people and prisoners.

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## Research Review Committee

Professor Bill Noble (Chair), Professor Joanna Coast, Professor Ala Szczepura, Professor John Norrie, Professor Miriam Johnson, Peter Buckle (REVG), Joanna Eley (REVG), Diana Robinson (REVG)

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**Authors** Shefali Shah, Sanjay Thakrar and Sabine Best

## Abbreviations

AMRC	Association of Medical Research Councils
CAT	Cancer Associated Thrombosis
COPD	Chronic Obstructive Pulmonary Disorder
HMRN	Haematological Malignancies Research Network
MRC	Medical Research Council
NIHR	National Institute for Health Research
PeolcPSP	Palliative and end of life care Priority Setting Partnership

# Appendix 1

## List of publications\* in peer-reviewed journals arising from Marie Curie research funding in 2015

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# Appendix 2

## List of 83 questions identified through the Palliative and end of life care Priority Setting Partnership with the James Lind Alliance

Communication	
1	What are the best ways for healthcare professionals to tell patients, carers and families that a patient's illness is terminal and also explain the dying process compassionately and honestly? Can literature, including leaflets, be helpful? Who is the best person to provide this information and communication?
2	How can carers and families of people at the end of life be supported to communicate better with each other and their loved one?
3	What are the benefits of Advance Care Planning and other approaches to listening to and incorporating patients' preferences? Who should implement this and when?
Managing symptoms and medications	
4	What are the best approaches to giving medicines, such as morphine, in a patient's home, for example using different cannulas such as BD-saf-T-intima™? What are the pros and cons of training carers, families and non-palliative professionals, such as healthcare assistants, to give these medicines?
5	What is the best way to give palliative care to patients with dementia and their carers and families? This includes communicating about their diagnosis when they are being cared for at home or elsewhere?
6	What are the best approaches to providing pain relief for people who have communication difficulties, perhaps as a result of their disease, such as motor neurone disease (MND), dementia, brain tumour (including glioblastoma) or head and neck cancer
7	What are the best ways to manage the problems associated with difficulty in swallowing, including for patients with Parkinson's disease, motor neurone disease (MND) and dementia who are at the end of their life?
8	What are the best ways to manage drooling and excessive salivation in patients with diseases such as motor neurone disease (MND) who are approaching the end of their life
9	What are the best ways to manage respiratory secretions (death rattle) in patients at the end of life?
10	What are the best ways to assess and treat pain and discomfort in people at the end of life with advanced dementia, Parkinson's disease and other diseases that affect cognition and communication?
11	What are the best ways to make sure that palliative care patients receive adequate pain and symptom relief and which drugs for pain management are best in terms of side-effects, such as drowsiness?
12	What are the best ways to manage acute and/or chronic breathlessness in patients with cancer and non-cancer terminal illnesses?
13	What are the pros and cons of withdrawing MST (morphine sulphate) in people at the end of life?
14	Which sedative drugs (such as midazolam, haloperidol and levomepromazine) are most beneficial for managing agitation at the end of life and which are best in terms of side-effects? Do these drugs have an effect on other symptoms?
15	What are the best ways to diagnose and treat delirium, agitation, distress, and restlessness in people at the end of life?

