



# Delivering impact: palliative and end of life care research

**Marie Curie research impact report 2016/17**

Improving care and support for people affected  
by terminal illness in the UK through research



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# Welcome



Trevor Smeaton/Marie Curie

In the UK, more people are living longer and to an older age than ever before. The number of people living with multiple conditions and more complex needs is expected to rise too, resulting in a greater demand for care.

As the largest charitable funder of palliative and end of life care research<sup>1</sup>, we are committed to meeting this challenge. One way we are doing this is by investing in this important and under-represented area of care. Since 2002, funding for palliative and end of life care research in the UK has remained consistently below 0.7% of the total spent on cancer research<sup>2</sup>. The same under investment can also be seen in general health-related research<sup>1</sup>.

At Marie Curie, we are focusing our investment on the questions that need addressing, making the findings of our research more widely available and using these to influence not only our own practices, but also inform clinical guidelines.

This is helping to improve the care and support we deliver to people at the end of life, as well as their carers, families, friends and communities. In 2016, we saw research we have funded make the front page of *The Times*. Our policy work on end of life care for the LGBT community is helping to shape our own services in hospices as well as inform and influence decision-making in the four nations. Research we have funded on lung disease was endorsed by the National Institute for Health and Care Excellence (NICE), which provides national guidance and advice to improve health and social care.

By continuing to build partnerships with other charitable research funders we can expand the scope of our research to meet the care and support needs of those affected by all terminal illnesses.

## **Dr Jane Collins**

Chief Executive, Marie Curie

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1 Data taken from the UK Health Research Analysis 2014 (UK Clinical Research Collaboration, 2015).  
2 Marie Curie's palliative and end of life care cancer research spend, Marie Curie and National Cancer Research Institute (NCRI), 2015.

# Foreword



Pete Jones/Marie Curie

I am delighted to share our research impact report for 2016/17. This report describes the strides we have made in generating new knowledge, while supporting scientists and clinicians to build their expertise in palliative and end of life care research.

We aim to focus on studies that will have practical importance to people affected by any terminal illness. Our analysis of the palliative and end of life care research landscape has described where resources are being invested and where uncertainties remain. This has allowed us to identify the questions that need answering and allocate our funding to close evidence gaps.

Thanks to partnerships with the Motor Neurone Disease (MND) Association and Chief Scientist Office (CSO), Scotland in 2016/17, we have funded research and projects that may change

clinical practice in MND, while adding to palliative care research capacity north of the border.

We also appointed a new professor in palliative medicine and another in palliative care at the Marie Curie Palliative Care Research Centre in Cardiff. We were pleased to award further funding for the centre following their independent quinquennial review. In partnership with the Royal College of General Practitioners (RCGP) we have offered our first joint fellowship for research in palliative and primary care.

This year, we started an ambitious new strand of work, our Marie Curie Design to Care programme. It brings together patients, carers, designers, clinicians, engineers and researchers to create and test a new system of palliative care, capable of meeting the growing need for care in the whole range of terminal illness.

By filling gaps, testing interventions and involving patients, carers and health professionals in partnership, our research is helping to influence practice and ensure people with terminal illness, their carers, families and friends receive the right support at the end of life.

## **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 2016/17, we identified the **gaps in palliative and end of life care research** and the areas where investment is still needed. **See page 9**
- In 2016, we announced our largest call for research **in partnership with the MND Association and CSO, Scotland. See page 10**
- We **awarded nine grants to researchers** across the UK to address the priorities identified by carers, health and social care professionals and people living with a terminal illness. **See page 13**
- Our **Marie Curie Palliative Care Research Centre, Cardiff University was successful in its bid for further funding** following an independent review. **See page 15**

## 2016/17 facts and figures

### We produce research through our...



UCL

**3**

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



Pete Jones/Marie Curie

**£1m**

Annual funding for research project grants awarded in open competition



Pete Jones/Marie Curie

**5**

Research leads across our nine hospices

### influenced by...



Marie Curie

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



- We awarded a **new fellowship for research in palliative and primary care** in collaboration with the RCGP. [See page 17](#)
- Our research lead programme is helping to **strengthen a research active culture**, for instance at our Marie Curie Hospice, Belfast. [See page 17](#)
- We launched **Design to Care** – an ambitious programme that aims to create a new type of palliative and end of life care service. [See page 24](#)
- Over **2,000 patients, carers, staff and members of the public were recruited to our research studies**. [See page 25](#)
- Our funding led to **80 papers being published in peer-reviewed journals**. We helped make 64 (80%) of these freely available. [See page 27](#)
- Our research continues to **inform and influence policy and practice**. [See page 29](#)
- Our funding is helping to **build capacity in palliative care research**. [See page 34](#)
- We **disseminate research findings widely** and engage the public through the media. [See page 35](#)
- Marie Curie and the researchers we fund **involve patients, carers and the public** in research. [See page 37](#)

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



**80**

Papers in peer-reviewed journals – 64 (80%) were open access



**74**

Instances of informing policy and practice



**2,623**

People recruited to our studies



**£2m+**

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

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

# 1 Research highlights and achievements in 2016/17

**Research is vital to improve the way care is delivered to those living with a terminal illness. It has the potential to significantly influence how care and support is provided to help people live as well as possible for as long as possible.**

At Marie Curie, we invest in high-quality palliative and end of life care research to address existing evidence gaps, build research capacity and strengthen the knowledge base. Research in this important area, however, remains

significantly underfunded. As the largest charitable funder of research in palliative and end of life care, we are working to ensure those funds address the questions that matter the most (see Box 1).



Ben Gold/Marie Curie

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3 Does current palliative and end of life care research match the priorities of patients, carers and clinicians? A grant mapping analysis of the UKCRC's Health Research Classification System dataset 2014, Marie Curie 2015.



### Box 1: Does current palliative and end of life care research match the priorities of patients, carers and clinicians?

In 2016/17, we conducted an analysis to identify the gaps in palliative and end of life care research. This involved mapping publicly available health-related research grant data to the 83 questions identified by the Palliative and end of life care Priority Setting Partnership (PeolcPSP). The PeolcPSP was initiated by Marie Curie and supported by a total of ten research funding organisations. It invited patients, carers and health and social care professionals to share the questions they felt research most needed to answer. The number one priority identified asked, ‘What are the best ways to provide palliative care outside of working hours?’

The UK Clinical Research Collaboration (UKCRC) Health Research Classification System captures information on £2 billion of UK health-related research project funding from government and charity sources. Using data from 2014 and the PeolcPSP priorities, we

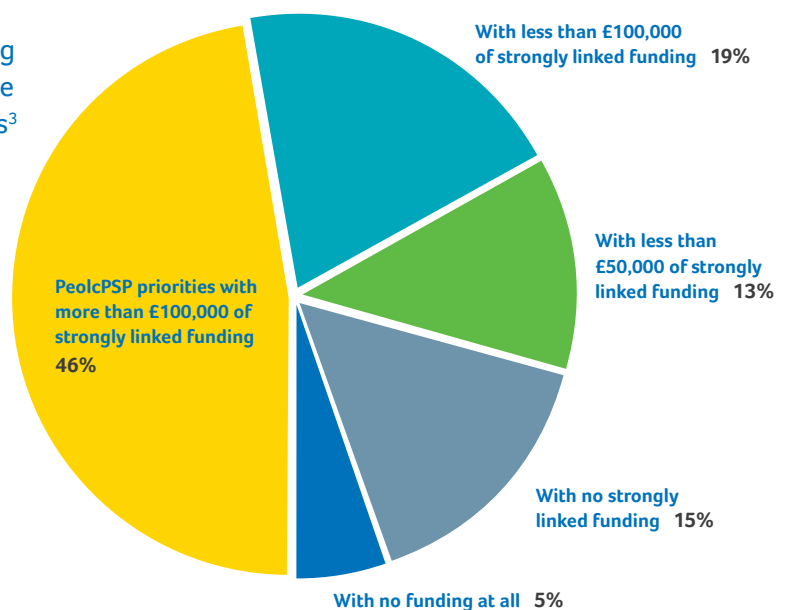
identified the extent to which current research is addressing the priorities that matter to patients, carers and health and social care professionals.

