

# Palliative and end of life care Priority Setting Partnership (PeolcPSP)

Putting patients, carers and clinicians at the heart of palliative and end of life care research

[www.palliativecarepsp.org.uk](http://www.palliativecarepsp.org.uk)

January 2015

Palliative and end of life care  
Priority Setting Partnership



James  
Lind  
Alliance

Priority Setting Partnerships

SUPPORTED AND GUIDED BY

IN PARTNERSHIP WITH

Care and support  
through terminal illness



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## Acknowledgements

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### Partners

The following organisations provided funding for the Palliative and end of life care Priority Setting Partnership (PeolcPSP), facilitated by the James Lind Alliance (JLA):

- Marie Curie
- National Institute for Health Research (NIHR) Evaluation, Trials and Studies Coordinating Centre (NETSCC)
- Chief Scientist Office (CSO)
- National Institute for Social Care and Health Research (NISCHR)
- Motor Neurone Disease Association (MND Association)
- All Ireland Institute of Hospice and Palliative Care  
(funded by Health and Social Care, Northern Ireland and the Health Research Board, Ireland)
- Macmillan Cancer Support
- Cancer Research UK
- Economic and Social Research Council
- Medical Research Council

### Many other organisations supported the PeolcPSP, including:

- Age UK
- Alzheimer's Society
- Association for Palliative Medicine of Great Britain and Ireland
- Barts Cancer Institute
- The Brain Tumour Charity
- Breast Cancer Campaign
- British Geriatrics Society
- British Lung Foundation
- Chest Heart & Stroke Scotland
- Childhood Bereavement Network
- Cicely Saunders Institute (King's College London)
- Cochrane Pain, Palliative and Supportive Care Group
- Dimpleby Cancer Care
- Hospice UK
- Multiple Sclerosis Society
- National Bereavement Alliance
- National Cancer Research Institute
- National Council for Palliative Care
- Parkinson's UK
- Pilgrims Hospices
- Roy Castle Lung Cancer Foundation
- Royal College of General Practitioners
- Royal College of Nursing
- Scottish Partnership for Palliative Care
- Scottish Stroke AHP Forum
- St Christopher's Hospice
- St Gemma's Hospice
- Stroke Association
- Target Ovarian Cancer

The PeolcPSP is grateful to Katherine Cowan, Senior Advisor to the James Lind Alliance, for independently facilitating the partnership, Project Coordinator Jennifer Tuft and Senior Research Information Officer Rhiannon Smith.

The PeolcPSP would like to thank Dr Annmarie Nelson, Dr Stephanie Sivell, Dr Jessica Bailey, Dr Bridget Candy, Jordan Van Godwin and Jennifer Tuft for their contribution to the data analysis.

The data analysis team gratefully acknowledge the advice given on search terms by Dr Liz Sampson, Dr Louise Jones, Professor Paddy Stone, Dr Nicola Atkin, Dr Jane Harrington, Dr Margaret Elliott, Sarah Davis, Dee Sissons, Dr Jane Neerkin, Dr Teresa Tate, Alison Penny, Dr Aine Burns, Dr Susie Lapwood, Professor Christopher Eccleston, Tricia Gilpin, Anthony Byrne, Dr Annmarie Nelson, Dr Stephanie Sivell and Dr Jessica Bailey.

The PeolcPSP would like to thank Katharine Peacock and Melisse Chee for their work on the project.

The PeolcPSP would not have been possible without the countless numbers of patients, current and bereaved carers, health and social care professionals, organisations and patient groups who disseminated and participated in the survey, prioritisation and workshop. Thank you for your time and your participation.

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# Forewords

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## Joanna Eley, Patient Representative, National Cancer Research Institute (NCRI) Consumer Hub

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This report will be welcomed by patients in the last stages of life and their carers, but it is of great importance to us all. It concerns things that affect absolutely everyone. This is evident from the top 10 research priorities that the careful consultative process, carried out over the last year, has generated. These have been developed using the James Lind Alliance's respected methodology which seeks the views of a directly affected population to determine the most important unanswered questions that could improve outcomes and experiences for this affected group.

Unlike many very focused clinical research projects, the top 10 questions this project has raised are overarching. This indicates the complex and subtle needs of patients, carers and their immediate community as the end of life approaches. It is to be hoped that the clear and simple presentation of the results of this work, to which so many have contributed, will help give this field the attention it needs and deserves. All researchers need to use this report as part of their applications for funding to demonstrate how important their work is to the entire UK population. And funders must appreciate the huge benefits that can result from an increased contribution to this work – the end of life is something that will never go away.

## Dr Sabine Best, Head of Research, and Dr Bill Noble, Medical Director, Marie Curie

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We are delighted to introduce the results of the Palliative and end of life care Priority Setting Partnership with the James Lind Alliance. It has been a privilege to work with so many partner organisations, all recognising the need for more research in palliative and end of life care. We are enormously grateful to everyone who responded

to the surveys, came to the workshop or helped in any other way to make the project a success. In particular, we are grateful to patients, current and former carers, and professionals for the openness with which they shared their views and experiences.

With so little resource going into this area of research, it is our responsibility to make policy makers aware of our profound deficit in knowledge in this important section of healthcare, while signalling where our most urgent needs for high quality research lie. We hope that this document will help to focus researchers and funding bodies on the questions about palliative and end of life care that concern patients, carers and clinicians most.

# Executive summary

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## Introduction

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Palliative and end of life care is an under-researched area and requires greater attention. The National Cancer Research Institute (NCRI) Cancer Research Database shows that since its inception in 2002 the funding for cancer-related palliative and end of life care research has been consistently below 0.7% of the total spent on cancer research in the UK. No data are available on spend in palliative and end of life care research in non-cancer conditions, but this is likely to be even lower.

There are many unanswered questions to be addressed. But with such scarce resources, it is important that researchers and research funders ensure that they address questions which will bring direct and tangible benefits to patients and their carers, families and friends.

The Palliative and end of life care Priority Setting Partnership (PeolcPSP) has allowed those whom research is intended to benefit – people who are likely to be within the last years of life, current and bereaved carers, and health and social care professionals – to identify unanswered questions which are most important for them.

With these priorities in mind, future research could look to answer the highest priority questions. We hope that this project will also raise awareness of the importance of research in palliative and end of life care and encourage research funders to invest in this area.

## Methodology and findings

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The PeolcPSP was initiated by Marie Curie in 2013, and involved around 30 other organisations and groups. The partnership was facilitated by the James Lind Alliance (JLA) and overseen by a steering group chaired by an independent JLA Adviser.

Through a **survey**, we asked people likely to be within the last years of life, current and bereaved carers, and health and social care professionals to submit their unanswered questions about palliative and end of life care. We received 1,403 responses from across the four nations and **analysed** them to draw out research questions which were combined where appropriate. Searches assessed whether any of the questions had already been answered by an up-to-date systematic review of existing research evidence.

From this, we produced a 'longlist' of 83 questions. This longlist was **ranked** from very low to very high priority in a second survey of people likely to be within the last years of life, current and bereaved carers, and health and social care professionals. We received 1,331 responses. The steering group reviewed these and produced a shortlist of 28 questions.

A **final prioritisation workshop** was held on 21 November 2014 to identify the top 10 unanswered research questions, or evidence uncertainties, in palliative and end of life care.

## Conclusions

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The following research questions or evidence uncertainties were identified and prioritised by patients, carers and health and social care professionals to inform the future of palliative and end of life care research.

The **Top 10 unanswered questions** in palliative and end of life care in order of priority are:

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?

## Next Steps

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### For research funders...

