



From research to policy and practice

Marie Curie annual research impact report 2014/15

Using evidence to inform clinical practice and improve care for people living with terminal illness throughout the UK

Contents

Welcome	4
Foreword	5
Report at a glance – 2014/15 facts and figures	6
1. Introduction	9
1.1 The palliative and end of life care research funding landscape	9
1.2 Marie Curie research activities	10
1.3 Engaging the people we support	17
1.4 How we govern research	21
1.5 Working in partnership	22
2. Research outputs and impact	24
2.1 Recruiting to research studies	25
2.2 Publications	26
2.3 Influencing policy and practice	27
2.4 Research funding from the government and other charities	30
2.5 Collaborations	30
2.6 Engagement activities	32
2.7 Awards and recognition	34
3. Capacity building for research in palliative and end of life care	35
3.1 PhD studentships at Marie Curie research centres	35
3.2 Academic Clinical Fellowships, Liverpool	36
3.3 Research at Marie Curie Hospices	37
4. Research engagement	42
4.1 Marie Curie Annual Research Conference	42
4.2 Susie Wilkinson Award	42
4.3 Joanna Mugridge Research Award	43
5. Looking ahead	44
Authors/Acknowledgements	46
Abbreviations	47
Appendix 1: List of publications arising from Marie Curie research funding in 2014	48

Welcome



Pete Jones/Marie Curie

Marie Curie is the largest charitable funder of palliative and end of life care in the UK and has been funding related research since 1999. In 2010, we made the decision to increase our investment in this underfunded area.

Measuring the impact of our investment is of particular importance to the field of palliative and end of life care. In 2013, Marie Curie funding accounted for 50% of the cancer-related palliative and end of life care research spend in the UK¹.

Through research, we are working to ensure evidence informs both clinical practice and policy. This helps deliver our vision of a better life for everyone living with any terminal illness, and their families, carers and friends. With a rapidly ageing population – and changing needs of people at the end of life – this work is now more vital than ever.

By putting the experiences of the people we support at the centre of our research, we address the issues that matter to them the most.

Dr Jane Collins

Chief executive, Marie Curie

¹ Marie Curie's contribution to palliative and end of life care research funding: an analysis of the NCRI Cancer Research Database, 2002-2013. Marie Curie and National Cancer Research Institute 2015.

Foreword



Trevor Smeaton/Marie Curie

Research in palliative and end of life care is desperately needed. This report is the first to highlight the impact of Marie Curie investment in this important area. Five years ago, we decided to address the knowledge gap, identified by the National End of Life Care Strategy in 2008 and National Cancer Research Institute (NCRI) Rapid Review in 2010. We increased funding for our palliative care research centre at University College London (UCL) and set up a new centre at Cardiff University, our first to be linked to a clinical trials unit. We also invested in three research leads based in our hospices, to increase research activity and support evidence-based practice in our services.

Two new open and competitive funding streams² were introduced as well as a central research management team. This team oversees and arranges peer

review of all our research activities. We are a member of the Association of Medical Research Charities (AMRC) and adhere to best practice they recommend.

Five years on, the time has come to look back and review. An initial period of setting up funding streams and projects has led to a steady flow of publications and reports. These have all focused on providing short- to medium-term benefits for people with terminal illness and their carers, families and friends. This report contains details of our research and its impact in 2014/15, highlighting some of the projects that have influenced policy and practice.

We are proud of the achievements of all researchers involved in Marie Curie funded studies and will strive to increase research investment even further in this under-funded area of care.

Professor Bill Noble

Executive medical director, Marie Curie

² Marie Curie research grants scheme (formerly known as the Marie Curie Research Programme) and the Dimbleby Marie Curie Research Fund jointly with Dimbleby Cancer Care.

Report at a glance

- We are the **largest charitable funder of palliative and end of life care research** in the UK – an area that is significantly underfunded.
- To strengthen the evidence base, **we invest £1 million annually** into our open and competitive calls, and provide funding for three research centres as well as four research lead posts across nine hospices.
- Our group of **Research Expert Voices** influence decision making on strategy, applications and the dissemination of our research (**see page 17**).
- We continue to **listen to the people that matter**. We initiated the Palliative and end of life care Priority Setting Partnership with the James Lind Alliance to find out what patients, carers and health and social care professionals identify as the most important unanswered questions in this area of research (**see page 19**).
- We have set up **governance systems** to ensure our research activities are informed by independent expert advice and the experience of research and practitioner members.

2014/15 facts and figures

We produce research through our...



3

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



£1m

Annual funding of
research project
grants



4

Research leads
across our nine
hospices

...influenced by...



Our group of Research Expert
Voices and Priority Setting
Partnership with the James
Lind Alliance

- Through our funded studies, **we are using data to improve care.** More than 18,000 health records have helped inform palliative and end of life care research projects (**see page 25**).
- Our funding led to **70 papers published in peer reviewed journals** and ensured 51 (73%) of these were made freely available (**see page 26**).
- Marie Curie funded researchers have collaborations in **over 30 locations around the globe.**
- Our research continues to **inform and influence policy and practice (see pages 28-29).**
- Researchers funded by Marie Curie received an additional **£1.2 million in funding from government and other charities (see page 30).**
- We **support the next generation of researchers** in palliative and end of life care through funding for PhD studentships at our centres, academic clinical fellowships and research lead posts at our hospices (**see page 35**).

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



70

Papers in peer-reviewed journals – 51 (73%) were open access



78

Instances of informing policy



37

Locations around the globe where we have collaborations



5,135

People recruited to our studies and 18,855 health records studied



£1m+

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

...which has helped to influence policy and practice.



1. Introduction

Research has the potential to improve the quality and experience of care for everyone affected by terminal illness. Investment in good quality research

can strengthen the evidence base for palliative and end of life care – an area which remains vastly underfunded.

1.1 The palliative and end of life care research funding landscape

Palliative and end of life care research as an underfunded area was highlighted in a recent report³ from the National Cancer Research Institute (NCRI) and Marie Curie. The analysis showed that of the £503 million spent on cancer research by NCRI members in 2013; only £3.08 million (0.61%) was spent on palliative and end of life care research. Half of this funding came from Marie Curie.

In 2014, the UK Clinical Research Collaboration (UKCRC) carried out a UK-wide analysis of public and charity-funded health research (relevant to all conditions, not just cancer). It showed that charitable and government funders spent over £2 billion on health-related research that year. According to the analysis, the proportion of spending on end of life care doubled from 0.08% in 2004/05 to 0.16% in 2014. Yet, this equates to only £3.25 million of the total spend.

These figures only include projects categorised as ‘end of life care research.’ To take account of the larger area of palliative care research, as well as infrastructure, we are currently carrying out a more detailed analysis, the results of which will be made available in 2016.

The figures show that there has been little sustained change in the amount invested in palliative and end of life care research, in spite of activities such as the NCRI Supportive and Palliative Care (SuPaC) Initiative and the National End of Life Care Strategy.

Marie Curie started funding research in palliative and end of life care research at a low level in 1999. In 2010, we increased funding with the Marie Curie open calls. Figure 1 outlines the key milestones resulting from our investment.

³ Marie Curie's contribution to palliative and end of life care research funding: an analysis of the NCRI Cancer Research Database, 2002-2013. Marie Curie and National Cancer Research Institute 2015.

1.2 Marie Curie research activities

Where we fund research in the UK

We fund research through our research centres, research grants schemes and research lead posts at Marie Curie Hospices. In our 2014 open call, we awarded five project grants:

Professor Jane Seymour from the **University of Nottingham** was awarded funding for her systematic review of evidence on the role of clinical nurse specialists for people with advanced cancer.