This information is important, not only for highlighting gaps in research but to reduce waste, cost and patient burden, guide research funders and future funding calls, encourage collaboration and show where research outcomes have the potential to be put into practice.

#### What the findings show

More research is needed to fully address the 83 PeolcPSP questions. In particular, research is needed, for instance, on bereavement, providing care outside of working hours, support for carers and how to ensure continuity of care in palliative care. The full report is available at [mariecurie.org.uk/research/reports](http://mariecurie.org.uk/research/reports).

The amount of funding with strong links to the 83 PeolcPSP questions<sup>3</sup>



## 1.1 New partnerships help address key research priorities in palliative and end of life care

In 2016, we announced the recipients of our largest open call for research to date – a joint funding initiative between Marie Curie, the MND Association and CSO, Scotland. Together we made £1,425,000 available, calling for

research to address the 83 questions in palliative and end of life care identified through our PeolcPSP with the James Lind Alliance. See how we're helping to improve care at the end of life for people with MND in Box 2.



### Box 2: Research to improve care and support for people with motor neurone disease

MND is a terminal, rapidly progressing disease. It is a neurodegenerative disorder that affects the brain and spinal cord, and attacks the nerves that control muscle movement. Despite its rapid progression, palliative care is often neglected as an approach for people with MND.

In 2016, Marie Curie, together with the MND Association, awarded funding to three projects addressing different aspects of care for people with MND. Researchers at the University of Manchester and the University of



Pete Jones/Marie Curie

Left to right: Dr Kirsten Kelly, Research Programmes and Partnerships Manager, MND Association, Dr Sabine Best, Head of Research, Marie Curie, Dr Belinda Cupid, former Head of Research, MND Association.



Katie Hyams/Marie Curie

Cambridge are helping to deliver better support to family carers of people with MND. At the University of Sheffield, researchers are addressing the problem of excessive saliva in MND patients, which is currently poorly treated. The need for more research on managing excessive saliva was highlighted in a recent NICE guideline for MND. A third study at the University of York aims to develop a more complete picture of the needs of people with MND and their carers.





“Thanks to our partnership with Marie Curie we can invest in research that ensures quality health and care at the end of life for people with MND. I am delighted to be continuing to work together with Marie Curie to fund high-quality research that could make a huge difference to so many people.”

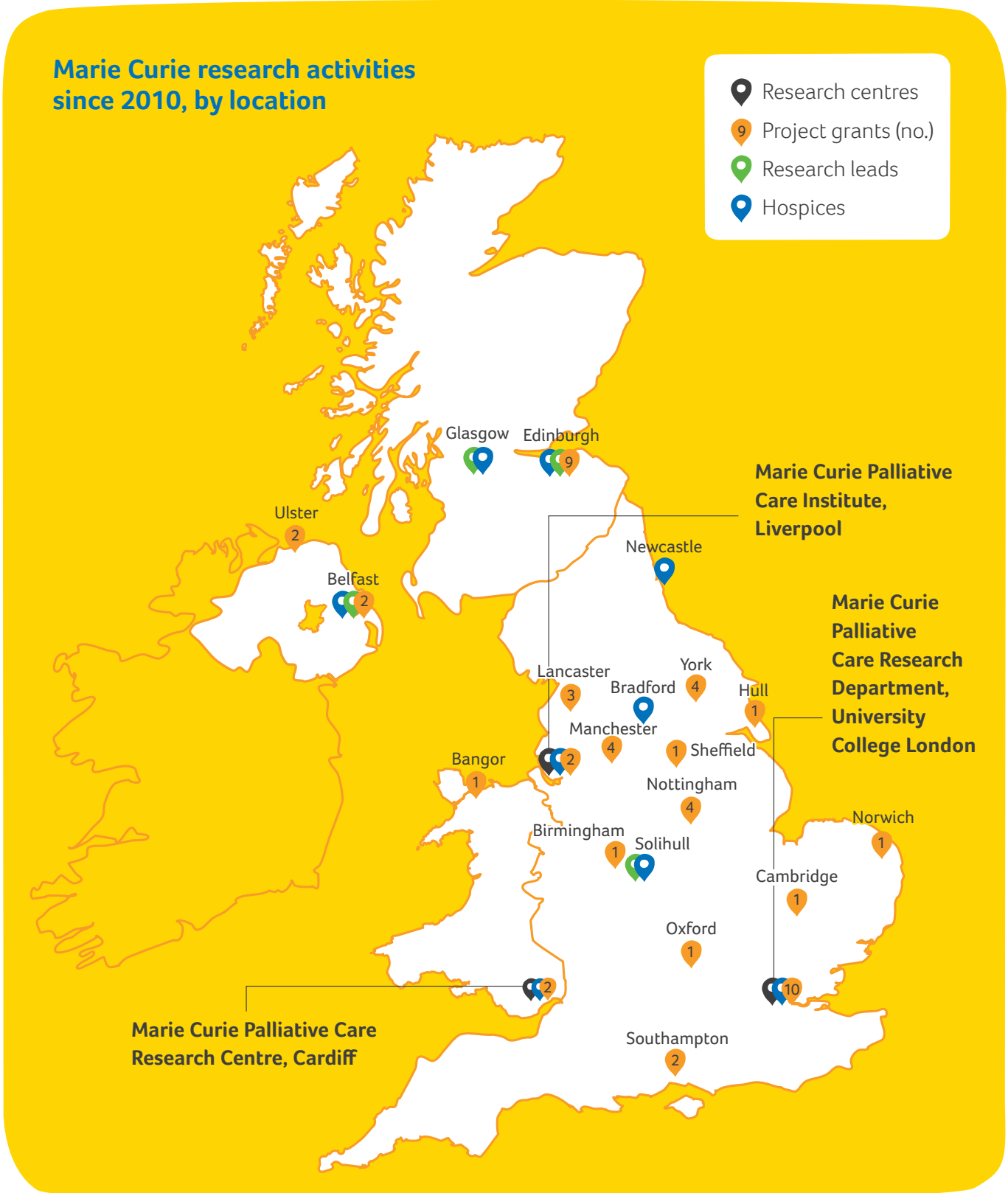
Dr Kirsten Kelly,  
Research Programmes and Partnerships Manager,  
MND Association

## 1.2 New research projects in 2016/17

In 2016, we awarded nine new grants through our annual open and competitive research grants scheme in partnership with the MND Association and CSO, Scotland.

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

-  Research centres
-  Project grants (no.)
-  Research leads
-  Hospices



## Projects funded by Marie Curie

<p>Professor Richard Harding and Dr Katherine Bristowe <b>King's College London</b></p>	<p>ACCESSCare II – bereavement outcomes for LGB and heterosexual bereaved partners: a population-based cross-sectional mixed methods study.</p> <p>This study aims to investigate what factors may influence bereavement outcomes for people who have lost a partner or spouse. It will explore whether there is a difference in bereavement outcomes for LGB and heterosexual partners and how their access to services and experiences may differ.</p>
<p>Dr Karen Shaw <b>University of Birmingham</b></p>	<p>A multi-perspective qualitative study to understand the experience and impact of the Child and Young Person's Advance Care Plan (CYPACP).</p> <p>There is little evidence evaluating the CYPACP and its benefits to families. This study aims to address this gap by examining how it is used by families and healthcare professionals.</p>
<p>Dr Bridget Candy <b>University College London</b></p>	<p>The effectiveness in alleviating pain, anxiety and enhancing wellbeing, and the expectations and experiences of palliative care patients of aromatherapy, massage and reflexology: A multi-level synthesis.</p> <p>This study aims to explore whether and how aromatherapy, massage and reflexology make a difference to the wellbeing of patients in palliative care.</p>
<p>Dr Morag Farquhar <b>University of East Anglia</b></p>	<p>Accessing and delivering person-centred care in advanced non-cancer conditions: developing and testing a Support Needs Approach for Patients (SNAP) with advanced COPD.</p> <p>SNAP is a new approach to enabling person-centred care, giving patients a tool to help them identify and express their support needs, and discuss these with healthcare professionals. The study aims to validate the tool and investigate its use in a range of clinical settings.</p>

## Projects funded by Marie Curie and the MND Association

<p>Professor Christopher McDermott <b>University of Sheffield</b></p>	<p>A prospective observation of secretion problems in MND (ProSec).</p> <p>This study aims to provide a comprehensive understanding of how common problems with saliva are in people with MND, and how they are currently treated. These findings will provide better knowledge of the tolerability and side effects of treatment options and help to identify a way to assess secretion problems and evaluate treatments.</p>
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Dr Kate Flemming  
**University of York**

The palliative care needs of people with MND and their informal care givers.