Funding for palliative and end of life care research is limited. The findings of the PeolcPSP will enable existing funders of research – including many of the project partners – to target their funds to the priorities that matter most to patients, current and bereaved carers, and health and social care professionals. Research funders will also be able to coordinate their efforts and tackle the highest priority questions together.

### For researchers...

The results will enable researchers who are applying for funding on these topics to demonstrate that their research will be valuable to the people who most need it. All of the longlisted questions will be made publicly available via the UK Database of Uncertainties about the Effects of Treatments (UK DUETs), which publishes treatment uncertainties from patients, carers, clinicians, and from research recommendations, covering a wide variety of health problems.

### For charities...

Charitable funders and their policy teams will be able to use this project to demonstrate the need for increased funding in palliative and end of life care, and campaign to achieve this. We hope that there will be increased awareness and interest in funding and conducting research in palliative and end of life care as a direct result of the PeolcPSP.

### For the PeolcPSP...

The original survey returned over 1,400 responses, many of which included comments and questions that did not fit with the JLA methodology of identifying and prioritising interventional research questions. The PeolcPSP is looking at ways to further analyse these out-of-scope data to highlight questions and comments that could be addressed by other types of research, eg qualitative research.

We will feed back lessons learned by the PeolcPSP to the JLA and we hope that future partnerships will build on these lessons.

# Introduction

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## Why set priorities for palliative and end of life care research?

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Palliative and end of life care is an under-researched area. So it is crucial that the limited resources available are spent on research which is most relevant to patients, carers and clinicians – those who will benefit from and use the results of research.

Patients and carers have never before been consulted in such a comprehensive and systematic way about their priorities for research in palliative and end of life care. Only two studies have specifically sought the views of palliative care patients on research priorities [Perkins et al, 2007 and 2008]. No studies have explicitly consulted carers. But it has been shown that there can be a mismatch between the areas that patients and carers would like to see research carried out, and the research that is actually done [Tallon and Dieppe, 2000]. It has been proposed that research investment that does not address the needs and concerns of its end users is wasted [Chalmers and Glaziou, 2009; Chalmers et al, 2014].

Once we identify and prioritise the questions, or evidence uncertainties, researchers can look to answer the highest priority questions and research funders can better direct their resources. This will bring tangible benefits and evidence-based treatments to people who may be in the last few years of life, their carers and their families.

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**"For research to make a fundamental difference, it is vital funders and researchers focus on what matters most to people with terminal illnesses, their families and carers, as well as their health and social care professionals."**

Dr Bill Noble, Marie Curie Medical Director and past president of the Association for Palliative Medicine of Great Britain and Ireland



# Background

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The National End of Life Care Strategy, published in 2008, and a rapid review by the National Cancer Research Institute in 2010 highlighted that palliative and end of life care research is underdeveloped. A recent analysis of the NCRI Cancer Research Database showed that spending on palliative and end of life care research was consistently below 0.7% of the total spent on cancer research in the UK [NCRI & Marie Curie, Nov 2014]. No data are available on spend in palliative and end of life care research in non-cancer conditions, but this is likely to be even lower. In light of this, in early 2013 Marie Curie approached the James Lind Alliance (JLA) to discuss working together to ensure that patient and carer voices are represented in setting research priorities in palliative and end of life care.

The JLA is coordinated by the National Institute of Health Research Evaluation, Trials and Studies Coordinating Centre (NIHR NETSCC). Its aim is to provide a framework to help patients, carers and

clinicians work together to agree which are the most important evidence uncertainties affecting their particular interest, and to influence the prioritisation of future research in that area.

The PeolcPSP attracted support from a number of other funding bodies who want to see improvements in evidence-based care, support and treatments at the end of life and – along with Marie Curie – committed to co-funding the project. Other organisations, representing a range of conditions and professional, patient and carer groups, signed up as stakeholders of the partnership, actively promoting the project and disseminating the surveys.

In October 2013, the PeolcPSP was officially launched – a new partnership bringing together over 30 organisations. The results of the partnership will help direct future research funding to areas most relevant to patients, carers and families.

# Project scope

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Palliative and end of life care is an area that intersects with many other disciplines, medical specialities such as oncology and elderly medicine, and social care. The PeolcPSP is different to most previous Priority Setting Partnerships (PSPs) facilitated by the JLA because it is not condition-specific. The PeolcPSP is looking at care, support and treatment across all settings – it is probably the broadest PSP so far.

The steering group took some early decisions to define, and – where necessary – limit, the scope of the project. The project considered palliative and

end of life care for adults with long-term illnesses who might be in the last years of life. The steering group consciously decided to keep the definition of end of life broad to try to reach as many patients as possible who might be willing to identify with that definition, as well as frail elderly people who may not have a diagnosed terminal illness.

The JLA methodology limits this project to identifying the research questions or evidence uncertainties that were deemed to be addressable by interventional research.

# Methodology

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The PeolcPSP followed the methodology described in the JLA Guidebook – [jlaguidebook.org](http://jlaguidebook.org)

## Stage 1: Establishing the partnership

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The PeolcPSP was initiated in 2013 by Marie Curie – with the support of the JLA – to give patients, carers and clinicians the chance to have their say in setting research priorities for palliative and end of life care.

In total, more than 30 organisations were involved either as co-funders or stakeholders. Stakeholders assisted in disseminating the survey, project updates, and results to their networks of patients, carers and professionals. Some stakeholder organisations sent representatives to the steering group. The steering group, independently chaired by Katherine Cowan, Senior Adviser to the JLA, met for the first time in August 2013. A project protocol (available online on the JLA website [lindalliance.org/palliativecare.asp](http://lindalliance.org/palliativecare.asp)) was agreed (appendix 1).

### Steering group

The steering group comprised patient and carer representatives, and health and social care professionals, as well as representatives from the funding bodies. Members of the steering group represented organisations relevant to a range of cancer and non-cancer conditions, as well as patient, carer and professional groups (appendix 2).

**Katherine Cowan** James Lind Alliance  
**Dr Alan McNair**, Chief Scientist Office (CSO)  
**Alison Penny**, Childhood Bereavement Network and National Bereavement Alliance  
**Amanda Cheesley**, Royal College of Nursing (RCN)  
**Andrea Dechamps**, St Christopher's Hospice  
**Angela McCullagh**, Lay Representative  
**Angharad Kerr / Dean Chapman**, National Institute for Social Care and Health Research (NISCHR)

**Dr Annmarie Nelson**, Cardiff University  
**Dr Belinda Cupid**, Motor Neurone Disease Association (MND Association)  
**Dr Bill Noble**, Marie Curie  
**Dr Bridget Candy**, University College London  
**Dr Catherine Burton**, Macmillan Cancer Support  
**Elaine Stevens**, Scottish Partnership for Palliative Care (SPPC)  
**Jennifer Tuft**, Marie Curie  
**Joanna Black**, National Council for Palliative Care (NCPC)  
**Joanna Eley**, National Cancer Research Institute (NCRI) Consumer Hub  
**Lauren Berry**, Royal College of Nursing (RCN)  
**Linda McEnhill**, Hospice UK  
**Nick Tracey**, Marie Curie Expert Voices Group  
**Rhiannon Smith**, Marie Curie  
**Dr Sabine Best**, Marie Curie  
**Sarah Fryett / Beccy Maeso**, National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre (NIHR NETSCC)  
**Professor Sonja McIlfatrick**, All Ireland Institute of Hospice and Palliative Care (AIHPC)  
**Dr Teresa Tate**, Marie Curie

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**"The James Lind Alliance PSP process is a tried and tested way of bringing together patients, carers and clinicians to prioritise treatment uncertainties, and is at the heart of the NIHR."**

Professor Dame Sally C. Davies, Chief Medical Officer and Chief Scientific Adviser at the Department of Health

## Stage 2: Identifying evidence uncertainties

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We gathered unanswered questions from patients, current and bereaved carers and health and social care professionals via a public survey (appendix 3). The survey was launched on 9 December 2013 and remained open until 16 May 2014. The survey asked:

- What question(s) do you have about **care, support and treatment** for people who are in the last few years of their lives that could help them to live as well as possible? This could also include question(s) about care and support for current carers or families.
- What question(s) do you have about **care, support and treatment** for those rapidly approaching the end of their lives? This could also include question(s) about care and support for current or bereaved carers or families looking after someone at the end of their life.