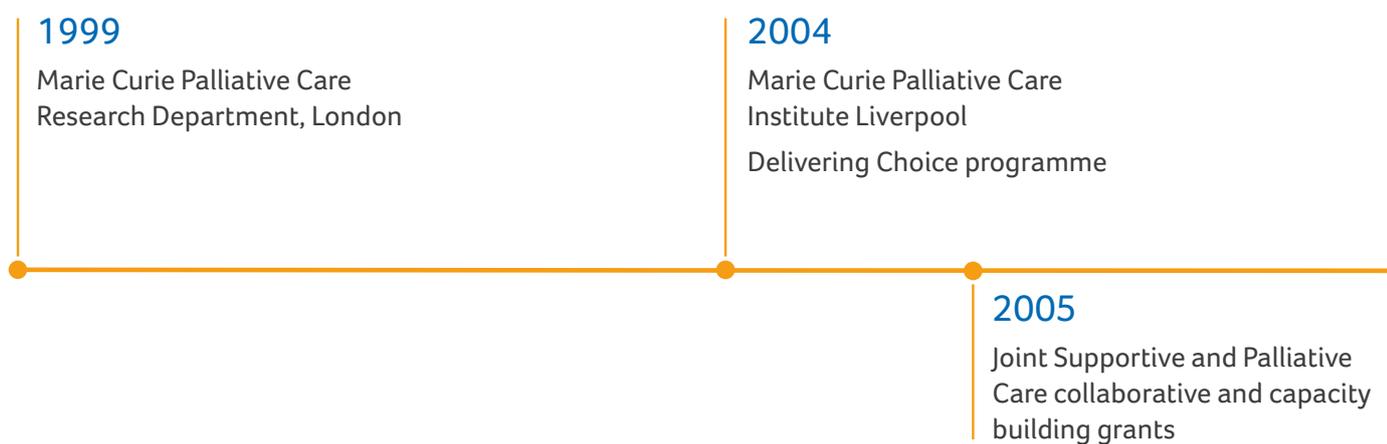
Dr Nathan Davies from **University College London** is using his funding to develop a set of heuristics (or rules of thumb) for improving end of life care for people with dementia.

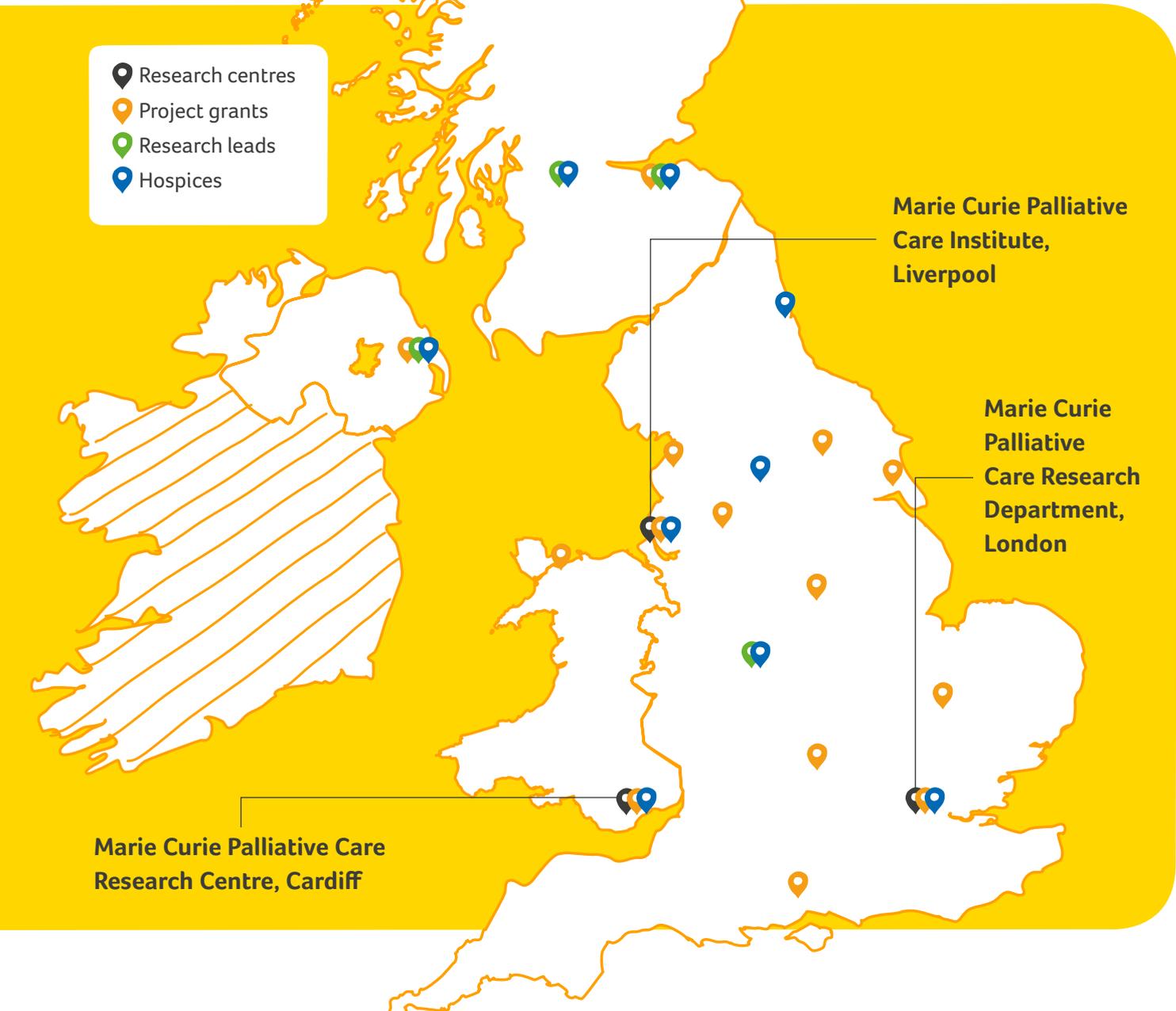
Professor Marie Fallon from the **University of Edinburgh** and Dr Kerry McWilliams from the **University of Hull** are investigating whether paracetamol can improve pain control for people already taking strong pain killers for cancer-related pain.

Professor Irene Higginson from **King's College London** is leading a study on relieving refractory breathlessness due to chronic illness.

Professor Marie Fallon from the **University of Edinburgh** was awarded funding for her study on who is most likely to benefit from palliative radiotherapy for cancer-induced bone pain.

Figure 1: Key milestones resulting from Marie Curie research funding





Our research centres

Marie Curie Palliative Care Research Department, London

Established at University College London (UCL) in 1999, the Marie Curie Palliative Care Research Department (MCPCRD) conducts world-class palliative care research. It is recognised for its work in end of life care planning, the evaluation of interventions in palliative care and end of life care in non-cancer conditions, in particular dementia.



Aubrey Wade

“Our research is providing evidence to develop and test new ways of improving care of people with a terminal illness. We always consider the patient and carer perspective, ensuring our work has direct benefits for people with terminal illness and their families.”

Professor Paddy Stone, chair of palliative and end of life care, MCPCRD, UCL

Professor Paddy Stone was appointed the first Marie Curie chair of palliative and end of life care in 2014. Bringing over 22 years’ experience in palliative medicine, Professor Stone is committed to combining UCL’s research strengths with Marie Curie’s clinical expertise, to ensure evidence informs practice. With more than 80 publications in high-impact journals, he has helped develop palliative medicine as an academic discipline.

Marie Curie Palliative Care Research Department, UCL, London





Dr Louise Jones has made a significant contribution to developing research at Marie Curie since joining the Marie Curie Hospice, Hampstead in 1993. Working with Dr Adrian Tookman and Professor Michael King, she secured the team's first research grant from The Leverhulme Trust. Dr Jones led the MCPCRD from 2005 until 2014.



Dr Liz Sampson, reader in old age psychiatry, leads the MCPCRD's research on dementia. Dr Sampson's epidemiology and health services research seeks to identify the barriers to accessing quality palliative and end of life care for older people.

The team's research on end of life care for people with dementia has influenced key guidelines from the National Institute for Health and Care Excellence (NICE), and Social Care Institute for Excellence. It has been cited in policy reports by Marie Curie and Alzheimer's Society (see Case study 3: Influencing policy – living and dying with dementia) and the NHS Confederation.

Experts in the field

The quality of research being undertaken at the MCPCRD was recognised in 2014 as part of UCL's submission to the Research Excellence Framework, a system which is used to assess the quality of research taking place in higher education institutions in the UK. Research at the centre has

informed national policy on major investments in, and the practice of, palliative and end of life care. The team has also expanded its scope to develop specific interventions to improve end of life care for people with a terminal illness such as an innovative model for caring for people with dementia in care homes.

Marie Curie Palliative Care Research Centre, Cardiff

Dr Anthony Byrne set up the Marie Curie Palliative Care Research Centre (MCPCRC) with Dr Annmarie Nelson at Cardiff University in 2010. Originally positioned within the Wales Cancer Trials Unit, the team has expertise in the development of clinical trials and the use of mixed methodologies to assess complex interventions in large scale studies. The centre has a particular emphasis on three key areas: patient and carer experience, palliative rehabilitation and cancer-associated thrombosis.