This study aims to explore the palliative care needs of adults with MND and their informal carers, or bereaved carers of people with MND. By identifying the gaps in existing research, this project will help to develop a more complete picture of the palliative care wants and needs of people with MND and their carers.

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Professor Gunn Grande  
**University of Manchester**  
and  
Dr Gail Ewing  
**University of Cambridge**

Enabling tailored and coordinated support for family carers of people with MND through adaptation of a Carer Support Needs Assessment Tool (CSNAT) Intervention.

This qualitative study builds upon an existing intervention (CSNAT) to help deliver better support to family carers of people with MND. The study aims to develop the tool to suit people with MND and help doctors identify the support needs of those caring for people with MND.

### Projects funded by Marie Curie and CSO, Scotland

Professor Scott Murray  
**University of Edinburgh**

Supporting people with palliative and end of life care needs “out of hours”: a mixed-methods study of needs, demands and experiences to inform person-centred service developments.

Using a mixed methods approach, this study will investigate how out of hours services in Scotland are used by people in their last year of life, and their carers. These findings will help to inform the re-design of proposed changes to health and social care delivery outside of working hours.

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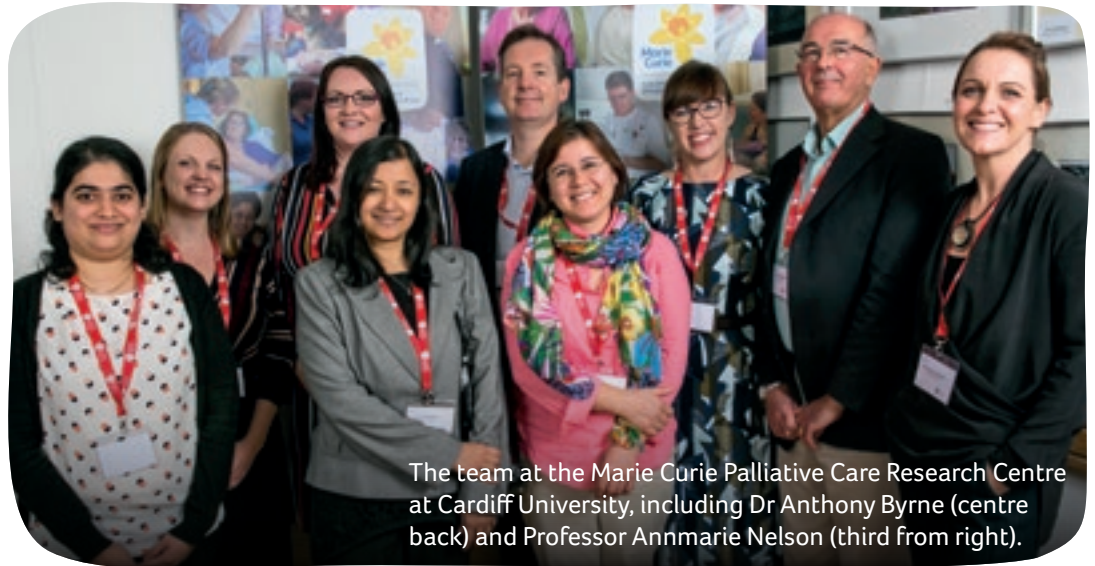
Professor Marie Fallon  
and  
Dr Barry Laird  
**University of Edinburgh**

ENeRgy: Exercise and Nutritional Rehabilitation in patients with advanced cancer: a single centre, randomised (1:1), open label, feasibility study of a rehabilitation programme (exercise and nutrition) versus wait list control, in patients with advanced cancer.

This clinical trial aims to investigate whether exercise and a nutrition based rehabilitation programme can improve the quality of life of patients with advanced cancer in hospices.



## 1.3 Further funding for the Marie Curie Palliative Care Research Centre, Cardiff



Peter Jones/Marie Curie

The Marie Curie Palliative Care Research Centre at Cardiff University conducts high-quality research that is focused on patient and carer experience and capable of informing and changing how care is delivered.

In 2016, funding of the Cardiff research centre was renewed for a further five years following independent peer review. Over the next five years, the Cardiff research centre will collaborate with national and international partners to expand its portfolio with a particular focus on patient and carer experience, late effects of treatment, palliative rehabilitation, and venous thrombotic events in advanced disease. The centre has expertise in a range of research methodologies including innovative evidence synthesis, qualitative and mixed methodological studies, national surveys and clinical trial design and implementation.

Another of the centre's strategic commitments is to support research capacity building across disciplines and care settings. This is being achieved through the development of the centre's academic leadership, with the aim of gaining grants and expanding infrastructure to support the personal and professional development of the team.

In 2017, **Professor Annmarie Nelson** was promoted to a personal chair in the School of Medicine, Cardiff University as the Marie Curie Professor of Supportive and Palliative Care. This recognises her expertise in patient and carer experience and clinical trials. She is one of only a small number of non-clinical Professors within the School.



**Professor Simon Noble**, above, leads on the theme of thrombosis. He became the research centre's first Clinical Chair in 2017. His role of Professor of Supportive and Palliative Medicine acknowledges his significant national and international influence on practice in the experience and management of thrombosis in people with advanced cancer.

**Dr Anthony Byrne**, Clinical Director, also leads one of the four research themes at the Wales Cancer Research Centre (WCRC), funded by the Welsh Government. As a result, the Marie Curie research centre hosts a team of five staff working to further the supportive care of patients with advanced cancer, including social care. Dr Byrne is also leading on integration of supportive and palliative care within Cardiff University's integrated cancer research strategy – key to future, sustainable capacity building.

Having established new posts with Wales Cancer and Palliative Care clinical implementation groups and the

WCRC, the centre is also developing a knowledge transfer platform which is capable of supporting implementation change. One initiative to reach multi-professional clinical audiences and demonstrate the utility of research is the Palliative Care Evidence Review Service: PaCERS (see section 2.5).

Alongside this, Dr Anthony Byrne, Professor Annmarie Nelson and Professor Simon Noble, with UK and international collaborations, are continuing to develop new areas of supportive and palliative care including:

- Patient experience, including Public and Patient Involvement in research – exploring what patients and carers think of the treatments being investigated through clinical trials, their personal involvement in studies, and the treatments or care they are receiving
- Rehabilitation (restoring function) and cachexia (weight loss) – considering how best to help patients keep as much physical function and independence as possible, for as long as they can
- Thrombosis (blood clots) – looking for new ways of finding out how important this problem is in palliative care and what may help.

## 1.4 New RCGP Marie Curie Fellowship awarded in palliative and primary care

We announced our first joint fellowship with the RCGP in 2016. The fellowship, which aims to bring palliative and end of life care to the forefront of primary care research, was awarded to **Dr Huw Williams**, a Clinical Research Fellow at Cardiff University and GP Partner at Westway Surgery, Cardiff.

Dr Williams is using the £40,000 grant to identify learning from patient safety

incident reports involving out-of-hours palliative care and to use these lessons to engage a stakeholder group to identify local priorities for improvement. He is then developing and evaluating initiatives that will lead to increased awareness of patients' preferences and treatment goals among out-of-hours providers.



“ I am delighted to receive this fellowship. My colleagues and I are excited at the opportunity this provides and are in the process of identifying local partners to implement and evaluate our ideas.”

Dr Huw Williams,  
RCGP Marie Curie Fellow, Cardiff University

## 1.5 Strengthening a research culture: Marie Curie Hospice, Belfast

Staff at the Marie Curie Hospice, Belfast are creating a research culture that is helping to improve the care and support delivered to people and their families at the end of life.

**Dr Lisa Graham-Wisener**, who oversees research activities at the hospice, is working with Queen's

University Belfast, Ulster University, research active Marie Curie Hospices in West Midlands and Edinburgh as well as non-Marie Curie hospices throughout the UK to facilitate research in a range of areas. These areas include finding ways to help manage cachexia in patients with cancer, evaluating the cost effectiveness of palliative

care day services and identifying how best to measure quality of life and psychological distress in palliative care.