The wording and design of the survey was piloted with a small group of current and bereaved carers, and patient representatives, adapted to incorporate feedback and then signed off by the steering group. The survey was built using SurveyMonkey online survey software. In anticipation of the challenges of reaching people in the last few years of their lives, a paper version was made available in hospices and through the Marie Curie Nursing Service. A large print version of the survey was available on request and respondents were also given the option to complete the survey over the phone.

To monitor who was responding, the survey asked respondents to identify as:

- I am in the last few years of my life.
- I am a carer or family member or partner or friend of someone in the last few years of their life.
- I am a bereaved carer or family member or friend.
- I am a professional working with people in the last few years of life.

- I am a volunteer working with people in the last few years of life.
- I am a member of the public who has an interest in the subject.
- Other, please specify.

In answer to the above, it was possible to tick multiple boxes, and indeed, many respondents identified as belonging to more than one category.

The survey was disseminated by stakeholders and steering group members to their networks via email, newsletters, social media, web posts, presentations and stands at conferences, and blogs.

We received 1,403 survey responses. Further information on who responded to the survey can be found in the results section of this report, including a breakdown of respondents by country, and a more detailed breakdown can be found in the appendices of this report (appendix 4).

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**"This survey helps the healthcare professionals improve their service to others. It is one way of sending a message of love and support to people who are in the same position as us."**

Bill Whiland, Marie Curie Expert Voices Group Member

## Stage 3: Refining questions and uncertainties

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### Identifying themes and questions

The steering group agreed that a separate data assessment group would be formed, comprising some members of the steering group, to oversee and validate the data management stage of the PeolcPSP. Details of who was in the data assessment group, as well as the agreed data management protocol, can be found in appendices 2 and 5 respectively. Data analysis was carried out by Jennifer Tuft, Marie Curie; Dr Bridget Candy, Marie Curie Palliative Care Research Department, UCL; Dr Annmarie Nelson, Dr Stephanie Sivell, Dr Jessica Bailey and Jordan Van Godwin, Marie Curie Palliative Care Research Centre at Cardiff University.

An initial coding framework based on the first 200 responses to the survey was created. This coding framework had six overarching themes: communication, support, service use, managing symptoms and medications, perceptions of palliative care, and understanding dying.

### Forming interventional questions and searching for evidence

Each survey response was analysed and formed into an interventional research question, where possible, using the Patient/Population, Intervention, Comparator and Outcome (PICO) format. Responses that were not within the scope of the project, including those pertaining to paediatric palliative care, non-terminal conditions, and questions that would be more appropriately addressed by other types of research, were removed and retained for separate analysis at a later stage. From 1,403 survey responses 749 provisional PICO questions were formed. These questions were then reviewed, duplicates combined and checked again to make sure they were within scope.

This left a total of 435 questions to be checked against relevant, reliable and up-to-date systematic reviews, to ascertain whether or not they were unanswered. Searches were limited to The Cochrane Library and the Database of Abstracts of Reviews of Effects (DARE). These databases cover systematic reviews of randomised

controlled trials (RCTs). Comprehensive and appropriate lists of search terms were generated to maximise the efficiency of the review process. To optimise the effectiveness of a search, only the Population and Intervention needed to be identified. To identify the systematic reviews, key terms were searched for through The Cochrane Library and DARE, the British National Formulary (BNF) and other internet sources such as the NHS website and various relevant charity sites. To improve the efficacy of the review process, the search terms of questions with similar themes were amalgamated; this meant that one set of search terms could cover numerous questions.

To ensure that the search terms created had not missed any key descriptors of the intervention or the disease in question, field experts were consulted. Once the relevance of the search terms had been verified, the Cochrane and DARE databases were searched to confirm whether the questions were true research uncertainties.

For many of the questions there were no systematic reviews identified. For those questions where a relevant review was identified, the citation and abstract details were extracted and recorded for further exploration. None of the identified systematic reviews fully answered the questions generated from the survey responses. This was either because the review found that the trials were limited or identified no relevant trial evidence. In some cases the identified reviews only partly answered the question identified from the survey responses. This supports the widely accepted belief that there is limited definitive research in palliative and end of life care.

A final list of 100 questions was formulated, which was then reduced to 83 by combining similar questions. This long list was reviewed by the data assessment group and the project steering group to go forward for interim prioritisation. The longlist of 83 questions can be found in the results section of this report.

## Stage 4: Prioritisation – interim and final stages

### Interim prioritisation

A second online survey was created that asked respondents to rate each of the 83 longlisted questions. The questions appeared in random order and respondents were asked to rate each from very low priority to very high priority.

The survey received 1,331 responses. A breakdown of respondents by the proportions of patients, carers and clinicians can be seen in the results section of this report as well as a more detailed breakdown in appendix 6. As in the first survey, it was possible for respondents to identify as more than one category.

The steering group reviewed how the rankings compared between respondents who identified as being in the last few years of life, current and bereaved carers, and professionals. Given that the distribution of respondents from these categories was not equal (for example patients made up around 2% of respondents, and bereaved carers comprised about 22%) the steering group took particular care to ensure that there were no major discrepancies between the groups' priorities, and that the highest ranking questions identified by patients were reflected in the shortlist.

The top 20 ranked questions were identified. There were some ties (for example, three questions ranked in fifth place) so the top 20 actually included 31 questions. The steering group combined several of these questions resulting in a final shortlist of 28.

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"I consider research in this area is vital to improve and inform care standards, and to encourage people in planning for their own end of life care."

Rose Amey, Marie Curie Expert Voices Group Member

### Final prioritisation

The final prioritisation workshop took place in central London on 21 November 2014. The workshop was attended by a group of 24 participants, including current and bereaved carers, patients, nurses, palliative care consultants, a social worker and former GP, among others. There were an additional 10 observers who attended on the day, but did not take part in discussions, including members of the project team and representatives of funding partners.

The workshop followed the JLA methodology, using the Nominal Group Technique to generate discussion, ranking and consensus agreement. The JLA sees value in providing this opportunity to reach the top 10 through discussion and the exchange of knowledge. The workshop was chaired and facilitated by Katherine Cowan with support from two co-facilitators from the JLA, Leanne Metcalf and Richard Morley.

Participants were asked to complete a declaration of interest form and biographies of each participant were circulated to everyone attending in advance of the workshop to encourage transparency and openness. Each participant was sent a ranking sheet listing the 28 shortlisted questions in a random order (appendix 7) in advance of the workshop and asked to complete this beforehand so that there was a record of their initial thoughts and a basis for the discussions to start from.

The workshop agenda can be seen in appendix 8. Participants worked in a series of small groups to rank the 28 questions. A final session was held where the aggregate ranking was presented and a consensus was reached by discussion. The interim rankings from the prioritisation survey were made available for reference during the discussions.