Trevor Smeaton/Marie Curie

“Research in palliative care is far behind other research areas. We are working hard to improve the methods we use. We continue to provide a clear message that people with terminal illnesses want to be involved in research and should have the opportunity to do so.”

Dr Anthony Byrne, clinical director, Marie Curie Palliative Care Research Centre, Cardiff

Dr Anthony Byrne, clinical director of the MCPCRC, Cardiff has almost 20 years’ experience in clinical academic medicine. He previously initiated the MSc in Palliative Medicine at Cardiff University and was appointed scientific lead for palliative care research, and subsequently associate director of the Wales Cancer Trials Unit. Dr Byrne leads on rehabilitation and symptom control research which considers how to maintain function for as long as possible, and has additional interests in the design and implementation of pragmatic trials and supporting clinical teams in undertaking research of importance to their practice.



Dr Annmarie Nelson, scientific director of the MCPCRC, Cardiff, leads on patient and carer experience, in particular on understanding how people with advanced disease experience the treatments and process of clinical trials. This work is providing insight into how and why qualitative research should be incorporated into clinical trials. Alongside this, Dr Nelson is honorary Professor at Swansea University and supportive and palliative care work package lead and academic lead for patient and public involvement at the Wales Cancer Research Centre.



Alongside his role as clinical reader in palliative medicine at Cardiff University, **Dr Simon Noble** is leading research into the management of cancer-associated thrombosis (CAT) in patients with advanced cancer. He is investigating patients' experiences, and how research can be translated into practice and methods for preventing CAT in hospice patients. Dr Noble is regarded as a world expert in his field and has produced a body of research designed to change practice.

Staff at the Marie Curie Palliative Care Research Centre, Cardiff with Baroness Ilora Findlay at the official centre opening in 2014



The Marie Curie Palliative Care Institute, Liverpool

The Marie Curie Palliative Care Institute, Liverpool (MCPCIL) leads research into care at the end of life and has become a hub for high-quality learning and teaching. It was set up in 2005 in partnership with the Royal Liverpool and Broadgreen University Hospitals NHS Trust and the University of Liverpool and is led by Professor John Ellershaw.



Dr Stephen Mason heads the research and development division at MCPCIL overseeing and mentoring a team of researchers, honorary and academic clinical lecturers, and clinical and research fellows. His specialisms in psychosocial care, medical education, and research methodology in palliative care have helped secure research awards and papers in peer-reviewed journals.



Professor John Ellershaw has been helping develop specialist palliative care services since 1994. As honorary professor of palliative medicine at the University of Liverpool, Professor Ellershaw provides a focal point for future educational and research developments.



Dr Andrew Dickman is an honorary consultant clinical pharmacist and research fellow at the MCPCIL. His research focuses on the safety and efficacy of drugs used to control complex symptoms that can occur towards the end of life.

“Since 2009, the institute has hosted three Academic Clinical Fellowships – recognising the outstanding potential of our staff to academic palliative medicine.”

Professor John Ellershaw, director, Marie Curie Palliative Care Institute, Liverpool

1.3 Engaging the people we support

At Marie Curie, people living with a terminal illness, and their families, friends and carers, help us to identify our research priorities, ensure we allocate funding efficiently and disseminate our results widely. The people we support are involved in our research through our group of Research Expert Voices. Our research priorities are also informed by the results of the Palliative and end of life care Priority Setting Partnership with the James Lind Alliance, which asked carers, health and social care professionals and people living with terminal illness to identify the questions they most wanted research to answer (see Box 1: Top 10 research priorities for palliative and end of life care).

Marie Curie Research Expert Voices

The Marie Curie Expert Voices Group (EVG) and Research Expert Voices Group (REVG) are helping to establish what makes a good quality service and develop

new and improved services that will enhance palliative and end of life care for people living with a terminal illness.

The REVG was set up in 2013 as a sub-group of the EVG to focus on research. Its nine members are carers, friends and bereaved family with experiences of end of life care services. Their insight and experience is directly informing our research. Members are involved in funding decisions for our research grants, reviewing project reports, informing our research strategy, assessing our research centres and selecting abstracts to be showcased at Marie Curie's Annual Research Conferences.



REVG member **Peter Buckle** is a part of Marie Curie's Research Review Committee and the Marie Curie Hospice, West Midlands' research lead steering group, as well as an ambassador for the Brain Tumour Charity.

“My lovely wife Wendy passed away at home less than six months after being diagnosed with a terminal illness. The help we received in her last weeks from Marie Curie Nurses was invaluable. I am now devoting my time to supporting Marie Curie in improving the end of life care experience for people with terminal illness and their families. One of the most important areas of the charity's work is through their various research committees, of which I am privileged to be a member.”

Peter Buckle, Research Expert Voice



Staff at the Marie Curie Palliative Care Research Centre, Cardiff with members of Health and Care Research Wales at the Four Nations conference, Wales

Sharing best practice

Public involvement in research is often described as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. The Marie Curie Palliative

Care Research Centre (MCPCRC), Cardiff, is working with Health and Care Research Wales (formerly NISCHR CRC) to share and build on patient and public involvement in health research in the UK. In 2014, they held a joint 'Four Nations' conference to share best practice in public involvement.

The vision of Health and Care Research Wales for public involvement in research focuses on public awareness, engagement, involvement and participation in health research. As part of this, the MCPCRC and other partners are working together to ensure patient and carer representatives are actively involved in the decision-making process, planning and evaluation of clinical trials, and not just treated as 'subjects'.



REVG member **Helen Findlay** is a member of the Marie Curie Research Funding Committee. She has spoken at conferences and with MPs in UK Parliament about her family's experience with terminal illness. She is an active member of the National Council for Palliative Care's People in Partnership group and the Cicely Saunders Institute's public and patient involvement group at King's College London.

Setting research priorities with the James Lind Alliance

Marie Curie initiated the Palliative and end of life care Priority Setting Partnership with the James Lind Alliance in 2013. Co-funded by nine other research funders, the partnership was formed to understand the gaps in the evidence for palliative and end of life care. The partnership brought together people likely to be within the last years of their life, carers, and health and social care professionals.

Following an extensive 18-month public consultation, the top 10 research priorities for palliative and end of life care were announced at the Palliative and End of Life Care Research Summit, hosted by NHS England and Public Health England's National End of Life Care Intelligence Network (see Box 1: Top 10 research priorities for palliative and end of life care).

Box 1: Top 10 research priorities for palliative and end of life care

- 1 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.
- 2 How can access to palliative care services be improved for **everyone regardless of where they are in the UK?**
- 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?
- 4 What **information and training** do carers and families need to provide the best care for their loved one who is dying, including training for giving medicines at home?
- 5 How can it be ensured that staff, including healthcare assistants, are **adequately trained** to deliver palliative care, no matter where the care is being delivered? Does increasing the number of staff increase the quality of care provided in all settings? To what extent does funding affect these issues?
- 6 What are the best ways to determine a person's palliative care needs, then initiate and deliver this 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, Parkinson's disease, dementia and stroke)?
- 7 What are the **core palliative care services** that should be provided no matter what the patients' diagnoses are?
- 8 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?
- 9 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?
- 10 What are the best ways to **assess and treat pain and discomfort** in people at the end of life with communication and/or cognitive difficulties, perhaps due to motor neurone disease (MND), dementia, Parkinson's disease, brain tumour (including glioblastoma) or head and neck cancer, for example?



1.4 How we govern research



Professor Sir Andy Haines, chair of the Marie Curie Research Strategic Advisory Committee (top), Professor Tim Peters, chair of the Marie Curie Research Funding Committee (middle) and Professor Bill Noble, chair of the Marie Curie Research Review Committee

We increased our research investment in palliative and end of life care in 2010, recognising the need to strengthen the wider evidence base. The money was allocated with the help of independent national and international experts on the Marie Curie Research Funding Committee and the Dimpleby Marie Curie Research Fund Advisory Board.

In 2014, we widened our research review structure, with independent experts and former carers to advise and guide us on our research activities. Two new committees were introduced: the Marie Curie Research Strategic Advisory Committee and the Marie Curie Research Review Committee. Independent site visit committees carry out five-yearly reviews of Marie Curie research centres, in accordance with best practice from the AMRC.

Our advisory committees

The **Marie Curie Research Strategic Advisory Committee** works under the leadership of Professor Sir Andy Haines from the London School of Hygiene and Tropical Medicine. The committee is responsible for advising us on the future direction of our research investment, through its panel of external members, including former carers and experts in palliative and end of life care.