Dr Lisa Graham-Wisener also collaborates with Dr Noleen McCorry who was first to develop and facilitate research at the hospice for five years prior to Lisa joining. She is now Lecturer in the School of Medicine, Dentistry and Biomedical Sciences at Queen's University Belfast.

### Involving patients and staff



Marie Curie

From left to right; Dr Tracey McConnell, Queen's University Belfast, Dr Lisa Graham-Wisener, Jenny Kirkwood, Every Day Harmony, Paula Bradley, Grace Watts, British Association for Music Therapy, Conall Dunlop, Every Day Harmony and Professor Joanne Reid.

The Marie Curie Hospice, Belfast, has been involved with research into the effectiveness of music therapy in improving the quality of life of palliative care patients. Between May 2016 and June 2017, Professor Joanne Reid from Queen's University Belfast and Professor Sam Porter from Bournemouth University led a pilot study involving more than 50 patients from the hospice.

In collaboration with the hospice team and the music therapy charity Every Day Harmony, music therapy sessions were delivered to patients to understand its benefits on their quality of life. The study highlighted the value of creative and holistic approaches for patients with palliative care needs. Dr Graham-Wisener and colleagues presented the findings at a Marie Curie policy event in Stormont, the home of the Northern Ireland Assembly, in October 2017. The seminar was attended by a wide range of stakeholder groups, departmental officials, health and social care representatives as well as Paula Bradley, Member of the Legislative Assembly, calling for better integration of such services across the UK.

Staff at the Belfast hospice are also helping to build capacity in palliative and end of life care by supporting students. Rebecca Hill, a PhD student at Queen's University Belfast, led research at the hospice to understand the potential benefits of mindfulness for staff who provide palliative care. Members of staff took part in a two-day mindfulness intervention in February 2017, facilitated by a clinical psychologist. The results were compared with staff from the Marie Curie Hospice, Edinburgh and showed that mindfulness can help to develop resilience, self-compassion and coping skills in palliative care staff.

Marie Curie Hospice, Belfast, is also working in collaboration with Ulster University on a project to help healthcare providers better manage

the issue of constipation, which can cause considerable suffering for people with long-term conditions or terminal illness. Professor Sonja McIlpatrick, who was awarded Marie Curie funding in 2015, is working with staff at two other hospices (Marie Curie Hospice, West Midlands and Marie Curie Hospice, Edinburgh) alongside Marie Curie Hospice, Belfast. The research, which aims to better understand the management of constipation from the perspective of patients, carers and healthcare professionals, involved 28 patients, carers and staff from the Belfast hospice. The findings will be used to develop an educational intervention that will be piloted in 2018 with Marie Curie nurses, doctors and pharmacists in the three hospices.

Marie Curie Hospice, Belfast also co-funded a research studentship with Queen's University Belfast in which two undergraduate medical students visited the hospice for eight weeks. The students were involved in

a project to assess the adequacy of community-based services available in Northern Ireland to meet the multidimensional needs of patients living with symptomatic heart failure, as experienced and perceived by GPs. Twenty interviews were conducted with GPs from each of the Health and Social Care Trust areas in the region.

The findings suggest that health and social care services in Northern Ireland have not adapted to assess and meet the needs of heart failure patients, with a key finding being a lack of understanding of specialist palliative care services. There is an important need for inter-professional collaboration on service planning, education and communication strategies between cardiology, specialist palliative care and general practices. Findings were presented at a conference on 'Palliative Care Beyond Cancer' in November 2017, organised by the Policy team at Marie Curie Northern Ireland.



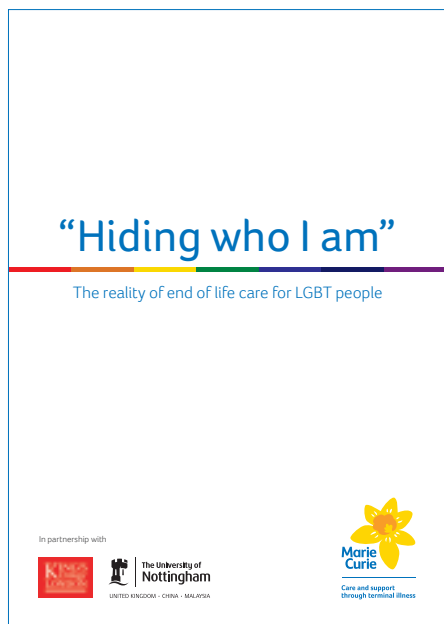
Marie Curie

“ I am pleased to see patients, carers and staff being involved in research to improve the management of constipation – a common and distressing symptom. Working in close collaboration with Ulster University and colleagues at three Marie Curie Hospices, I look forward to seeing the outcomes of this important study.”

Dr Lisa Graham-Wisener,  
Research Lead, Marie Curie Hospice, Belfast



## 1.6 Hiding Who I Am: the reality of end of life care for LGBT people



Research funded by Marie Curie on end of life care for sexual and gender minorities has been used to inform policy and improve practice.

**Professor Richard Harding** leads the ACCESSCare project at the Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, King's College London. This aims to develop and disseminate evidence-based resources for the lesbian, gay, bisexual and/or trans (LGBT) communities. Research has shown LGBT people experience significant barriers to palliative care when they need it. ACCESSCare aims to increase the demand for appropriate end of life care among LGBT people and improve delivery through relevant and informative end of life care training for professionals and resources for LGBT people.

The study, which was based on interviews with lesbian, gay, bisexual or trans people nearing the end of life, their caregivers as well as bereaved caregivers from across the UK, shows that healthcare professionals need to make changes to their practice to improve the care experiences of LGBT people facing advanced illness.

### Influencing policy

In June 2016, the Marie Curie Policy and Public Affairs team launched a policy report highlighting the barriers to care faced by the LGBT community. 'Hiding Who I Am: the reality of end of life care for LGBT people' draws on the findings from ACCESSCare, as well as Marie Curie-funded research from Dr Kathryn Almack at the University of Nottingham, now at the University of Hertfordshire. The report included the results of a survey of staff across Marie Curie hospices to better understand how LGBT needs and concerns are perceived



Dr Katherine Bristowe from the ACCESSCare team, King's College London

Pete Jones/Marie Curie



and how supported staff members feel in addressing any relevant issues. The results showed Marie Curie staff have positive attitudes, acceptance and respect for the choices of LGBT people but do not always recognise they may have specific needs, particularly relating to fears of discrimination.



Pete Jones/Marie Curie

Professor Richard Harding

The report received significant media coverage, appearing in over 120 print and online news articles. Professor Harding presented at a policy event at Portcullis House, Westminster, organised by Marie Curie in December 2016. The seminar was sponsored by MP Stuart Andrew and attended by MPs including the former Shadow Care Minister. Professor Harding was supported by a panel of practitioners, academics and decision makers as well as trans activist Jenny-Anne Bishop to discuss the role everyone can play in improving end of life care for LGBT people. The research team recently published a set of recommendations to help improve care for LGBT people facing advanced illness (see Box 3), which gained significant media interest.

“I always talk in terms of ‘those who are important to you’ as opposed to ‘family’ so I am open to that being whoever it is. The key for me is asking the patient.”

Marie Curie Hospice staff member

### Improving practice

The report, alongside dissemination events and the Care Quality Commission ‘A Different Ending’ report published earlier in 2016, has brought the issue of inequality in care delivery for LGBT people with advanced illness to the attention of policy makers, healthcare professionals and the public. A question posed by Andrew Percy MP to the Secretary of State for Health and Social care was raised in UK Parliament, asking what steps have been taken to improve care for LGBT people at the end of life. The ‘Hiding Who I Am’ report has also been launched in Wales and Northern Ireland, and continues to gain traction and promote debate.

Drawing on the findings of the study, the ACCESSCare team have delivered training to over 1,400 health and social care professionals across England on improving care for LGBT people facing advanced illness.

The researchers have since launched an end of life information guide with GMFA/HERO – Health Equality and Rights Organisation, to help inform LGBT people of what care to expect when they have a terminal illness and support them to receive care and support in line with their preferences and priorities.