This process was challenging, requiring discussion and consensus to be reached between diverse groups. Participants were pragmatic, respectful of others' views and open to compromise, which helped to make the workshop a success. All groups engaged in discussion and debate and the facilitators were sensitive to the relative input of different participants and endeavoured to ensure that no one dominated, or was excluded from, the discussion. By the nature of the topic, the day was emotional and tiring for many participants (and observers). A quiet space was made available for anyone who was distressed or wanted to take some time to reflect.

## Stage 5: Publishing results

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The results published in this report will be disseminated to researchers, funders, and those who participated in the project, surveys or workshop.

All longlisted questions will also be made publically available via the UK Database of Uncertainties about the Effects of Treatments (UK DUETs - [www.library.nhs.uk/duets](http://www.library.nhs.uk/duets)), which publishes treatment uncertainties from patients, carers, clinicians, and from research recommendations, covering a wide variety of health problems.

Further work is planned to analyse the non-PICO questions received through the initial survey and these results will be published separately where appropriate. More information regarding this work can be found at [www.palliativecarepsp.org.uk](http://www.palliativecarepsp.org.uk)

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**"Patients, carers, and clinicians have a significant role to play in shaping the research we do in palliative and end of life care."**

Professor Sonja McIlfrack, University of Ulster, former Head of Research at the All Ireland Institute of Hospice and Palliative Care (AIHPC)

# Results

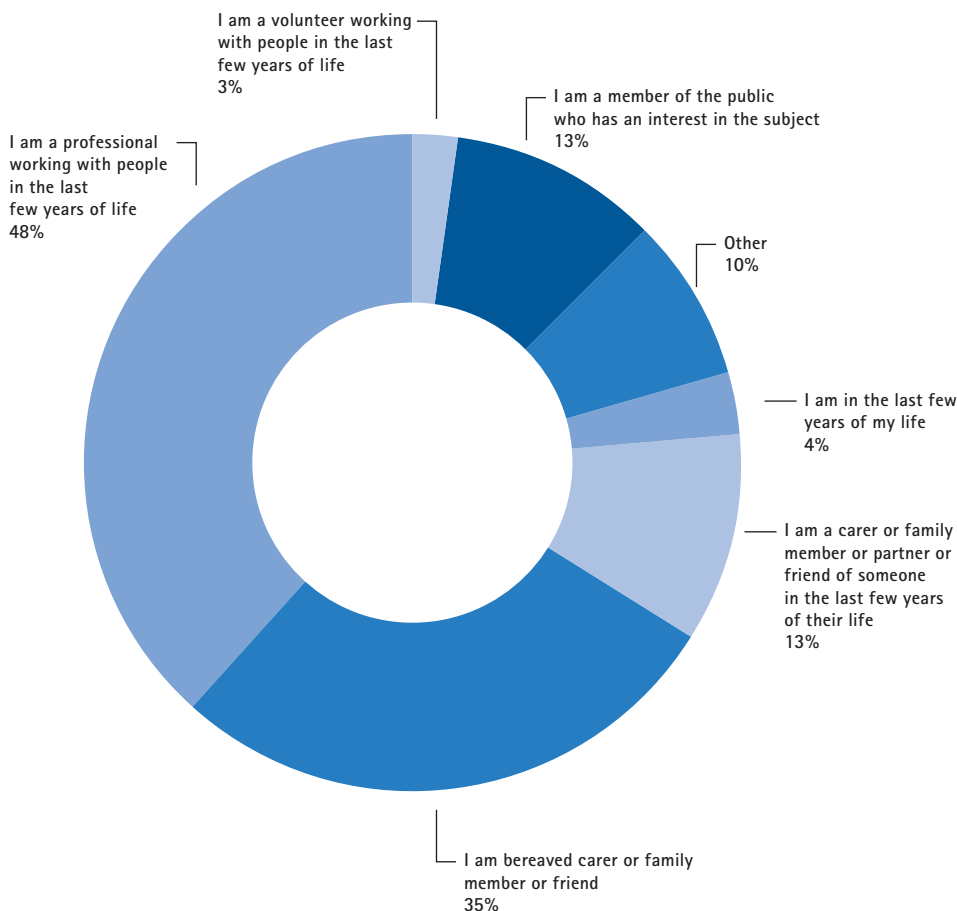
## Initial survey

A survey, open from 9 December 2013 until 16 May 2014, asked people likely to be within the last years of life, current and bereaved carers, and health and social care professionals to submit their unanswered questions about palliative and end of life care. We received 1,403 responses and analysed them to draw out research questions which were combined where appropriate. Searches assessed whether any of the questions had already been answered by an up-to-date systematic review of existing research evidence.

Most respondents identified as a professional working with people in the last years of life (48%). Of these, several different professions were represented. Of those who identified their profession, palliative care doctors, specialist palliative care nurses and nurses made up the highest proportion. GPs, other specialist nurses and professionals allied to medicine were also among the professions represented.

Bereaved carers, family members and friends made up 35% of respondents, while 13% identified as being a current carer. There was overlap between all categories, and many professionals also identified as a current or bereaved carer.

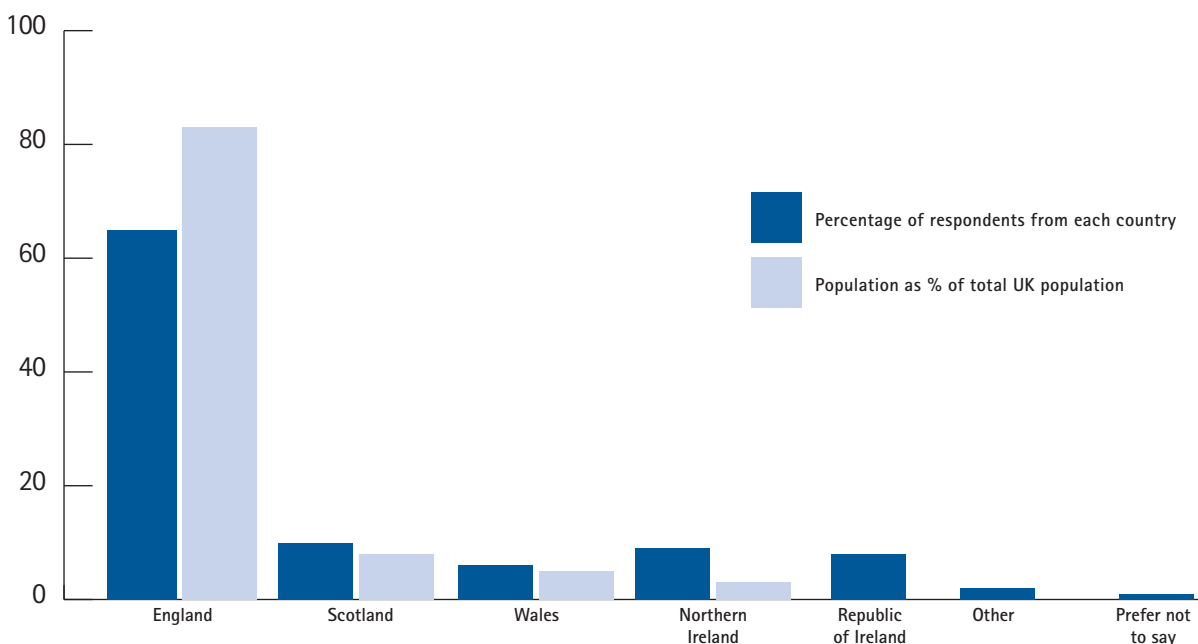
**Figure 1: Respondents to first survey**



Those who identified as being in the last few years of life comprised 4% of the respondents. It was anticipated that this group would be difficult to reach and the steering group took measures to make the survey as accessible as possible. For example, patient networks were specifically approached to disseminate the survey, a paper version was made available in hospices and through the Marie Curie Nursing Service, a large print version of the survey was available on request, and people were able to respond by telephone.