The **Marie Curie Research Funding Committee** independently reviews and awards our project grants. It was formed in 2010 when we introduced our open calls. Currently chaired by Professor Tim Peters from the University of Bristol, it helps allocate funds to research studies based on their scientific excellence and how relevant they are to our research strategy. All grants are externally peer reviewed by national and international experts to ensure the highest quality research is funded. The funding committee is an invaluable source of expertise during the five-yearly reviews of our research centres.

The **Marie Curie Research Review Committee** reviews research activities we conduct or fund, advising us on how best to maximise the impact of our research on policy and practice. Chaired by Marie Curie's executive medical director, Professor Bill Noble, the committee is made up of external experts, the people we support and internal staff. This ensures research is effectively communicated among the research community, practitioners inside and outside of Marie Curie, supporters and the general public.

Collectively, Marie Curie's research committees ensure that our research activities are informed by independent expert advice from researchers and practitioners as well as people with personal experience of terminal illness.

1.5 Working in partnership

Marie Curie works in partnership with a wide range of organisations. By sharing knowledge and best practice in research, we can more efficiently improve care and support for people living with a terminal illness, their carers and their families.

Membership organisations



Marie Curie is a member of the **Association of Medical Research Charities (AMRC)**, a network of medical and health research charities that support medical research in the UK. The AMRC provides guidelines on peer review that help ensure our research management processes follow best practice.



We are one of 21 member organisations of the **National Cancer Research Institute (NCRI)** that are working together to coordinate research relating to cancer in the UK.



We are a non-commercial partner of the **National Institute for Health Research (NIHR)**. Studies funded by Marie Curie are automatically eligible for NIHR Clinical Research Network

(CRN) support if required. The CRN supports the delivery of clinical trials, for example by helping with recruitment.



The **All Ireland Institute of Hospice and Palliative Care (AIHPC)** are experts in the academic preparation for and delivery of hospice and palliative care across Ireland. We are a funding member of the AIHPC through the Marie Curie Hospice, Belfast.



The **UK end of life care Research Interest Group** was launched by the NCRI in 2012, and is now managed by Marie Curie. The aim of the group is to bring supportive, palliative and end of life care for all diseases and conditions more into the mainstream of health and social care research. The group has more than 25 member organisations – comprising research funders, who operate competitive peer-reviewed funding streams for high quality research, and other organisations with an interest in palliative and end of life care.

Our partners



Cancer Research UK provides expert advice and help to administer the application process of our research grants scheme.



Dimbleby Cancer Care supports people living with cancer as well as their families and carers. The Dimbleby Marie Curie Research Fund awarded grants to eight research studies in 2010-11, with a particular focus on unpaid carers and volunteers involved in end of life care (see Case study 4: Influencing practice – supporting home-based carers).



With **Alzheimer's Society** and a range of other partner organisations, we are helping to raise awareness and understanding of key aspects of dementia and end of life care. Marie Curie and Alzheimer's Society produced a set of policy reports in 2014 identifying the barriers to care for people living and dying with dementia (see Case study 3: Influencing policy – living and dying with dementia).



Since 2011, Marie Curie, the **British Heart Foundation** and **NHS Greater Glasgow and Clyde** have been working in partnership on a five-year programme for people with heart failure, called Caring Together. The programme is a response to the Scottish government's action plan for palliative care services, which calls for a more equitable provision of end of life care services for people with any advanced, progressive or incurable conditions.



The **Palliative and end of life care Priority Setting Partnership** with the James Lind Alliance was initiated by Marie Curie. It works to identify the evidence gaps in palliative and end of life care from the perspectives of health and social care practitioners as well as people living with a terminal illness, their families and carers. As well as the 10 co-funders, more than 25 organisations are involved in the project.

2. Research outputs and impact

This section highlights the research outputs for 2014/15 from our:

- three research centres
- four research leads
- nine hospices
- 25 research projects from open and competitive funding calls.

The data was gathered from the annual reports of the research centres and research leads. Research project grant information was collected from 24 principal investigators across 12 institutions through a new reporting tool, called Researchfish.

The results are categorised according to:

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



Simon Ratlives/Marie Curie

2.1 Recruiting to research studies

Between 1 April 2014 and 31 March 2015, Marie Curie funded studies recruited:



1,436
patients



1,308
carers



2,028
members of staff across hospitals,
care homes and hospices



363
members of the
public

As we increase our investment in palliative and end of life care research, we are giving more people with a terminal illness, carers, staff members and members of the public the opportunity to take part in research studies to improve palliative and end of life care.

More than 18,800 health records also helped inform palliative and end of life care research projects. A high proportion of these are being used to provide recommendations that can support individuals to die in their place of choice (see Case study 1: Using data to improve care).

Case study 1: Using data to improve care



Layton Thompson/Marie Curie

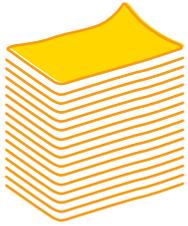
Better understanding of where children and young people with cancer die can enhance care and inform care planning and policy for this group.

Dr Wei Gao and Professor Irene Higginson from King's College London

were awarded funding from the Marie Curie research grants scheme in 2013 for their study into end of life cancer care in children and young people under 24.

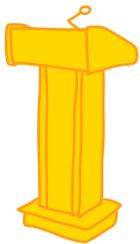
Thanks to existing health records, the team was able to investigate how patterns in where children and young people die have changed over time – an area that has never been evaluated nationally. Their project is helping inform service providers, NHS management and policy makers on how end of life care can be improved for children and young people.

2.2 Publications



70

Publications in journals



41

Conference abstracts



8

Publications in books

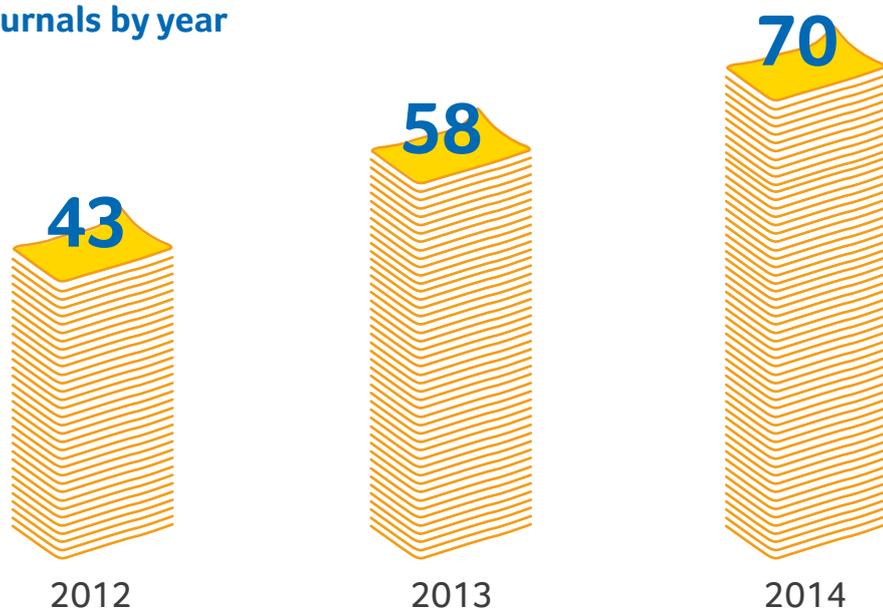
In 2014, Marie Curie researchers published 70 papers in peer-reviewed journals, which is up from 58 in 2013 (see Figure 2: Publications by year). Of the wide variety of research undertaken, 23 were qualitative, 10 were systematic reviews and five were clinical trials or feasibility studies (of complex interventions or drugs). This reflects the themes of Marie Curie’s open and competitive funding calls and the nature of palliative and end of life care research in general. We aim to increase the number of interventional studies in our portfolio (see Case study 2: Investing in clinical trials), and add more implementation and knowledge translation research.

Of the 70 publications, 73% are openly available, versus 53% in 2012. This is in line with our commitment to sharing knowledge widely and supporting open access publishing. Marie Curie is a member of Europe PubMedCentral and believes the research we fund should be easily available to practitioners and the people we support.

An additional 41 publications were reported as national and international conference proceedings or abstracts and another eight publications were books or book chapters.

See Appendix 1 for a full list of the 70 publications from 2014.

Figure 2: Publications in peer reviewed journals by year



Case study 2: Investing in clinical trials – future care planning for people with advanced heart disease

People with advanced heart disease often do not receive the additional supportive care they need at the end of life. There are few clinical trials that measure the effectiveness of a holistic approach to care for people with terminal illnesses.