**Box 3: Ten recommendations to improve care for LGBT people facing advanced illness<sup>4</sup>**

<b>Individual level</b>	Avoid using heterosexually framed or assumption-laden language
	Demonstrate sensitivity in exploration of sexual orientation or gender history
	Respect individuals' preferences regarding disclosure of sexual identity or gender history
	Carefully explore intimate relationships and significant others, including biological and chosen family (friends)
	Explicitly include partners and/or significant others in discussions
<b>Service/institutional level</b>	Make clear statements of policies and procedures related to discrimination
	Include content regarding LGBT communities in training on diversity and discrimination
	Increase LGBT visibility in materials (in written content and images)
	Provide explicit markers of inclusion (e.g. rainbow lanyards or pin badges)
	Initiate partnerships and/or engagement with LGBT community groups

4 Bristowe, K., Hodson, M., Wee, B., Almack, K., Johnson, K., Daveson, BA., Koffman, J., McEnhill, L., & Harding, R. (2018), Recommendations to reduce inequalities for LGBT people facing advanced illness: ACCESSCare national qualitative interview study, Palliative Medicine; 32(1):23-35

## 1.7 Promoting research uptake in a clinical setting

**Dr Nathan Davies**, below, and his team at University College London (UCL) have developed and tested a set of ‘heuristics’ or rules of thumb that aim to help healthcare professionals facing uncertainty in areas of dementia care where there are limited guidelines. The heuristics are designed to act as aide-mémoires to help healthcare staff to make decisions around end of life care in dementia.

The heuristics, which include information on caring for patients experiencing swallowing or eating difficulties, managing agitation or restlessness and rationalising medication and other treatments,

were tested in a variety of settings (palliative care, general practice, community nursing and hospitals), including by nurses, junior doctors and consultants at Princess Alexandra Hospital Trust in Essex in 2016.

The rules of thumb have since been rolled out to the whole Trust, presented at forums and used to train staff in 14 wards, including the complex elderly care ward. They are helping practitioners and carers to make confident decisions when faced with complex challenges so that patients with dementia receive the best possible care at the end of life.



“ This has been a hugely successful study and I am so proud to see the value of the rules of thumb to those involved in testing them. They continue to be used in clinical practice in these sites and have now been taken up by a group of GPs in charge of care homes in Central Manchester. The Alzheimer’s Society who funded this work alongside Marie Curie have also incorporated them into their end of life care training programme – a fantastic achievement.”

Dr Nathan Davies, Senior Research Fellow, UCL

“ Difficult conversations often happen outside of working hours so these aide-mémoires are particularly useful in helping doctors at the hospital to ask the right questions. Supporting people with dementia, especially communication, can be a significant challenge – these tools act as reminders to ensure professionals ask the right questions at the right time.”

Andy Dixon, Matron for Quality Improvement/Lead Nurse for Dementia and Learning Disabilities, Princess Alexandra Hospital

## 1.8 Marie Curie Design to Care Programme

The Marie Curie Design to Care programme aims to transform the future of palliative care by using eclectic design principles and rigorous scientific evaluation to tackle one of our generation's greatest health and social care challenges:

How can we meet growing and increasingly complex palliative care needs of the UK's ageing population in years to come?

In 2017, after a series of consultations with leading clinicians, academics, civil servants and service users, Marie Curie launched 'Design to Care', a five-year programme. Together with experts in research, design, public health and engineering from the University of Cambridge and Sheffield Hallam

University, Marie Curie are developing and piloting a toolkit that will support local areas to design and commission their own model of palliative care provision, tailored to the needs of their community. In its first two years, the programme focuses on research and design and will be followed by a pilot and evaluation phase.

So far, the team have worked with commissioners, patients, carers, clinicians and the public to identify stakeholder needs and wants from palliative care services. These are being used to inform a set of interventions that can be selected or modified to suit local communities. The programme is led by Professor Bill Noble, Executive Medical Director at Marie Curie.

Pete Jones/Marie Curie



“This programme will take a completely fresh look at how health services and society in general looks after people at the end of their lives. It will build on what we know about palliative care and combine the expertise of families with experience of terminal illness and academic experts in healthcare design to find new ways of caring.

We are particularly excited to be working with such a diverse group of people who are eminent in their field and have a proven track record of improving services. We know that one in four people in the UK don't get the care and support they need, so there is an urgency to act now.”

Professor Bill Noble,  
Executive Medical Director for Marie Curie and Programme Lead

## 2 Research outputs and impact

This section highlights the research outputs for 2016 from our:

- three research centres (including associated student and research programmes)
- five research leads and all nine hospices
- 45 past and present research projects, programmes and studentships from our various funding mechanisms.

The data was gathered from the annual reports of research centres and Research Leads as well as the online reporting tool, Researchfish.

Research project grant information was collected from 40 principal investigators from 17 institutions.

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
- collaborations.

### 2.1 Recruiting to research studies

Marie Curie-funded research gives people with a terminal illness, carers, staff and members of the public the opportunity to take part in research studies to improve palliative and end of life care. Health records are also being used to inform palliative and end of life care research projects.

In 2016/17, a total of 2,623 people were recruited to research studies funded by Marie Curie or carried out by our researchers (see Table 1). On average, the total number of patients has been increasing each year since 2014. These figures vary due to the different type and number of studies active in a given year. A record number of people were recruited from Marie

Curie hospices – 454 in 2016/17, up from 198 in 2015/16. Our hospices are also supporting research across institutions; Dr Matthew Maddocks from King's College London is carrying out research involving patients from Marie Curie Hospice, Hampstead and West Midlands (see Box 4).

Patient health records are often invaluable in informing research projects. A total of 10,156 health records were analysed in 2016/17, up from 80 in 2015/16. Dr Emma Carduff from Marie Curie Hospice, Glasgow has used health records to investigate the relationship between a person's socioeconomic background and their place of death (see Box 5).

**Table 1: Study recruitment from 1 April 2016 to 31 March 2017 for research studies funded by Marie Curie or carried out by our researchers**

Patients	Carers	Staff	Members of the public	Health records
1,600	242	738	43	10,156

**Box 4: Marie Curie Hospice patients involved in research**



Katie Hyams/Marie Curie

Patients at Marie Curie Hospice, Hampstead and Marie Curie Hospice, West Midlands have been involved in a research study into improving rehabilitation services in palliative care. The research, funded by the Dunhill Medical Trust, is led by **Dr Matthew Maddocks**, a Senior Lecturer and Specialist Physiotherapist at the Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, King’s College London. Dr Maddocks and his team are investigating the benefits of physiotherapy and allied health professions in people receiving palliative care and what improvements could be made to better meet patient needs.

A total of 60 patients were recruited from Marie Curie Hospice, Hampstead and Marie Curie Hospice, West Midlands between April 2016 and March 2017. Patients worked with staff to set specific goals for their rehabilitation, such as walking without carer support. These goals were recorded and monitored to see if they had been achieved at the end of treatment. Hospice patients benefited most when using rehabilitation services that were relevant to the goal they wanted to achieve. The findings will be used to help improve the way health professionals deliver care and discuss rehabilitation with patients receiving palliative care by providing training and resources for setting specific goals.



### Box 5: Using health records to identify and address inequity

**Dr Emma Carduff**, right, Research Lead at the Marie Curie Hospice, Glasgow, and colleagues looked at 4,585 patient health records as part of a study to identify the relationship between the socioeconomic status and place of death of patients known to specialist palliative care, who died between 2010 and 2015 in Scotland.

The study found that patients living in deprived areas were more likely to die in hospital, while those living in affluent areas were more likely to die in the hospice. Thanks to patient health records, the research sheds light on the potential inequity of access to hospice



care at the end of life. Further research is needed to understand the possible reasons for this.