Please see appendix 4 for a full breakdown of respondents.

**Figure 2: Respondents to initial survey by location**



Respondents were given the option to identify where they lived in the UK, to allow us to monitor responses in terms of geographical location and ensure each of the devolved nations was adequately represented.

The dark blue bars on the chart above show the percentage of respondents who identified as being from each of the devolved nations, from the Republic of Ireland, or 'other'. For England, Scotland, Wales and Northern Ireland, the light blue bars show the population of that country as a percentage of the total UK population. All countries were well represented. Indeed, some of the devolved nations were over-represented in their response to the survey. For example, while Northern Ireland has only 2.9% of the UK population, 9% of respondents to the survey were from Northern Ireland.

A more detailed breakdown of responses to the initial survey can be found in appendix 4.

### The 83 longlisted questions

Below is the list of research questions (or evidence uncertainties) resulting from analysis of the initial survey to identify interventional research questions. This list was included in the interim prioritisation survey in September and October 2014 which asked respondents to rate each question on a scale of very low priority to very high priority.

The questions are listed here by theme. However, they were not presented by theme in the survey; the questions appeared in a random order. To skip to the next section, please go to page 21.

#### Communication

- What are the best ways for healthcare professionals to tell patients, carers and families that a patient's illness is terminal and also explain the dying process compassionately and honestly? Can literature, including leaflets, be helpful? Who is the best person to provide this information and communication?
- How can carers and families of people at the end of life be supported to communicate better with each other and their loved one?



- What are the benefits of Advance Care Planning and other approaches to listening to and incorporating patients' preferences? Who should implement this and when?

### Managing symptoms and medications

- What are the best approaches to giving medicines, such as morphine, in a patient's home, for example using different cannulas such as BD-saf-T-intima? What are the pros and cons of training carers, families and non-palliative professionals, such as healthcare assistants, to give these medicines?
- What is the best way to give palliative care to patients with dementia and their carers and families? This includes communicating about their diagnosis when they are being cared for at home or elsewhere?
- What are the best approaches to providing pain relief for people who have communication difficulties, perhaps as a result of their disease, such as motor neurone disease (MND), dementia, brain tumour (including glioblastoma) or head and neck cancer?
- What are the best ways to manage the problems associated with difficulty in swallowing, including for patients with Parkinson's disease, motor neurone disease (MND) and dementia who are at the end of their life?
- What are the best ways to manage drooling and excessive salivation in patients with diseases such as motor neurone disease (MND) who are approaching the end of their life?
- What are the best ways to manage respiratory secretions (death rattle) in patients at the end of life?
- What are the best ways to assess and treat pain and discomfort in people at the end of life with advanced dementia, Parkinson's disease and other diseases that affect cognition and communication?
- What are the best ways to make sure that palliative care patients receive adequate pain and symptom relief and which drugs for pain management are best in terms of side-effects, such as drowsiness?
- What are the best ways to manage acute and/or chronic breathlessness in patients with cancer and non-cancer terminal illnesses?
- What are the pros and cons of withdrawing MST (morphine sulphate) in people at the end of life?
- Which sedative drugs (such as midazolam, haloperidol and levomepromazine) are most beneficial for managing agitation at the end of life and which are best in terms of side-effects? Do these drugs have an effect on other symptoms?
- What are the best ways to diagnose and treat delirium, agitation, distress, and restlessness in people at the end of life?
- How can distress that is not related to pain be best assessed and managed in palliative patients with dementia, Parkinson's disease and other diseases that affect communication?
- What are the benefits and limitations (physical, social, psychological) of providing artificial hydration and nutrition (for example, a drip) to patients at the end of life, including those with bowel obstruction? When should this be done?
- What are the best ways of managing cachexia (weight loss) in palliative care patients, including people with cancer or motor neurone disease (MND)?
- Is it ever necessary to withdraw food and water (non-artificial hydration/nutrition)?
- Is there an appropriate time to withdraw artificial hydration and nutrition (for example, a drip) and how can this be done sensitively and consensually? What is the best way to communicate with the carers and family about this process?
- What is the best diet for palliative care patients? For example can maintaining a healthy weight and eating fatty or protein-rich foods have an impact on their disease progression?
- When should patients be (deeply) sedated? What are the benefits and limitations of sedation and what are the best ways of consulting patients, carers and families?

- What are the best treatments for nausea and vomiting (including for people with bowel obstruction and those having palliative chemotherapy)?
  - How is incontinence best managed in people who are approaching the end of life (including those with Parkinson's disease)?
  - What are the best treatments for fluid retention in patients approaching the end of life?
  - What are the best ways to prevent blood clots, deep vein thrombosis and pulmonary embolism for patients at the end of life? What is the role of low molecular weight heparin (LMWH)?
  - How are steroids best used in palliative care (dose, duration, etc) for patients with different conditions, including those with brain tumours?
  - What are the benefits and limitations of chemotherapy and radiotherapy for patients approaching the end of life, including those with brain tumours? How can healthcare professionals best communicate this?
  - What are the best ways of managing constipation, including when caused by medication, such as opioids?
  - What are the benefits and limitations (physical, social, psychological) of blood transfusions at the end of life?
  - What are the best ways to recognise and treat depression, anxiety and low mood in people who are dying? What are the pros and cons of different psychotherapeutic interventions, including drug therapies, and when is the best time to provide them?
  - What are the best ways to treat dry mouth in patients at the end of life, including medications and foods, such as pineapple?
  - What are the best ways to ensure that people with motor neurone disease (MND) receive essential care promptly on diagnosis, when is the best stage to transition to palliative care and when should a "just in case kit" be considered?
  - What are the best models of palliative care for people who have learning difficulties?
  - What are the best models of palliative care for people who have mental health issues?
- Support**
- Carers and families**
- Does respite for people caring for a family member or friend who is dying benefit the patient's care and the quality of life for both the patient and carer? What is the best way to provide respite?
  - How can carers and families be encouraged to seek support for themselves at the right time?
  - What information and training do carers and families need to provide the best care for their loved one who is dying?
  - Do people who are dying and their carers and families fare better if domestic support with shopping, washing up, laundry, etc, is provided?
  - What are the benefits, and best ways, of ensuring patients, carers, families and friends are given privacy and not restricted in visiting hours when palliative care is given in a hospital, care home or hospice?
  - What are the benefits of, and best approaches to, providing palliative care in care homes, including symptom relief, emotional and spiritual support for patients, carers and families?
  - Does practical advice for concerns about housing, finance and transport, etc, reduce anxiety for carers and families and increase their wellbeing?
  - What are the best approaches to support carers and families of people at the end of life where there are substance and/or alcohol addiction and/or domestic violence issues?
  - What are the best ways to support children and young people when someone close to them is dying or has died? This includes communicating with them about the diagnosis and dying process, enabling them to talk about their experience and providing bereavement support.

- What are the best ways and times to meet the emotional support needs of patients, carers and families, including one-on-one peer support, support groups and professional counselling?
- How can patients, carers and families be supported when the patient does not want their carers and families to know their prognosis?
- Since patients are often seen by a variety of professionals and services, would care improve if patients carried their own medical notes?
- What are the benefits of increasing the number of palliative clinical nurses/nurse specialists in hospitals, GP surgeries, nursing homes and other settings?