In 2013, Marie Curie awarded Dr Martin Denvir from the University of Edinburgh funding to examine the challenges of designing and running a clinical trial that can assess the effectiveness of better supportive care for people with

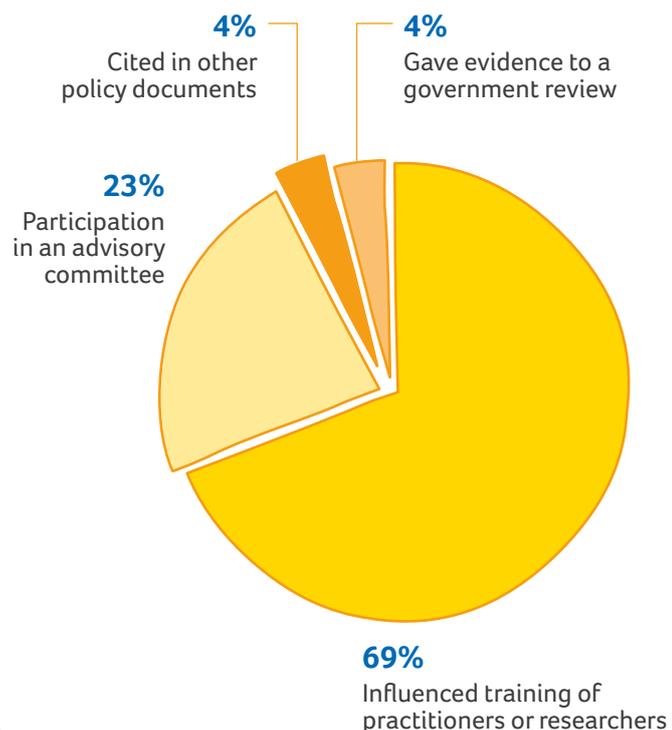
advanced heart disease nearing the end of life.

Dr Denvir and his team asked patients, carers, doctors and nurses about their views on how a clinical trial for an end of life intervention could be designed and run. The paper was published in the British Medical Journal Open in 2014. Through his study, the team has been able to design and run a clinical trial that assesses an intervention for future care planning of patients with advanced heart disease.

2.3 Influencing policy and practice

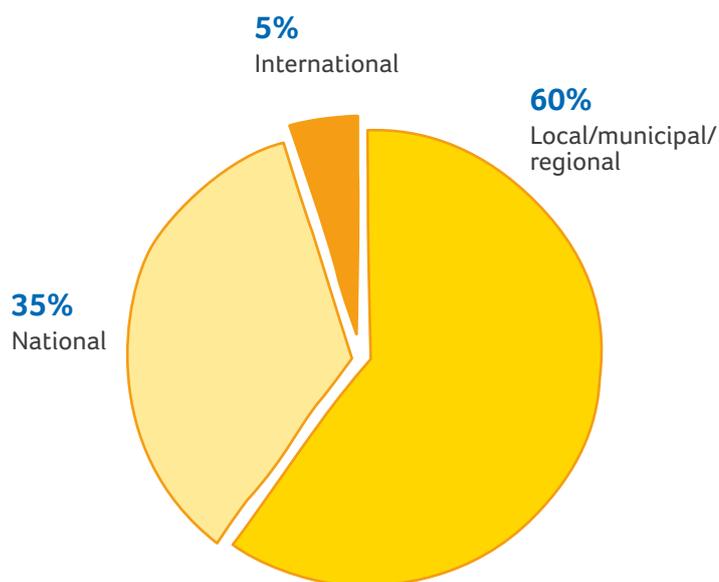
At Marie Curie, we firmly believe that research should be used to inform and influence policy and practice. In 2014, Marie Curie researchers reported 78 influences on policy and practice from research alone, such as training of researchers or practitioners, participation in advisory committees, citations in policy documents and through giving evidence to government reviews (see Figure 3: Policy influence by type).

Figure 3: Policy influence by type



The majority of influences took place locally or regionally (see Figure 4: Policy influence by location), with 35% of research influencing policy and practice at the national level (see case studies 3 and 4 for examples: Living and dying with dementia, Supporting home-based carers and Box 2: Supporting research – research governance: a guide for hospices).

Figure 4: Policy influence by location



Case study 3: Influencing policy – living and dying with dementia: barriers to care

In 2014, Marie Curie released a policy report addressing the challenges of providing adequate and accessible care for people with dementia who are approaching the end of life.

Living and Dying with Dementia – Barriers to Care, which covers England, Scotland, Northern Ireland and Wales, was produced in collaboration with Alzheimer’s Society and based on research being undertaken at the Marie Curie Palliative Care Research Department, London.

“People with dementia have very specific needs. All too often, services do not respond to the needs of the individual. That is why we are calling on a number of organisations to work with Marie Curie and Alzheimer’s Society to improve care and support for people with dementia at the end of life.”

Joan McEwan, head of policy and public affairs, Northern Ireland, Marie Curie

In a follow-up seminar organised by Marie Curie with speakers from the charity, the University of Stirling, the Scottish Government and Alzheimer Scotland to discuss how to overcome the barriers to care for people at the end of life with dementia, the Scottish Government reiterated its commitment to include end of life care in the upcoming third national dementia strategy – a key recommendation of the Scotland report.

Case study 4: Influencing practice – supporting home-based carers

Making sure that a friend or loved one living with a terminal illness receives the right support can be a huge responsibility. Many home-based carers will take on aspects of care themselves, and providing this support can be unfamiliar and challenging.

Professor Jane Seymour from the University of Nottingham was awarded funding from the Dimbleby Marie Curie Research Fund for her project to research and develop a resource pack

for carers of people with a terminal illness, and a training programme⁴ for people who provide support to those carers. This free, one-day course is already being used by several organisations that offer support for carers, including Marie Curie's new Support Line.

Professor Seymour and her team used existing evidence on carers' support needs, building on research by Professor Gunn Grande and Dr Gail Ewing from the Universities of Manchester and Cambridge respectively. They also collaborated with stakeholders from organisations such as the Carers Federation.

This led to the development of a training programme in 2014 for people who provide support to home-based carers of people with a terminal illness. Participants gain insight into the practical and emotional needs of carers and the confidence to deliver support and mentorship.

“The experience of caring for a loved one at the end of their life is likely to be unknown territory for most people and there is undoubtedly a great need for effective mentorship and support. The training programme enables people who support carers to provide relevant, jargon-free explanations of care concepts and practical demonstrations.”

Robin Pritchard, director, Dimbleby Cancer Care

Box 2: Supporting research – research governance: a guide for hospices

In 2014, researchers from the Marie Curie Palliative Care Research Centre, Cardiff led on the development of an online research governance toolkit, in collaboration with hospices, Health and Care Research Wales and the All Wales Palliative Care Implementation Board.

The toolkit⁵ helps hospices overcome the challenges of involving people with terminal illness and staff in research. Since its launch, the toolkit has been presented at national conferences and is being developed as a smartphone application.

⁴ The training is available at: nottingham.ac.uk/helm/dev/end_of_life/

⁵ The toolkit is available at: nischr-cancerrrg.org/research/

2.4 Research funding from the government and other charities

In 2014, researchers funded by Marie Curie received an additional £1.2 million to support their work in palliative and end of life care. Of this, 60% came from public or government

funders, such as the NIHR and Cabinet Office. The remaining 40% was from charitable funders, including Prostate Cancer UK and Tenovus Cancer Care.

2.5 Collaborations

In 2014, Marie Curie researchers collaborated with a variety of sectors, including the academic, private and non-profit sector, in over 30 locations worldwide (see Figure 5: Marie Curie international collaborations). One example is a collaboration between the Rivierenland Hospital in the

Netherlands and the Marie Curie Palliative Care Institute, Liverpool, where Marie Curie researchers are helping develop palliative care services to improve care of patients with lung cancer, lung disease and chronic obstructive pulmonary disease.