<b>16</b>	How can distress that is not related to pain be best assessed and managed in palliative patients with Dementia, Parkinson's disease and other diseases that affect communication?
<b>17</b>	What are the benefits and limitations (physical, social, psychological) of providing artificial hydration and nutrition (for example, a drip) to patients at the end of life, including those with bowel obstruction? When should this be done?
<b>18</b>	What are the best ways of managing cachexia (weight loss) in palliative care patients, including people with cancer or motor neurone disease (MND)?
<b>19</b>	Is it ever necessary to withdraw food and water (non-artificial hydration/nutrition)?
<b>20</b>	Is there an appropriate time to withdraw artificial hydration and nutrition (for example, a drip) and how can this be done sensitively and consensually? What is the best way to communicate with the carers and family about this process?
<b>21</b>	What is the best diet for palliative care patients? For example can maintaining a healthy weight and eating fatty or protein-rich foods have an impact on their disease progression?
<b>22</b>	When should patients be (deeply) sedated? What are the benefits and limitations of sedation and what are the best ways of consulting patients, carers and families?
<b>23</b>	What are the best treatments for nausea and vomiting (including for people with bowel obstruction and those having palliative chemotherapy)?
<b>24</b>	How is incontinence best managed in people who are approaching the end of life (including those with Parkinson's disease)?
<b>25</b>	What are the best treatments for fluid retention in patients approaching the end of life?
<b>26</b>	What are the best ways to prevent blood clots, deep vein thrombosis and pulmonary embolism for patients at the end of life? What is the role of low molecular weight heparin (LMWH)?
<b>27</b>	How are steroids best used in palliative care (dose, duration, etc) for patients with different conditions, including those with brain tumours?
<b>28</b>	What are the benefits and limitations of chemotherapy and radiotherapy for patients approaching the end of life, including those with brain tumours? How can health care professionals best communicate this?
<b>29</b>	What are best ways of managing constipation, including when caused by medication, such as opioids?
<b>30</b>	What are the benefits and limitations (physical, social, psychological) of blood transfusions at the end of life?
<b>31</b>	What are the best ways to recognise and treat depression, anxiety and low mood in people who are dying? What are the pros and cons of different psychotherapeutic interventions, including drug therapies, and when is the best time to provide them?
<b>32</b>	What are the best ways to treat dry mouth in patients at the end of life, including medications and foods, such as pineapple?
<b>33</b>	What are the best ways to ensure that people with motor neurone disease (MND) receive essential care promptly on diagnosis, when is the best stage to transition to palliative care and when should a "just in case kit" be considered?
<b>34</b>	What are the best models of palliative care for people who have learning difficulties?
<b>35</b>	What are the best models of palliative care for people who have mental health issues?

<b>Support: Carers and families</b>	
<b>36</b>	Does respite for people caring for a family member or friend who is dying benefit the patient's care and the quality of life for both the patient and carer? What is the best way to provide respite?
<b>37</b>	How can carers and families be encouraged to seek support for themselves at the right time?
<b>38</b>	What information and training do carers and families need to provide the best care for their loved one who is dying?
<b>39</b>	Do people who are dying and their carers and families fare better if domestic support with shopping, washing up, laundry, etc, is provided?
<b>40</b>	What are the benefits, and best ways, of ensuring patients, carers, families and friends are given privacy and not restricted in visiting hours when palliative care is given in a hospital, care home or hospice?
<b>41</b>	What are the benefits of, and best approaches to, providing palliative care in care homes, including symptom relief, emotional and spiritual support for patients, carers and families?
<b>42</b>	Does practical advice for concerns about housing, finance and transport, etc, reduce anxiety for carers and families and increase their wellbeing?
<b>43</b>	What are the best approaches to support carers and families of people at the end of life where there are substance and/or alcohol addiction and/or domestic violence issues?
<b>44</b>	What are the best ways to support children and young people when someone close to them is dying or has died? This includes communicating with them about the diagnosis and dying process, enabling them to talk about their experience and providing bereavement support.
<b>45</b>	What are the best ways and times to meet the emotional support needs of patients, carers and families, including one-on-one peer support, support groups and professional counselling?
<b>46</b>	How can patients, carers and families be supported when the patient does not want their carers and families to know their prognosis?
<b>Bereavement</b>	
<b>47</b>	Should bereavement support be made available to all bereaved people and, if so, how? Should GPs or other professionals provide bereavement visits?
<b>48</b>	How can the risk of intense and long-lasting grief best be assessed and treated? Can this be prevented through early bereavement support?
<b>49</b>	What are the benefits of bereavement support, including preventing depression and other illness?
<b>50</b>	When is the best time to introduce bereavement support, and for how long? Should it be offered before the death of a loved one? How can this support be catered to individual needs, including access to 24-hour support?
<b>Training and staff support</b>	
<b>51</b>	What are the benefits of setting up universal training courses for volunteers, carers, families and complementary therapists who have regular contact with palliative care patients?
<b>52</b>	Are hospices, hospitals and care homes providing adequate staff training to deliver specialist palliative care, and to what extent does funding affect this? How can high-quality trained staff be ensured no matter where the care is being delivered?
<b>53</b>	What are the benefits of all health and social care staff having training in bereavement awareness and support? Is this possible?