### **Bereavement**

- Should bereavement support be made available to all bereaved people and, if so, how? Should GPs or other professionals provide bereavement visits?
- How can the risk of intense and long-lasting grief best be assessed and treated? Can this be prevented through early bereavement support?
- What are the benefits of bereavement support, including preventing depression and other illness?
- When is the best time to introduce bereavement support, and for how long? Should it be offered before the death of a loved one? How can this support be catered to individual needs, including access to 24-hour support?
- Who should be part of the care team (such as chaplains, occupational therapists, GPs, etc)?
- When is it appropriate to receive care virtually (such as via Skype or video-phone calls)? What are the benefits and potential harms for patients, carers and families?
- 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?
- What are the best care packages for patients, carers, family and staff which combine healthcare and social care and take individual prognosis into consideration?

### **Training and staff support**

- What are the benefits of setting up universal training courses for volunteers, carers, families and complementary therapists who have regular contact with palliative care patients?
- Are hospices, hospitals and care homes providing adequate staff training to deliver specialist palliative care, and to what extent does funding affect this? How can high quality trained staff be ensured no matter where the care is being delivered?
- What are the benefits of all health and social care staff having training in bereavement awareness and support? Is this possible?
- Much palliative and end of life care is provided by charities. What are the benefits and risks of this and is it sustainable and efficient?
- Is there evidence that some volunteer services that provide support for patients, carers and families reduce the need for paid trained staff?
- Do people at the end of life who receive support from volunteers, carers, family or friends, have better end of life experiences than those who do not?

### **Service use**

#### **Care coordination**

- What are the best ways to facilitate communication across services and between healthcare professionals, including effective IT systems, team meetings and remote technology?
- How can patients, carers and families easily access care services, equipment and statutory welfare benefits? How can people learn what resources are available and limit the time it takes to access these?

- How can palliative care information and services be made more accessible to people whose first language is not English?
- How can access to palliative care services be improved for everyone regardless of where they are in the UK?
- 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.
- Are outcomes (for example, symptom control and incidental prolonging of life) better for terminally ill patients the sooner palliative care is introduced and services are accessed?
- How can people who live alone and do not have friends or family nearby receive adequate palliative care, particularly if they wish to stay in their homes?

#### **Place and type of care**

- What are the best ways to begin and deliver palliative care for patients with non-cancer diseases (such as chronic obstructive pulmonary disease (COPD), heart failure, motor neurone disease (MND), AIDS, multiple sclerosis, Crohn's disease and stroke)?
- Does earlier palliative intervention for patients with chronic obstructive pulmonary disease (COPD) improve quality of life? When is the right time to intervene to improve understanding of prognosis, exercise tolerance, overall progression and access to pulmonary rehabilitation?
- What are the core palliative care services that should be provided no matter what the patients' diagnosis are?
- What are the benefits for patients, carers and families of day hospices and day therapies such as complementary therapies, rehabilitation and physical exercise? Do they help people stay more independent? When are the best times to refer palliative patients to these services and who benefits most?

- 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?
- What are the pros and cons of receiving palliative care in different environments, including at home, in a hospice, hospital or care home? Are there certain people and conditions that each are best for?
- What are the best models of palliative care in an acute setting, such as a hospital?
- How can the spiritual support needs of palliative care patients and their carers and families best be met in a way that is appropriate for people of different religions and people who are not religious?
- Are some palliative care approaches better than others (eg holistic support, coordinated care, nurse-led care, early intervention) and for whom?
- What are the benefits of occupational, beauty and diversion therapies (such as mindfulness, meditation, art, dance and gardening) for palliative care patients? How and where are these best provided?
- What are the benefits of alternative therapies (such as homeopathy) or complementary therapies (such as acupuncture) for palliative care patients? How and where are these best provided?

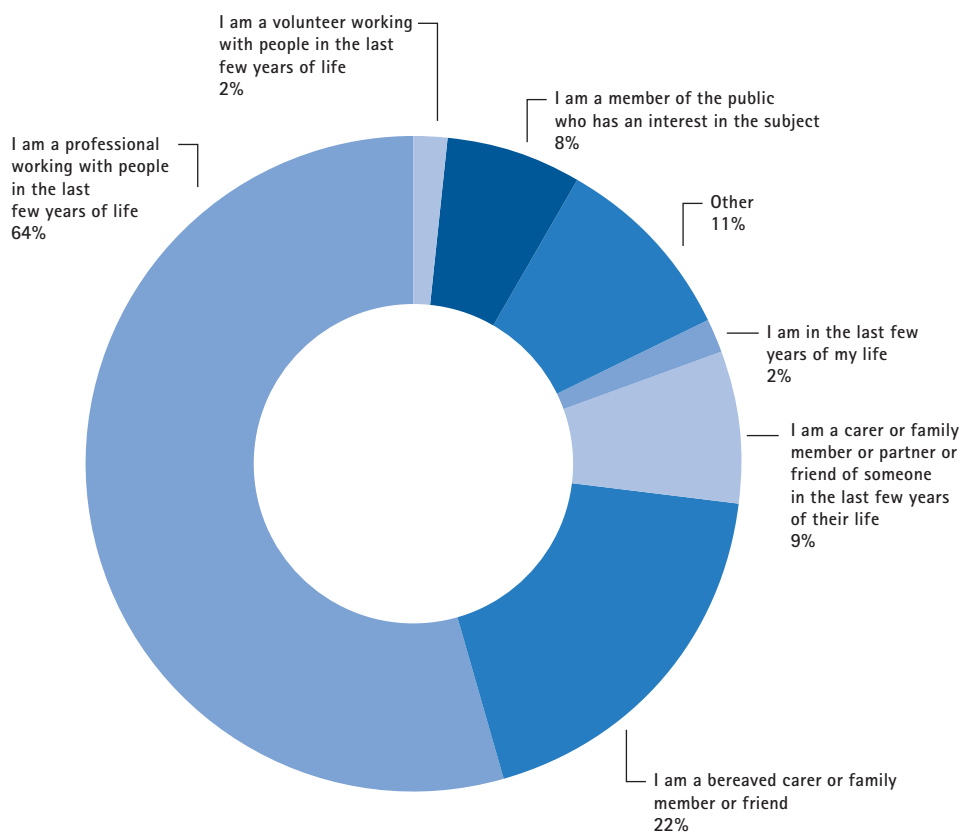
#### **Understanding dying**

- How can we best determine a person's palliative care needs, particularly for patients with non-cancer diseases such as motor neurone disease (MND), Parkinson's disease, dementia and heart failure?
- Do people with various types of terminal cancer have different palliative care needs? If so, what are the best ways of managing their symptoms?
- What are the signs that a person will die in the next few days and how can detection of these signs be improved? How can families be made aware?

## Interim prioritisation survey

The interim prioritisation survey was open from 29 September 2014 to 26 October 2014. We received 1,331 responses from people likely to be within the last years of life, current and bereaved carers, and health and social care professionals. These results were reviewed by the steering group and resulted in a 'shortlist' of 28 questions.

**Figure 3: Respondents to second survey**



Most respondents were professionals working with people in the last few years of life (64%) followed by bereaved carers, family members or friends (22%). Current carers made up 9% of respondents.