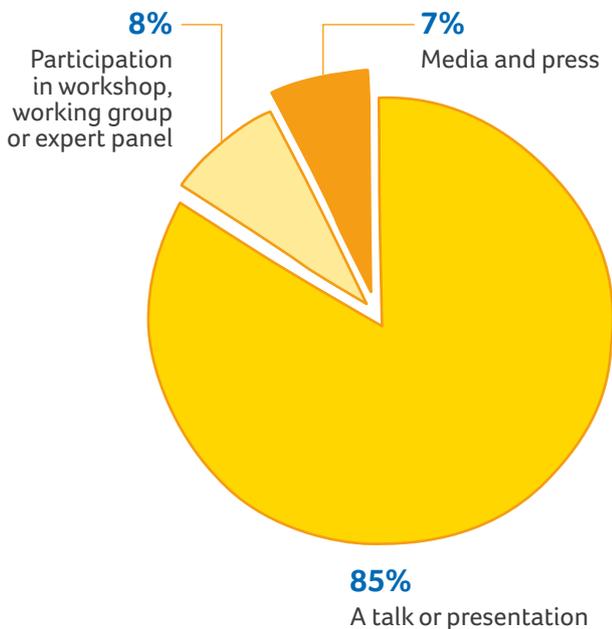
Figure 5: Marie Curie international collaborations





2.6 Engagement activities

Figure 6: Engagement activities by type in 2014

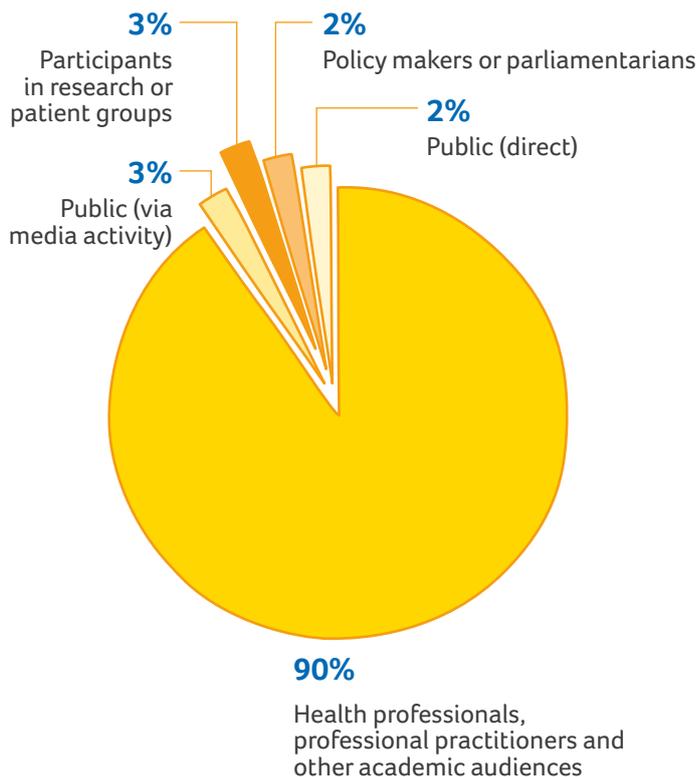


Engaging with a wide range of audiences outside of academia is a key component of Marie Curie research, and one of our strategic aims. Sharing findings widely promotes partnerships and helps inform our research, policy and practice.

Types of engagement

In 2014, researchers reported that they were involved in a range of engagement activities outside of academia, such as working groups, expert panels, presentations and media engagement. Of the 122 instances reported, the most common forms of engagement were a talk or presentation (85%), a workshop, working group or expert panel (8%) or through the media and press (7%) (see Figure 6: Engagement activities by type in 2014).

Figure 7: Research engagement activities by audience in 2014

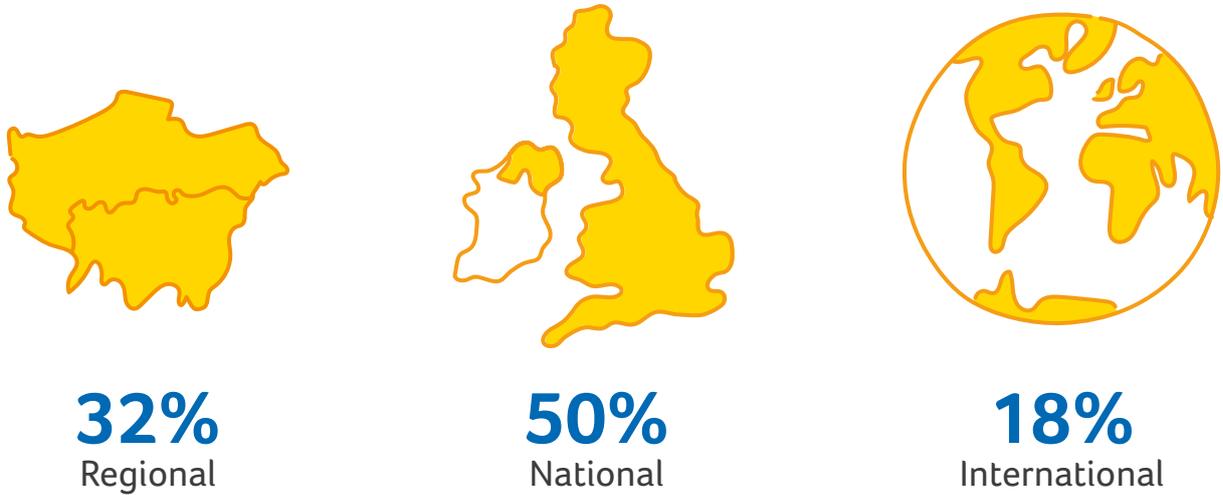


Audiences and locations

Around 90% of engagement activities were delivered to audiences of health professionals, practitioners and other academics (see Figure 7: Research engagement activities by audience in 2014 and Box 3: Engaging with the general public).

More than 80% of the activities reported by researchers took place throughout the UK with the rest occurring internationally (See Figure 8: Research engagement activities by location in 2014).

Figure 8: Research engagement activities by location in 2014



Marie Curie staff and volunteers at Pride

Box 3: Engaging the general public

In 2014, research funded through the Marie Curie research grants scheme was presented at the Economic and Social Research Council Festival of Social Science.

Dr Kathryn Almack spoke about the first UK study of its kind to examine end of life care for older lesbian, gay, bisexual and transgender people.

2.7 Awards and recognition

We are proud of the achievements of researchers funded by Marie Curie in 2014, which have been widely recognised. They were awarded at least 100 measures of esteem for the quality of their research in the field of palliative and end of life care – including research prizes and medals as well as invitations to be keynote speakers at conferences.



Research prizes

In 2014, the Worshipful Society of Apothecaries awarded **Dr Liz Sampson** from the Marie Curie Palliative Care Research Department, London, the prestigious **William Farr Medal**. This was in recognition of her research on the care of older people with dementia in acute hospitals. Dr Sampson is the first woman and the first psychiatrist to be awarded the William Farr Medal.



Trevor Smeaton/Marie Curie

Professor Scott Murray, St Columba's Hospice chair of primary palliative care at the University of Edinburgh, was awarded the **George Abercrombie Award** in 2015. The Royal College of General Practitioners gave Professor Murray this award in recognition of his outstanding contribution to the literature of general practice, including his work describing typical illness trajectories at the end of life. Professor Murray holds multiple Marie Curie and Dimpleby Marie Curie project grants.

Professor Murray's research and training programmes aim to make end of life care available for people across the world, particularly in developing countries. His research informs palliative care development and policy in Africa, Europe and the Far East. The International Primary Palliative Care Network, which he chairs, is currently advising the World Health Organisation about the integration of palliative care for people with all life-threatening illnesses worldwide.

3. Capacity building for research in palliative and end of life care

Marie Curie is working to support the next generation of palliative and end of life care researchers. We do this through funding for PhD studentships at our research centres, academic

clinical fellowships and research lead posts at our hospices – who lead on collaborations between hospices and universities.

3.1 PhD studentships at Marie Curie research centres

Left to right: Emma Day, Dr Louise Jones and Professor Myra Bluebond-Langner at the Marie Curie Annual Research Conference 2014

With joint funding from Marie Curie and the Raisa Gorbachev Foundation, **Emma Day** was awarded a four-year Lebedev PhD studentship in 2012. Her research is about understanding decision making around the care and treatment of teenagers with leukaemia. Based on their experiences, the study has the potential to better inform

healthcare professionals of these young people's needs. The study was presented at the 20th International Congress for Palliative Care, Montreal, in 2014 and the 7th International Cardiff conference on paediatric and palliative care. Emma is supervised by Dr Louise Jones at the Marie Curie Palliative Care Research Department, London and Professor Myra Bluebond-Langner.



Trevor Smeaton/Marie Curie

Helping to build capacity and champion evidence-based practice in children's palliative care, **Professor Myra Bluebond-Langner** oversees the research of students including Emma Day. Professor Bluebond-Langner is the True Colours chair in palliative care for children and young people at the Louis Dundas Centre for Children's Palliative Care. She is the UK's first professional chair in children's palliative care.