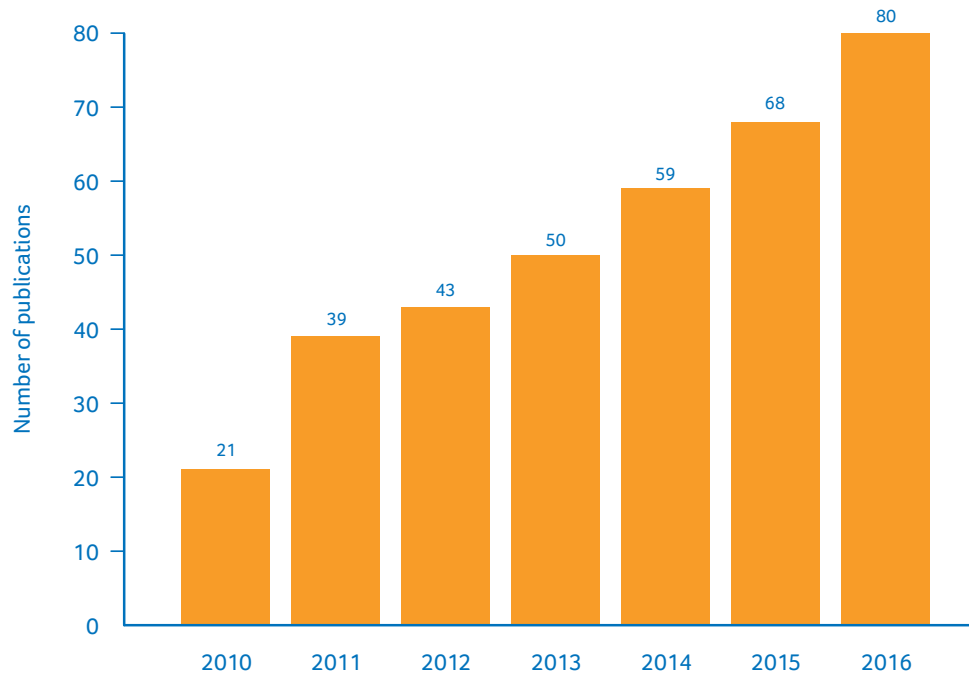
## 2.2 Publications

In 2016, Marie Curie researchers published 80 papers in peer-reviewed journals. This is an increase from 68 in 2015, with publications overall rising steadily since 2010 (see Figure 1). Of these, 25 were qualitative studies, 18 were systematic reviews and 10 were feasibility studies/clinical trials (see Box 6 for an example of research we have funded). We are committed to ensuring publications resulting from our funding

are accessible to all. Of those papers published in 2016, 64 (80%) are openly available.

An additional 64 publications were reported as national and international conference proceedings or abstracts in 2016, and another 11 publications were books, book chapters or other types of literature.

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



**Box 6: Hospital still the most common place of death for children with cancer**

**Dr Wei Gao** and **Professor Irene Higginson** from the Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, King’s College London, published the findings of their research on place of death for children and young people in the journal *BMC Cancer* in 2016.

The study used a range of statistical and mathematical approaches to identify patterns in the changing place of death of young people with cancer between 1993 and 2014, following a number of national initiatives to improve end of life

care since the late 1990s. Researchers analysed close to 13,000 medical health records of children and those aged under 24 years who had died of cancer.

The findings showed that hospice deaths more than doubled from 6% in 1993-2000 to 13% in 2005-2014 but deaths in hospitals were still the most common among children and young people, dropping from over 50% to 45%. The paper highlights the urgent need for initiatives to improve support for children and young people wishing to die at home or in hospices.

## 2.3 Influencing policy and practice

In 2016, there were 74 reported instances of Marie Curie researchers influencing policy and practice. Researchers participated in advisory committees, trained practitioners and researchers, gave evidence to government reviews, worked with

Marie Curie Policy teams in the four nations, and contributed to policy documents (see Figure 2 on page 31). See Box 7 for an example of how research has informed guidelines produced by NICE.

### Box 7: Research tool endorsed by NICE



Pete Jones/Marie Curie

**Professor Miriam Johnson**, above, and her team at Hull York Medical School have carried out research to help improve the care and support provided to people with interstitial lung disease (ILD) and their carers.

People with ILD have specific palliative care needs, which are not routinely assessed by healthcare professionals and, as a result, are often unmet.

In 2013, Professor Johnson was awarded Marie Curie funding to develop and test a new tool that could help doctors

and nurses identify the care and support needs of people with ILD. The tool was adapted from The Needs Assessment Tool: Progressive Disease-Cancer (NAT:PD-C) which was originally developed to help non-palliative care clinicians identify the support needs of people with cancer and their carers.

The tool comprises a consultation guide that can be used by doctors and nurses during routine clinical practice. It aims to prompt clinicians to assess the holistic needs of patients and their carers, as well as gaining the information needed to make a judgement about the level of help required and whether a referral to specialist palliative care is necessary. By helping doctors to identify and address the palliative care needs of people with ILD and their carers as early as possible, it is hoped the tool will improve patients' quality of life and ensure that referrals to specialist services, where necessary, are timely.

In 2016, the team published their first paper in the Journal of Palliative

Medicine. The paper reports results from the study that tested the adapted version of the tool on patients and their caregivers, clinicians and academics as part of a series of focus groups. Participants confirmed the tool's accuracy in reflecting patient experience.

The tool was endorsed by NICE in October 2016 for use alongside its current clinical guidelines for the diagnosis and management of idiopathic pulmonary fibrosis (one of the most rapidly progressive ILDs). NICE states that the tool supports the recommendations relating to best supportive care, review, follow-up and palliative care in the NICE guideline. It also supports the statements about

palliative care, oxygen, pulmonary rehabilitation and nurse access in the NICE quality standard for idiopathic pulmonary fibrosis in adults.

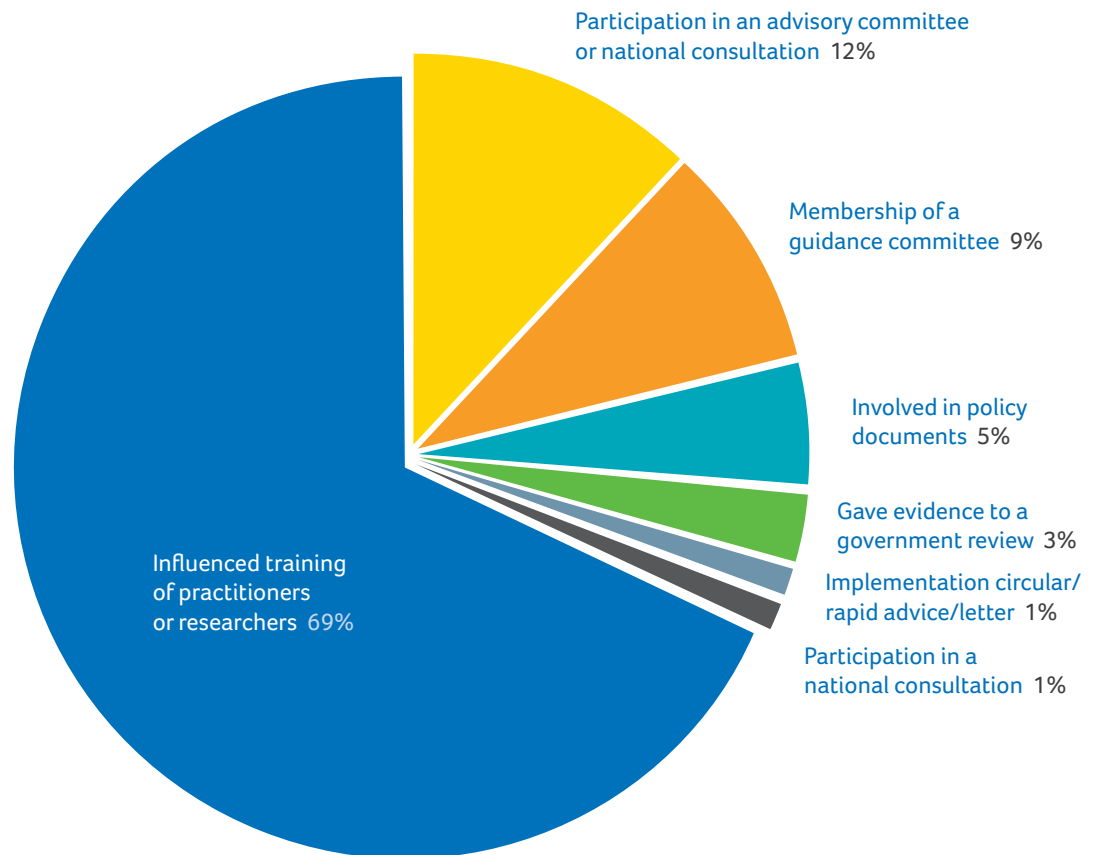
The team have since tested the tool to see if it is helpful to doctors and nurses in picking up the concerns that are important to patients. The findings were published in two papers in the journal *Thorax* in 2017.