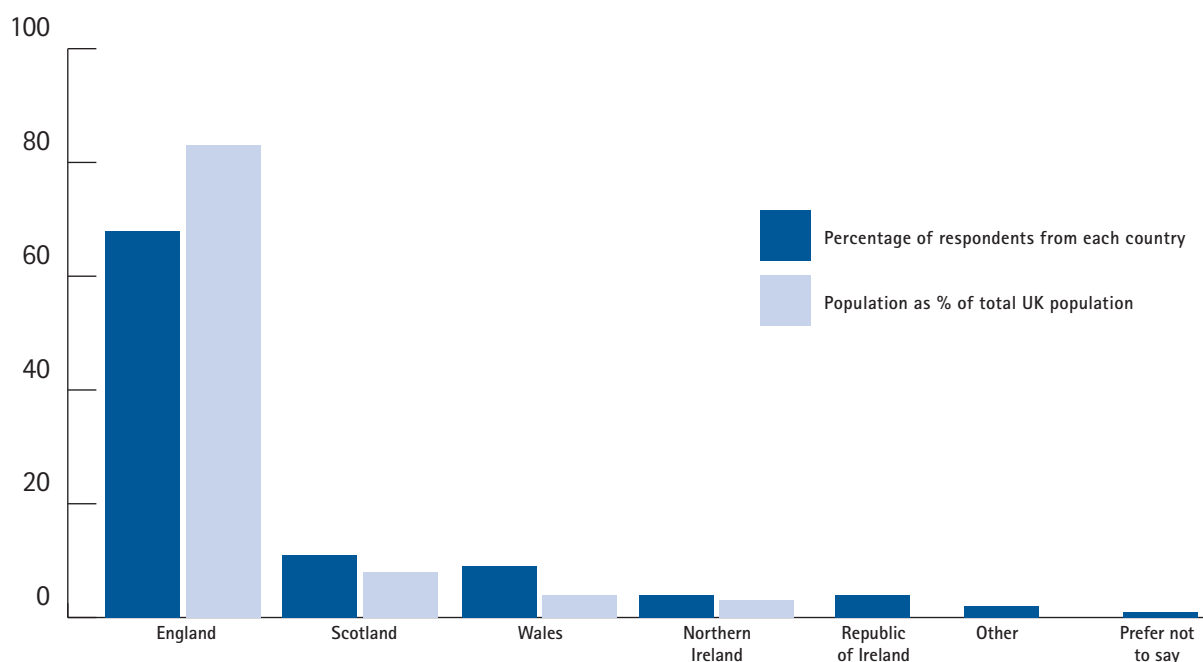
Some respondents identified themselves as belonging to more than one category, so there was overlap between categories.

People in the last years of life made up 2% of respondents. Again, efforts were made to reach patients – paper copies were made available upon request, and patient networks were specifically approached to disseminate the survey. To ensure

that the priorities of people who identified as in the last years of life were not "lost" amongst responses from other groups, such as professionals, the steering group took special care to ensure that the highest ranking questions identified by those in the last years of life were reflected in the top 28 questions that were taken to the final workshop.

A more detailed breakdown of respondents can be found in appendix 6.

**Figure 4: Respondents to interim prioritisation survey by location**



Again, respondents were given the option to identify where they lived in the UK, to allow us to monitor responses in terms of geographical location and ensure each of the devolved nations was adequately represented.

The dark blue bars on the chart above show the percentage of respondents who identified as being from each of the devolved nations, from the Republic of Ireland, or other. For England, Scotland, Wales and Northern Ireland, the light blue bars show the population of that country as a percentage of the total UK population. All countries were well represented. Indeed, some of the devolved nations were over-represented in their response to the survey. For example, while Scotland has only 8.4% of the UK population, 12% of respondents to this survey were from Scotland.

A more detailed breakdown of responses to the interim prioritisation survey can be found in appendix 6.

*"My biggest concern is the lack of continuity for patients and carers, and for the healthcare assistants and nurses who care for them. This issue was talked about thoroughly on the day of the workshop. I was delighted that it was one of the 10 areas which will be prioritised for further research."*

Susan Bell, Marie Curie Senior Healthcare Assistant

## Final workshop

A final prioritisation workshop was held on 21 November 2014 to identify the top 10 unanswered research questions, or evidence uncertainties, in palliative and end of life care. The workshop participants ranked all 28 questions in order of priority. The full list can be found in appendix 9.

### 24 participants attended:

- 11 professionals working with people in the last few years of life
- Four people who were bereaved carers as well as professionals working with people in the last few years of life
- Four bereaved carers
- Two current carers
- One patient
- One person who was a patient representative as well as a professional working with people in the last few years of life
- One person who was a patient, a current carer and a bereaved carer.

"My mother, who had Parkinson's, died last year. Although she had a good death at her nursing home, I also went through very stressful times when we thought death was close and things were not good in the hospital. I wanted to use those experiences to support work that can help improve end of life and palliative care for everyone."

Anne Ferrett, workshop participant

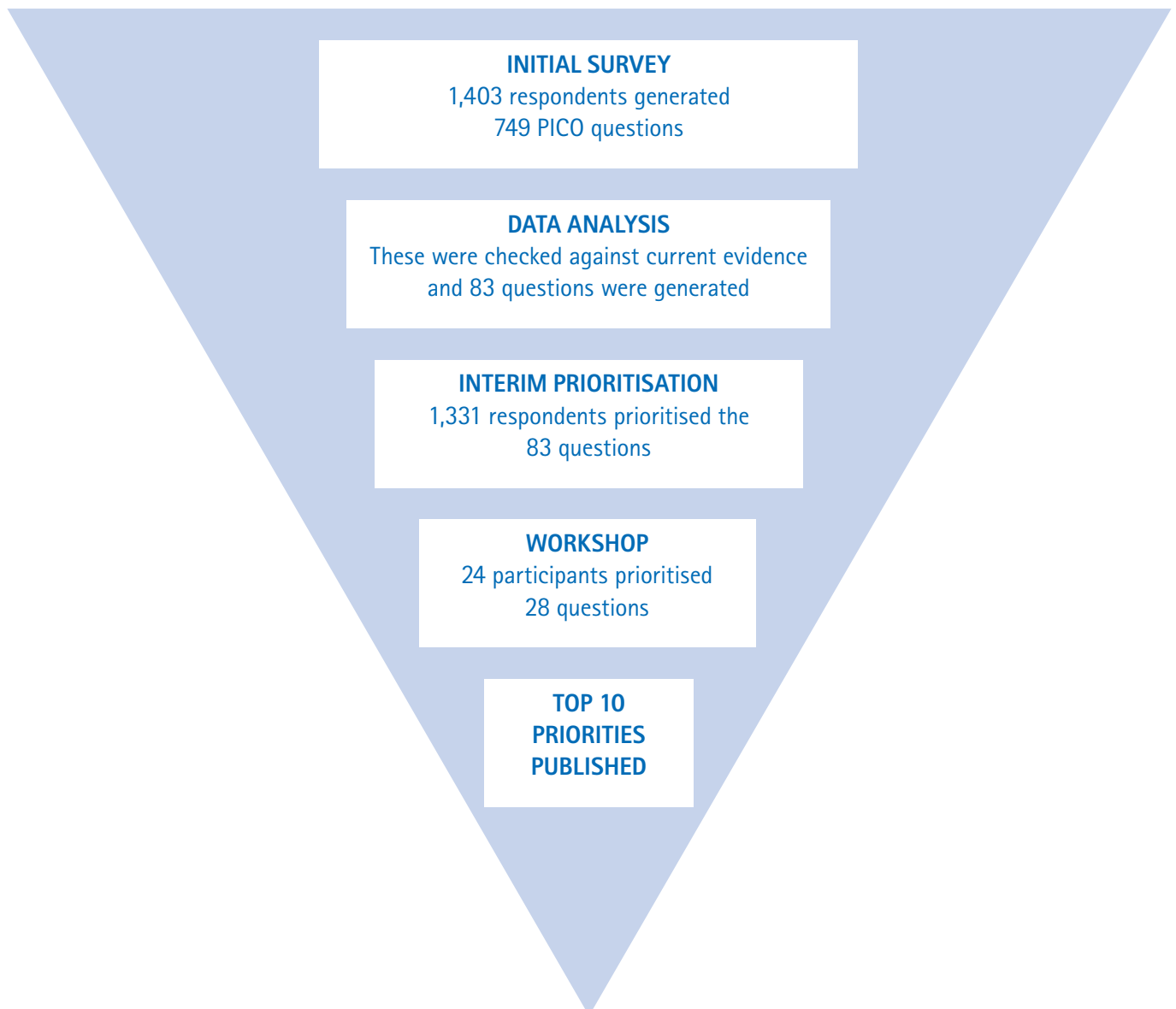
"At the workshop, there was an excellent mix of people – it was fascinating to see people from different areas of work and background coming together for the discussion. Some people who came had two hats on – both as a care professional and a service user."