<b>Service use: care coordination</b>	
<b>54</b>	What are the best ways to facilitate communication across services and between healthcare professionals, including effective IT systems, team meetings and remote technology?
<b>55</b>	Since patients are often seen by a variety of professionals and services, would care improve if patients carried their own medical notes?
<b>56</b>	What are the benefits of increasing the numbers of palliative clinical nurses/nurse specialists in hospitals, GP surgeries, nursing homes and other settings?
<b>57</b>	Who should be part of the care team (such as chaplains, occupational therapists, GPs, etc)?
<b>58</b>	When is it appropriate to receive care virtually (such as via Skype or video-phone calls)? What are the benefits and potential harms for patients, carers and families?
<b>59</b>	What are the best ways to make sure there is continuity for patients at the end of life, in terms of the staff that they have contact with, and does this improve quality of palliative care? Would having a designated case-coordinator improve this process?
<b>60</b>	What are the best care packages for patients, carers, family and staff which combine health care and social care and take individual prognosis into consideration?
<b>61</b>	Much palliative and end of life care is provided by charities. What are the benefits and risks of this and is it sustainable and efficient?
<b>62</b>	Is there evidence that some volunteer services that provide support for patients, carers and families reduce the need for paid trained staff?
<b>63</b>	Do people at the end of life who receive support from volunteers, carers, family or friends, have better end of life experiences than those who do not?
<b>Service use: Accessing services</b>	
<b>64</b>	How can patients, carers and families easily access care services, equipment and statutory welfare benefits? How can people learn what resources are available and limit the time it takes to access these?
<b>65</b>	How can palliative care information and services be made more accessible to people whose first language is not English?
<b>66</b>	How can access to palliative care services be improved for everyone regardless of where they are in the UK?
<b>67</b>	What are the best ways of providing palliative care outside of 'working hours' to avoid crises and help patients to stay in their place of choice? This includes symptom management, counselling and advice, GP visits and 24-hour support, for patients, carers and families?
<b>68</b>	Are outcomes (for example, symptom control and incidental prolonging of life) better for terminally ill patients the sooner palliative care is introduced and services are accessed?
<b>69</b>	How can people who live alone and do not have friends or family nearby receive adequate palliative care, particularly if they wish to stay in their homes?
<b>Place and type of care</b>	
<b>70</b>	What are the best ways to begin to deliver palliative care for patients with non-cancer diseases (such as chronic obstructive pulmonary disease (COPD), heart failure, motor neurone disease (MND), Aids, multiple sclerosis, Crohn's disease and stroke)?
<b>71</b>	Does earlier palliative intervention for patients with chronic obstructive pulmonary disease (COPD) improve quality of life? When is the right time to intervene to improve understanding of prognosis, exercise tolerance, overall progression and access to pulmonary rehabilitation?

<b>72</b>	What are the core palliative care services that should be provided no matter what the patients' diagnosis is?
<b>73</b>	What are the benefits for patients, carers and families of day hospices and day therapies such as complementary therapies, rehabilitation and physical exercise? Do they help people stay more independent? When are the best times to refer palliative patients to these services and who benefits most?
<b>74</b>	What are the benefits, and best ways, of providing care in the patient's home and how can home care be maintained as long as possible? Does good coordination of services affect this?
<b>75</b>	What are the pros and cons of receiving palliative care in different environments, including at home, in a hospice, hospital or care home? Are there certain people and conditions that each are best for?
<b>76</b>	What are the best models of palliative care in an acute setting, such as a hospital?
<b>77</b>	How can the spiritual support needs of palliative care patients and their carers and families best be met in a way that is appropriate for people of different religions and people who are not religious?
<b>78</b>	Are some palliative care approaches better than others (eg holistic support, co-ordinated care, nurse-led care, early intervention) and for whom?
<b>79</b>	What are the benefits of occupational, beauty, diversion therapies (such as mindfulness, meditation, art, dance and gardening) for palliative care patients? How and where are these best provided?
<b>80</b>	What are the benefits of alternative therapies (such as homeopathy) or complementary therapies (such as acupuncture) for palliative care patients? How and where are these best provided?
<b>Understanding dying</b>	
<b>81</b>	How can we best determine a person's palliative care needs, particularly for patients with non-cancer diseases such as motor neurone disease (MND), Parkinson's disease, dementia and heart failure?
<b>82</b>	Do people with various types of terminal cancer have different palliative care needs? If so, what are the best ways of managing their symptoms?
<b>83</b>	What are the signs that a person will die in the next few days and how can detection of these signs be improved? How can families be made aware?





**For further information contact**

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