To receive endorsement of a tool or resource from NICE, researchers should check that their resource is designed to support current care guidance and meets the criteria outlined on the NICE website – [nice.org.uk/about/what-we-do/into-practice/endorsement](http://nice.org.uk/about/what-we-do/into-practice/endorsement).

“The NICE endorsement is hugely important not only in helping to raise awareness of the issue, it gives credibility to the tool as a potential solution to improving care for people with ILD. From this research, we now have an understanding of what is needed to implement the tool in clinical practice and we are working to assess its impact on patients and their families.”

Professor Miriam Johnson, Professor of Palliative Medicine, Hull York Medical School

Figure 2: Influence on policy and practice by type in 2016



## 2.4 Research funding from the government and other charities

In 2016, Marie Curie researchers received an additional £2,133,699 of funding from external sources, up from £727,187 in 2015/16. Of the total, over 61% came from public or government funders, such as the National Institute for Health Research (NIHR).

### Marie Curie early stage funding leads to further investment

Professor Janelle Yorke from the University of Manchester received £335,508 from the NIHR's Research

for Patient Benefit Scheme in 2016 for her randomised controlled trial investigating how to help people with lung cancer manage their symptoms better. This was awarded following Professor Yorke's pilot feasibility study funded by Marie Curie in 2011. Professor Yorke and Professor Alex Molassiotis received funding to test the effectiveness of an intervention to manage respiratory distress (a cluster of symptoms comprising shortness of breath, cough and tiredness) in advanced lung cancer.

## 2.5 Collaborations

Led by Mala Mann, researchers at the Marie Curie Palliative Care Research Centre, Cardiff are working with palliative care professionals to find the evidence they need to support changes to their clinical practice. The PaCERS service, funded by the Welsh Government, aims to meet the needs of clinical services staff and other decision makers in palliative care in Wales who – because of the demands of their roles – may not have time to access and evaluate evidence. The rapid review service uses a modified systematic review method to conduct reviews within seven to 10 weeks.

Since launching in December 2015, the team have completed five reviews on:

- models of palliative care provision in rural communities
- clinical management of upper gastrointestinal malignant bleeds
- the impact of advance care planning on care at the time of a medical event
- managing risk of opioid toxicity at the time of interventional nerve blocks

- models for outpatient management of the late effects of pelvic radiotherapy.

Clinicians and/or clinical services are using these reviews in a range of ways. For example, the reviews have helped to inform an action plan in response to a Welsh Assembly report on challenges for healthcare delivery in rural settings. They are being used to inform proposals for continued funding of an advance care planning service in Wales, and in the development of a new outpatient service for gynaecological malignancy patients at the regional cancer centre.

The End of Life Board (EoLB) for Wales, which is the clinical implementation board for palliative care delivery, formally receives updates from PaCERS reviews and is working with the team to support its strategic aims and delivery. A new research post, jointly funded by the EoLB and WCRC, will identify evidence gaps and work with the PaCERS service to establish the evidence base, develop pragmatic studies and support the Board in its implementation of change.

Pete Jones/Marie Curie



“What is different about PaCERS is that it is up-front engagement with and involvement of clinicians/services. PaCERS carries out its reviews on topics defined by services and clinicians as of immediate relevance to their practice – so its intention is to save time and resource for clinical teams and provide information in a useful format that they can implement at pace.”

Dr Anthony Byrne, Director, Marie Curie Palliative Care Research Centre, Cardiff



## 2.6 Awards and recognition

**Dr Amara Nwosu** from the Marie Curie Palliative Care Institute at the University of Liverpool was appointed Digital Technology Editor of the Palliative Medicine journal in 2016. Dr Nwosu leads the development of the journal's 'Palliative Medicine and Chronic Care' podcast, which allows authors to record an audio summary of their research, to enable dissemination of the journal's work to a wider audience.

His appointment stems from research interests in the evaluation of technology to support care for patients with advanced disease, and exploring the use of clinically assisted hydration to manage symptoms.

**Dr Bridget Candy** from the Marie Curie Palliative Care Research Department at UCL was awarded the EAPC Postdoctoral Researcher Award in 2016, recognising the contribution of her research specialty in palliative care. Led by Dr Candy, systematic reviews generated within the centre have provided the evidence to inform

UK and international clinical guidelines including those of NICE, as well as identify evidence uncertainties that can direct research agendas. Dr Candy was presented with the award at the EAPC Congress in Dublin in 2016.

### Susie Wilkinson Award

The Susie Wilkinson Award was set up in 2009 in recognition of Dr Susie Wilkinson's achievements for Marie Curie. The prize is awarded annually to a member of staff who has made significant personal progress in research.



Rachel Grubb (left) with Professor Bill Noble, Executive Medical Director, Marie Curie

Pete Jones/Marie Curie

In 2016, the award was presented to **Rachel Grubb** from the Marie Curie Hospice, West Midlands at the annual Marie Curie Palliative Care Research Conference (see section 3.2).

Alongside her role as a registered nurse at the hospice, Rachel worked as a research nurse, funded by the Clinical Research Network West Midlands. Rachel's input had a significant impact in developing research as a core hospice activity, making it more accessible for staff, patients and their families.



L to r: Professor Stein Kaasa, Chair of the EAPC Research Network, Dr Bridget Candy with fellow award winners and Professor Christoph Ostgathe, EAPC board member

C Jackson/Marie Curie

# 3 Advancing research

At Marie Curie, our research funding is helping to build capacity in palliative and end of life care by supporting PhD studentships at our research centres.

We also support our researchers to communicate their findings widely to audiences within and outside Marie Curie.

## 3.1 PhD studentships

In 2016, **Anna-Maria Krooupa**, below, was awarded the Baillie Marie Curie PhD fellowship following a generous donation by Sir Adrian Baillie and The Gawaine Stamp Fund. Her research focuses on the feasibility of objectively monitoring sedative use in hospice inpatients. Objective monitoring of

sedative use may have benefits in terms of better titration of medication and patient comfort. However, standard care for patients receiving sedatives at the end of life receiving palliative care and nearing the end of life. The findings will be used to inform the development of guidelines and teaching materials that can help doctors with little practical experience communicate better with family members of patients. Rebecca is supervised by Dr Steven Bloch from UCL, Professor Paddy Stone and Dr Joseph Low from the UCL research centre.

sedative use may have benefits in terms of better titration of medication and patient comfort. However, standard care for patients receiving sedatives at the end of life

currently does not include objective monitoring. Anna-Maria is supervised by Professor Paddy Stone, Marie Curie Chair of Palliative and end of life care at the UCL research centre.

**Rebecca Anderson** joined the UCL research centre in 2017. Her PhD focuses on understanding how experienced healthcare professionals communicate end of life care to the family and friends of patients

**Chandni Hindocha** is investigating how discomfort is managed in people with advanced dementia. Her PhD titled 'How can we improve the detection and management of distress in people with advanced dementia and communication difficulties who are nearing end of life?' forms part of the centre's wider research in this area. The findings will be used to develop a new intervention to help improve the wellbeing of people with advanced dementia. Chandni's three-year PhD is funded by the Healthcare Management Trust. She is supervised by Dr Liz Sampson and Dr Kirsten Moore from the UCL research centre.



Elizabeth Cuthbertson/Marie Curie

## 3.2 Disseminating research findings

### Research in the press



**Nicola White** carried out her PhD at the Marie Curie Palliative Care Research Department, UCL between 2014 and 2017 looking at how specialist palliative care doctors recognise when a patient is in the last days of life. In clinical practice, clinical intuition is the most common method for predicting survival of patients. Nicola's PhD aimed to investigate what influences a doctor's prognostic skills, whether some are better than others and how their skills could be improved to make more accurate prognoses.

Nicola published the first of her papers in the journal *Plos One* in 2016, a systematic review which showed that clinicians were frequently inaccurate when predicting how long their patient had left to live. These ranged from

an underestimate of 86 days to an overestimate of 93 days<sup>5</sup>. The study also showed that more experienced doctors were not necessarily better at making more accurate predictions.