Through Marie Curie funding at the MCPCRD, London, **Dr Bridget Candy's** PhD explored promising ways to combine the findings from studies on how people cope with a chronic severe disease and studies on interventions to help people manage such a disease. The aim of the project was to see if what people thought was important in coping could help pinpoint key aspects of an intervention – for example, the health provider explaining the relationship between medicine and symptoms or giving

guidance on fitting medicine around a daily routine. The results suggest linking these different studies may provide new information to help improve the advice given on self-management of a disease.

Dr Candy was supervised by Professor Michael King from the UCL division of psychiatry and Professor Sandy Oliver from UCL's social science research unit. She was also advised by Dr Louise Jones from the MCPCRD.

3.2 Academic Clinical Fellowships, Liverpool



The Marie Curie Palliative Care Institute, Liverpool has hosted three academic clinical fellowships recognising the outstanding potential of staff to academic palliative medicine. **Dr Amara Nwosu** (above), **Dr Andrew Khodabukus** and **Dr Seamus Coyle** each held an **Academic Clinical Fellowship** between 2009 and 2015.

Dr Amara Nwosu's PhD used non-invasive scientific methods to study hydration status in patients with advanced cancer. The technique, known as bioelectrical impedance vector analysis (BIVA), uses a small electrical current to measure the resistance of tissues and fluids as it flows around an individual. The information obtained from the measurement allows for estimating fluid volume in a few seconds in a completely painless way.

As well as gaining the Academic Clinical Fellowship, Dr Nwosu was awarded the **Twycross Research Prize** by the Association of Palliative Medicine in 2014, and received joint third place in the **Early Researcher Award** of the **European Association for Palliative Medicine**. Posters on his PhD won **NCRI Prize Awards** in both 2012 and 2014.

3.3 Research at Marie Curie Hospices

Our research lead programme helps engage staff at our nine hospices in research activities, enhancing the care of patients through evidence-informed practice. As part of the programme, we appointed research leads at the Marie Curie Hospices in Belfast, Edinburgh, West Midlands and most recently, Glasgow.

Our research leads



Trevor Smeaton/Marie Curie

Dr Anne Finucane at the Marie Curie Hospice, Edinburgh has raised awareness of research amongst clinicians and carers. She has also strengthened ties with local academic institutions to ensure research helps

“The research lead plays a vital role in engaging clinicians in research design and the implementation of evidence-based practice. Working closely with universities, we ensure that all research involving the hospice is of the highest quality. This has important benefits for people with a terminal illness as well as their families.”

Dr Anne Finucane, research lead, Marie Curie Hospice, Edinburgh

meet the needs of patients and their families at the end of life. As an Honorary Fellow at the University of Edinburgh, her work includes research relating to palliative care in care homes, carer experience, eHealth, and evaluating national palliative care initiatives across Scotland. Dr Finucane contributed to a project to help identify carers in primary care (see Case study 5: Identifying carers in primary care).



Richard Dyson

Before taking on the new role of research lead at the Marie Curie Hospice, Glasgow in 2015, **Dr Emma Carduff** was interim lead at the Marie Curie Hospice, Edinburgh. She has helped guide research, which has successfully informed carer legislation in Scotland (see case study 5: Identifying carers in primary care) By working closely with medical and hospice staff, Dr Carduff has helped build a strong research culture within the hospice. As research lead at the Marie Curie Hospice, Glasgow, Dr Carduff facilitates research that is clinically relevant, and meaningful to patients, carers and staff.



Trevor Smeaton/Marie Curie

Dr Kathy Armour at the Marie Curie Hospice, West Midlands has encouraged a diverse portfolio of research projects which has involved 250 patients, families and professionals over four years. Making use of her scientific experience, Dr Armour is mentoring doctors, nurses and staff about research. She is also working closely with the University of Birmingham, in particular with Professor Joanna Coast on her project about the economics of end of life care (see Case study 6: Economics of end of life care).



Trevor Smeaton/Marie Curie

Dr Noleen McCorry oversees research students and provides support and mentoring to hospice staff. She also leads on research into the psychosocial wellbeing of patients, carers and staff. Her research has led to new practices at the hospice, such as quality of life and psychological needs assessments. An honorary research fellow at Queen's University Belfast, Dr McCorry is also supervising research into a psychological intervention to aid staff wellbeing.

“Investing in end of life care research is so important – it has to ask the right questions, involve our patients and stand on its own two feet to really make a difference to how we carry out clinical practice. Without investment, we risk losing that momentum.”

Dr Kathy Armour, research lead at the Marie Curie Hospice, West Midlands

Case study 5: Hospice and university collaboration – identifying carers in primary care

Funded by the Dimbleby Marie Curie Research Fund, Professor Scott Murray at the University of Edinburgh set out to explore better ways for health and social care services to identify carers. He worked with the Marie Curie Hospice, Edinburgh, NHS Lothian, and Voices of Carers Across Lothian.

The study found that carers often prefer to think of themselves as a wife or a son rather than a ‘carer’, which can mean they don’t ask for help until they are struggling. Carers can become overwhelmed, managing both their own wellbeing and that of the person they are looking after. GPs and nurses should be alert to asking their patients if they have a relative with a serious illness. Given the appropriate support,

carers will experience greater personal empowerment that will in turn increase the quality of care they provide.

The research findings have been used to inform Marie Curie’s response to the Scottish Government’s proposed Carers (Scotland) Bill and were promoted to Members of the Scottish Parliament (MSP) through a motion of support by MSP Michael McMahon. MSPs received a parliamentary briefing highlighting the key findings from the study.

Following Marie Curie’s engagement with MSPs, the Scottish Government has committed to amending the Bill so that the newly proposed adult carers support plans, which all carers will be entitled to, will be fast-tracked for those caring for people with a terminal illness.

The team’s work led to media coverage across Scotland, including features in *The Scotsman* and *The Herald* newspapers.

Dr Emma Carduff, who was the lead researcher on the study, is now research lead at the Marie Curie Hospice, Glasgow.

Left to right:
Dr Emma Carduff,
Professor Scott
Murray and
Dr Anne Finucane



Case study 6: Hospice and university collaboration – economics of end of life care

Research at the Marie Curie Hospice, West Midlands investigated how economists can make better assessments of end of life care, to ensure health providers make informed decisions about people's needs.

People living with a terminal illness, their loved ones, and hospice staff took part in the research, which was led by Professor Joanna Coast at the University of Birmingham and funded by the European Research Council. The study considered seven factors that are important to people receiving end of life care, including having a say in their care, being with people who care about them, and having help, support and dignity. Patients at the

Marie Curie Hospice, West Midlands and their family members answered questionnaires including a 'supportive care measure' based on the seven key factors, developed by researchers at the university, and reported positive feedback on the questions asked.

The study showed that patients and those around them felt the supportive care measure questionnaire captured important aspects of end of life care. Although further work is needed to see how the measure works in other settings, this first evidence suggests that it will be helpful in providing a short, simple measure for capturing the benefits of end of life care for use in evaluating different interventions.

Professor Joanna Coast (far left) with members of the advisory group in May 2012





4. Research engagement

4.1 Marie Curie Annual Research Conference

Professor Gunn Grande and other researchers at the Marie Curie Annual Research Conference in 2014

In 2014, Marie Curie hosted its 9th Annual Research Conference jointly with the Royal Society of Medicine's Palliative Care Section. Entitled 'Palliative care in the community – making a difference in practice', the conference highlighted the research being carried out to improve palliative care in community settings. It focused on research into

quality of care and the experiences of end of life care at home, by community care teams and in care homes. More than 300 delegates attended.

Two awards are presented at the Marie Curie conference every year – the Susie Wilkinson Award and the Joanna Mugridge Research Awards.



Trevor Smeaton/Marie Curie

4.2 Susie Wilkinson Award

Dr Susie Wilkinson
(left) with Rachel Perry



Trevor Smeaton/Marie Curie

The Susie Wilkinson Award was established in recognition of Dr Susie Wilkinson's contribution as head of the Marie Curie Palliative Care Research Department, London. Dr Wilkinson established the original centre at the Royal Free Hospital in London, in 1999.

The award is presented at the Marie Curie Annual Research Conference. It acknowledges and supports a member of Marie Curie staff who has made significant personal progress in developing their research capacity. It is particularly aimed at Marie Curie Healthcare Assistants, Allied Health Professionals and Nurses.

In 2014, the £1,000 prize for professional development was awarded to Rachel Perry, a staff and research link nurse at the Marie Curie Hospice, West Midlands.