Suzanne Slater, practice educator assistant at the Marie Curie Hospice, Liverpool

"If research is for the benefit of people, then people should be involved in guiding research."

Rebecca Woodward, healthcare assistant for a Hospice at Home service in central London and doctoral researcher

## Overview and results of the PeolcPSP methodology





# Conclusions

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## Top 10 priorities for palliative and end of life care research

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The following unanswered research questions or evidence uncertainties were identified and prioritised by patients, carers and health and social care professionals to inform the future of palliative and end of life care research. The top 10 questions were launched on 15 January 2015 at the Palliative and End of Life Care Research Summit organised by the National End of Life Care Intelligence Network (part of Public Health England) and NHS England.

### The Top 10 unanswered questions in palliative and end of life care in order of priority are:

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?

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"I found the experience of being involved in the workshop very stimulating. The facilitation of the event was flawless and I have complete confidence in the results produced, given that the process was so democratic and represented such a range of experiences and voices."

Rebecca Woodward, healthcare assistant for a Hospice at Home service in central London and doctoral researcher

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"This project will be invaluable to help guide our research priorities for the future, as we strive towards a world free from motor neurone disease."

Dr Belinda Cupid, head of research at the Motor Neurone Disease Association



# Next steps

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## For research funders...

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Funding for palliative and end of life care research is limited. The findings of the PeolcPSP will enable existing funders of research – including many of the project partners – to target their funds to the priorities that matter most to patients, current and bereaved carers and health and social care professionals. Research funders will also be able to coordinate their efforts and tackle the highest priority questions together.

## For researchers...

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The results will enable researchers who are applying for funding on these topics to demonstrate that their research will be valuable to the people who most need it. All of the longlisted questions will be made publicly available via the UK Database of Uncertainties about the Effects of Treatments (UK DUETs), which publishes treatment uncertainties from patients, carers, clinicians, and from research recommendations, covering a wide variety of health problems.

## For charities...

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Charitable funders and their policy teams will be able to use this project to demonstrate the need for increased funding in palliative and end of life care, and campaign to achieve this. We hope that there will be an increased awareness and interest in funding and conducting research in palliative and end of life care as a direct result of the PeolcPSP.

## For the PeolcPSP...

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The original survey returned over 1,400 responses, many of which included comments and questions that did not fit with the JLA methodology of identifying and prioritising interventional research questions. The PeolcPSP is looking at ways to further analyse these out-of-scope data to highlight questions and comments that could be addressed by other types of research, eg qualitative research.

We will feed back lessons learned by the PeolcPSP to the JLA and we hope that future partnerships will build on these lessons.

# Recommendations

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- 1) We encourage research funders to integrate the priorities into their research strategy.
- 2) We encourage funders, researchers and interested parties to use this report to promote awareness of the project and its results among the public, and among decision makers, to raise the profile of palliative and end of life care research in the UK.
- 3) We encourage researchers to focus their efforts on answering the highest priority questions to patients, carers and clinicians, and to refer to the PeolcPSP results in their applications.
- 4) We encourage organisations that are not yet funding palliative and end of life care research to do so, since there is a clear and urgent need for research in this area.
- 5) We encourage other charities and organisations to investigate palliative and end of life care priorities for their specific audience, including specific conditions relevant to end of life care. Paediatric palliative care may also warrant specific investigation as this was out of scope and there was a notable interest in it.

# How to get involved

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## 1) Use the priorities

These priorities have been determined to be most important to patients, carers and clinicians, so please consider how you and your organisation can use these priorities to inform the work that you do. This might involve using the priorities to guide your research funding strategy if you work for an organisation or charity, or to influence policy or campaigning work, or guide your research funding applications if you are a researcher. We all owe it to the patients, carers and clinicians who told us what their most important questions are to make every effort to answer these through research.

## 2) Tell us how you are using the priorities

The more information we have about how the priorities are influencing the palliative and end of life care research agenda in the UK, the more weight is lent to the importance of future Priority Setting Partnerships. This will also allow us to learn from each other's successes and mistakes and to forge partnerships to more effectively tackle the priorities.

## 3) Tell other people about the priorities

The more people within palliative and end of life care who know about the priorities, the more likely organisations and individual researchers are to take these priorities on board. The higher palliative and end of life care research is on the public agenda, the more likely this research is to improve policy and practice – ultimately benefiting people likely to be in the last years of life, and their families and carers.

If you have any queries or comments, please contact the Project Coordinator on [peolcpsp@mariecurie.org.uk](mailto:peolcpsp@mariecurie.org.uk). More information on the project process, news coverage and partners is available at [www.palliativecarepsp.org.uk](http://www.palliativecarepsp.org.uk)

If you have been affected by any palliative and end of life issues and need further information or support, please visit the support page at [www.palliativecarepsp.org.uk](http://www.palliativecarepsp.org.uk) for links to organisations who may be able to help.

# Disclosures

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The budget covered funds for a part-time (50%) project coordinator for 18 months, and an information scientist employed for six months at the Marie Curie Palliative Care Research Centre at Cardiff University, to check the available evidence.

The project was independently overseen by the James Lind Alliance, a non-profit-making initiative, which is coordinated by the National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre (NIHR NETSCC). The project was managed by a steering group, led by an independent chair from the James Lind Alliance. The steering group included representation of patient/carer groups and clinicians, as well

as representatives from funding partners. All decisions about the project's development, delivery and dissemination were made by the steering group.

There are no known conflicts of interests for the organisations co-funding the project, or the organisations or individuals represented on the steering group.

## The PeolcPSP was initiated by Marie Curie and jointly funded by the following funding partners:

Organisation	Funding
Marie Curie	£20,000
National Institute for Health Research (NIHR) Evaluation, Trials and Studies Coordinating Centre (NETSCC)	£10,000
Chief Scientist Office (CSO)	£10,000
National Institute for Social Care and Health Research (NISCHR)	£10,000
Motor Neurone Disease Association (MND Association)	£5,000
All Ireland Institute of Hospice and Palliative Care (AIHPC)	£4,170 (€5,000)
Underspend from the National Cancer Research Institute (NCRI) Lung Cancer SuPaC Initiative, co-funded by Macmillan Cancer Support, Cancer Research UK (CRUK), Department of Health (DH), Medical Research Council (MRC), Economic and Social Research Council (ESRC), Chief Scientist Office (CSO) and Health and Social Care R&D (Northern Ireland)	£20,000
<b>Total</b>	<b>£79,170</b>

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## For more information contact:

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If you have any queries or comments, please contact the Project Coordinator on [peolcsp@mariecurie.org.uk](mailto:peolcsp@mariecurie.org.uk)

More information on the project process, news coverage and partners is available at [www.palliativecarepsp.org.uk](http://www.palliativecarepsp.org.uk)

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## Palliative and end of life care Priority Setting Partnership

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