A second paper reviewing the accuracy of the 'Surprise Question' – a screening tool that aims to identify people nearing the end of life was published in *BMC Medicine* in 2017<sup>6</sup>. The findings showed that the tool, that helps clinicians to recognise those patients who might benefit from palliative care, was frequently inaccurate. Based on a review of existing literature and 25,718 predictions made using the 'Surprise Question' over a ten-year period, over half (54%) of those predicted to die within a specified time period lived longer than expected.

Nicola worked with the Marie Curie Public Relations team to produce a press release for both papers that gained significant media coverage, including the front page of *The Times* as well as coverage in *The Daily Telegraph* and *Independent*. Nicola was supervised by Professor Paddy Stone, the Marie Curie Chair of Palliative and end of life care at the UCL research centre.

5 White, N., Reid, F., Harris, A., Harries, P., & Stone, P. (2016). A Systematic Review of Predictions of Survival in Palliative Care: How Accurate Are Clinicians and Who Are the Experts? *Plos One*, 11(8), e0161407. <https://doi.org/10.1371/journal.pone.0161407>

6 White, N., Kupeli, N., Vickerstaff, V., & Stone, P. (2017). How accurate is the 'Surprise Question' at identifying patients at the end of life? A systematic and meta-analysis. *BMC Medicine*, 15;139



“Based on my research and conversations with medical doctors, there is a clear need to improve the support available for doctors when working with people in the final days of life; in the recognition and communication of this phase, and in the confidence of working with such a population. I am now building on this evidence to find ways to help train medical students to recognise dying.”

Dr Nicola White, Research Associate  
Marie Curie Palliative Care Research Department, UCL.

Aubrey Wade/Marie Curie



“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. This research suggests that there is no simple way to identify which doctors are better at predicting survival. Being more senior or more experienced does not necessarily make one a better prognosticator but we now want to see if we can identify how and why some doctors are better at predicting survival than others and to determine if this is a skill that can be taught.”

Professor Paddy Stone,  
Professor of Palliative and End of life care,  
Marie Curie Palliative Care Research Department, UCL.

## The 11th annual Marie Curie Palliative Care Research Conference

The 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 October 2016. The theme of the conference was 'Round the clock: Making 24/7 palliative care a reality.' This was selected because it reflected the number one priority identified by patients, carers and health and social care professionals through the PeolcPSP. Dr Eleanor Wilson from the University of Nottingham and Dr Deborah Fitzsimmons from Western University, Ontario were invited to speak at the conference. Dr Wilson presented

her research on the role of nurses in decision-making around anticipatory prescriptions. Dr Fitzsimmons spoke about an electronic solution to 24/7 palliative care successfully trialled at St Luke's Hospice in Sheffield.

Other speakers included Doa'a Kerwat from Imperial College London and Barts and The London School of Medicine and Dentistry, Dr Florence Todd Fordham from Marie Curie, Dr Bruce Mason from the University of Edinburgh and Dr Anna-Maria Bielinska from Imperial College London.

## 3.3 Involving people in research

The Marie Curie Research Expert Voices Group (REVG) was set up in 2013 as a means of enabling those who have first-hand experience of end of life care as a family member, friend or carer to be involved in research.

Between 2014 and 2017, palliative and end of life care researchers throughout the UK requested REVG involvement in more than 20 research studies. In 2017, we carried out a survey to understand more about how the REVG were involved in research and the value of their contribution to this research.

Our findings showed that members of the REVG are contributing in all aspects of the research process, from helping to develop research proposals to informing

the design of research studies. From our survey, most researchers felt that REVG input had enhanced the relevance of their study to patients and the public. Researchers also found that REVG input improved study design, increased the acceptability of their study to participants and helped ensure proposals met ethical requirements.

For example, REVG members helped to inform Dr Nathan Davies' research question as part of his study on hydration and nutrition in people with advanced dementia being cared for at home, as well as advise on ways of reaching family carers to participate in the study. Overall, Dr Davies felt that the REVG were very helpful and made his research proposal much stronger.

## 4 Looking ahead

We know that important questions remain unanswered in palliative and end of life care research. Our work is helping to highlight some of these gaps, in particular the evidence gaps most important to patients, carers and healthcare professionals. With our investment, we encourage researchers to build on existing knowledge to address these priorities. We are also:

- bringing together researchers, clinicians and methodologists to explore how to improve the way palliative and end of life care research deals with missing data – information that is sought but rarely collected.
- collaborating to find ways of addressing the issue of continence in older populations and people with long-term health conditions. With other charities, we are providing a set of recommendations for researchers, research funders, charities and service providers to encourage more research into this important area of unmet need.
- part of an NIHR consortium committed to improving the delivery of research in hospices and communities. We are working together to increase the portfolio of studies in supportive and palliative care research involving patients and staff from hospices and communities.
- part of an international initiative co-led by the NIHR to ensure value in research.
- strengthening collaboration between our hospices and leading universities in the UK through Marie Curie Clinical and Academic Research Fellowships. Building on our research lead programme, we're supporting the next generation of palliative and of life care researchers to work closely with Marie Curie hospices to facilitate clinically relevant research that makes a difference to people nearing the end of life.



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### Research Strategic Advisory Committee

Professor Sir Andy Haines (Chair),  
Professor Tim Peters (Vice-chair),  
Professor Allan Kellehear,  
Professor Chris Eccleston,  
Professor Ian Tannock,  
Professor Phil Hannaford,

Professor John Norrie,  
Professor Mike Bennett,  
Professor Declan Walsh,  
Professor Jane Seymour,  
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Joanna Eley (Research Expert Voice),  
Peter Buckle (Research Expert Voice)

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## Abbreviations

**CSO** – Chief Scientist Office

**EoLB** – End of Life Board

**HERO** – Health Equality and Rights Organisation

**ILD** – Interstitial Lung Disease

**MND** – Motor neurone disease

**NICE** – The National Institute for Health and Care Excellence

**NIHR** – National Institute for Health Research

**PeolcPSP** – Palliative and end of life care Priority Setting Partnership

**RCGP** – Royal College of General Practitioners

**REVG** – Research Expert Voices Group

**UCL** – University College London

**UKCRC** – The UK Clinical Research Collaboration

# Appendix 1

List of publications in peer-reviewed journals arising from Marie Curie research funding in 2016 (excluding e-publication dates, where possible)

1. Aggio, R. B. M., Mayor, A., Coyle, S., Reade, S., Khalid, T., Ratcliffe, N. M., & Probert, C. S. J. (2016). Freeze-drying: an alternative method for the analysis of volatile organic compounds in the headspace of urine samples using solid phase micro-extraction coupled to gas chromatography - mass spectrometry. *Chemistry Central Journal*, 10(1), 9. <https://doi.org/10.1186/s13065-016-0155-2>
2. Amador, S., Goodman, C., Mathie, E., & Nicholson, C. (2016). Evaluation of an Organisational Intervention to Promote Integrated Working between Health Services and Care Homes in the Delivery of End-of-Life Care for People with Dementia: Understanding the Change Process Using a Social Identity Approach. *International Journal of Integrated Care*, 16(2), 14. <https://doi.org/10.5334/ijic.2426>
3. Bailey, C., Kinghorn, P., Orlando, R., Armour, K., Perry, R., Jones, L., & Coast, J. (2016). "The ICECAP-SCM tells you more about what I'm going through": A think-aloud study measuring quality of life among patients receiving supportive and palliative care. *Palliative Medicine*, 30(7), 642–52. <https://doi.org/10.1177/0269216315624890>
4. Beecham, E., Hudson, B. F., Oostendorp, L., Candy, B., Jones, L., Vickerstaff, V., Bluebond-Langner, M. (2016). A call for increased paediatric palliative care research: Identifying barriers. *Palliative Medicine*, 30(10), 979–80. <https://doi.org/10.1177/0269216316648087>
5. Bennett, P., Patterson, K., & Noble, S. (2016). Predicting post-traumatic stress and health anxiety following a venous thrombotic embolism. *Journal of Health Psychology*, 21(5), 863–71. <https://doi.org/10.1177/1359105314540965>
6. Bhatnagar, S., Noble, S., Chaturvedi, S. K., & Gielen, J. (2016). Development and Psychometric Assessment of a Spirituality Questionnaire for Indian Palliative Care Patients. *Indian Journal of Palliative Care*, 22(1), 9–18. <https://doi.org/10.4103/0973-1075.173939>
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