4.3 Joanna Mugridge Research Award

Vivien Mugridge with
Rita Doyle (left) and Dr
Jonathan Totman



Trevor Smeaton/Marie Curie

Joanna Mugridge worked as a nurse at the former Marie Curie Hospice in Caterham, Surrey. When she died in May 2000, her family created the Joanna Mugridge Research Award in her memory.

It is awarded in open competition to the best work on display at the conference, supporting the education and development of young researchers.

Due to the outstanding quality of posters, the 2014 judges – Dr Chris



Trevor Smeaton/Marie Curie

Barton from the Royal Society of Medicine and Dr Kathy Seddon from the Research Expert Voices Group – awarded a joint first prize. The first winner was Rita Doyle from the Marie Curie Palliative Care Institute, Liverpool, for her poster 'A living community presence: training of end of life care volunteers'. The second winner was Dr Jonathan Totman from University College London, with his poster 'You only have one chance to get it right: caring at home for a family member with terminal cancer'.

5. Looking ahead

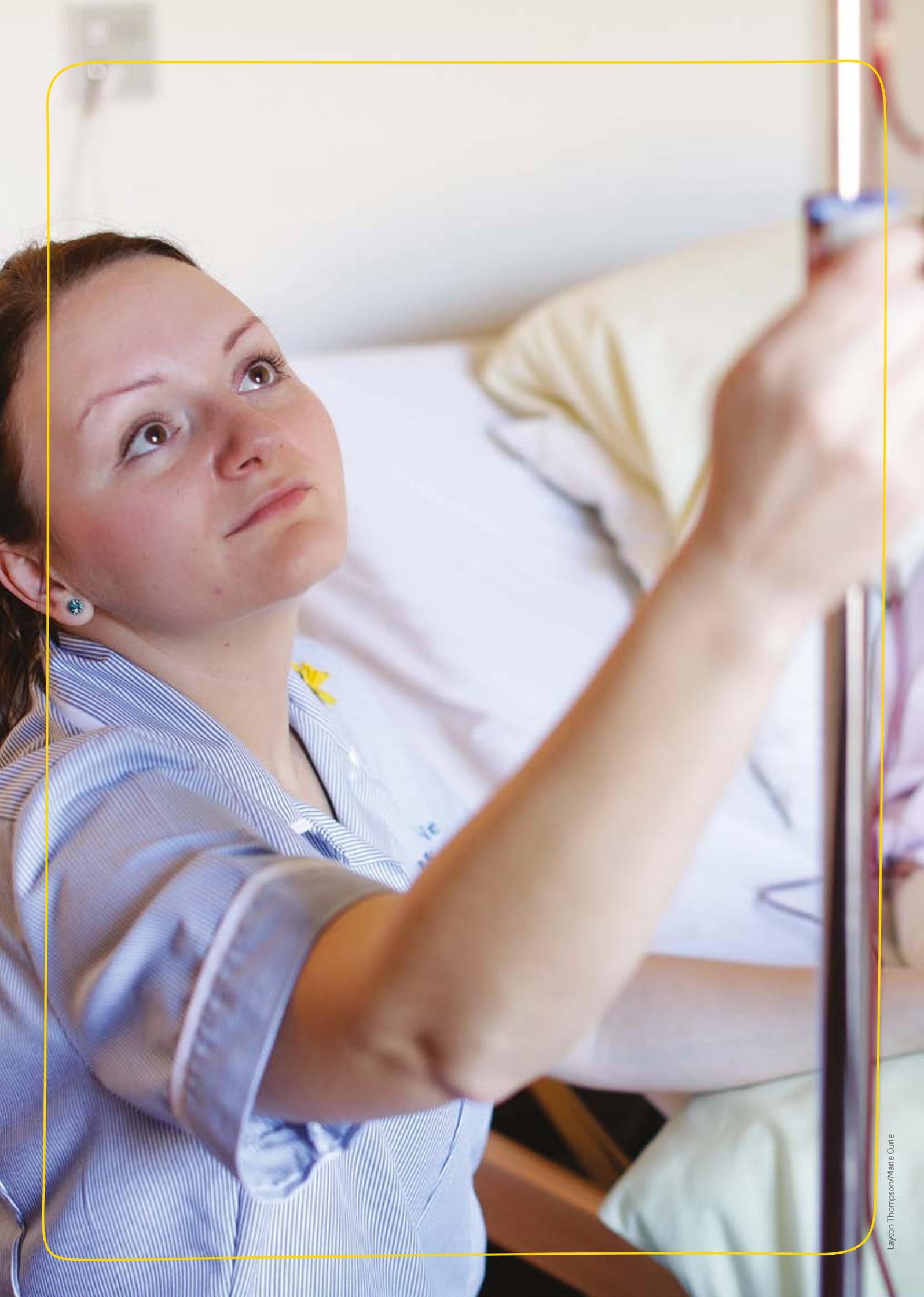
Despite the progress we've made over the past few years, funding for palliative and end of life care research remains too low. Over the next five years, we aim to double our investment in research for people living with a terminal illness – with cancer and non-cancer conditions – and we will use our influence to encourage other funders to invest in this area too.

We will:

- Continue to **analyse the huge data set of responses from carers, patients and health and social care professionals** collected through the Palliative and end of life care Priority Setting Partnership (PeolcPSP) with the James Lind Alliance, working with our Palliative Care Research Centre at Cardiff University to analyse the 'out of scope' data from the PeolcPSP to **ensure all participants' voices are heard**.
- Help Marie Curie policy and public affairs teams across the country to **ensure relevant research findings influence the policy environment**.
- Continue to **disseminate findings widely to maximise impact** on practice.
- **Make all research funded by Marie Curie openly accessible to all**, not just researchers.

- **Increase research activity in our hospices**, building on our successful research lead programme and establishing a new position at our Bradford Hospice, in collaboration with Bradford University.
- Start working on a more detailed research strategy, looking at **potential new funding mechanisms to support palliative and end of life care** in the UK – involving our Research Expert Voices closely in this process as well as our Research Strategic Advisory Committee.
- Continue to **work in partnership with other organisations**, for example through the UK end of life care Research Interest Group, to raise the profile of palliative and end of life care research and address the lack of evidence in this area.

We know that by investing in our palliative care research centres, research leads and project grants we can strengthen the evidence base for palliative and end of life care research and build capacity to support the next generation of palliative and end of life care researchers. **Overall, our guiding vision remains a better life for people living with a terminal illness and their families.**



Authors

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Research Funding Committee

Professor Tim Peters (chair), Professor Ala Szczepura, Dr Anthony Byrne, Professor Carlos Centeno Cortés, Professor Joanna Coast, Professor Marie Fallon, Professor Matthew Hotopf, Dr Kerina Jones, Dr

Jonathan Koffman, Professor John Norrie, Professor Stephen Peckham, Professor Jane Seymour, Professor Stephanie Taylor, Professor Kate O'Donnell, Carol Bridge (REVG), Helen Findlay (REVG), Professor Sarah Purdy, Professor Naomi Fulop, Professor Stein Kaasa, Professor Tim Maughan, Professor Mike Bennett, Professor Brendan McCormack, Professor Julian Hughes, Professor Sir Andy Haines, Professor Henry McQuay, Professor Ann Netten, Professor Phil Hannaford, Professor Henk ten Have, Professor Sandy Oliver, Professor Ruud ter Meulen.

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).

Dimbleby Marie Curie Research Fund Advisory Committee

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Abbreviations

AIIPHC All Ireland Institute of Hospice and Palliative Care

AMRC Association of Medical Research Charities

CAT Cancer Associated Thrombosis

CSO Chief Scientist Office

JLA James Lind Alliance

MND Motor Neurone Disease Association

NCRI National Cancer Research Institute

NHS National Health Service

NIHR National Institute for Health Research

NICE National Institute for Health and Care Excellence

PPI Public and Patient Involvement

REVG Research Expert Voices Group

UCL University College London

WHO World Health Organisation

Marie Curie Research Centres:

MCPCRD Marie Curie Palliative Care Research Department, London

MCPCRC Marie Curie Palliative Care Research Centre, Cardiff

MCPCIL Marie Curie Palliative Care Institute, Liverpool

Appendix 1

List of publications* arising from Marie Curie research funding in 2014

- Adamson, D. et al., 2014. Palliative radiotherapy in addition to self-expanding metal stent for improving dysphagia and survival in advanced oesophageal cancer (ROCS: Radiotherapy after Oesophageal Cancer Stenting): study protocol for a randomized controlled trial. *Trials*, 15, p.402. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/25336193>
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