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

A grant mapping analysis of the UK Clinical Research Collaboration's Health Research Classification System dataset 2014

Contents

Forewords

This report is based on data collected via the 2014 UK Health Research Analysis, supported by the UK Clinical Research Collaboration (UKCRC). By analysing changes in the UK research funding landscape over a 10-year period, UKCRC reports have strengthened coordination of health research funding at an organisational and national level, and allowed funders to identify research needs. This report is one example of how this data can be re-used to provide evidence for more strategic decision-making.

The UKCRC sought to expand and enhance the 2014 analysis by encouraging more research organisations to participate than had been included previously (in 2004 and 2009). This meant Marie Curie and 47 other organisations were included, adding £128 million to the analysis – 6% of the £2 billion total. The data clearly shows how this adds value to the whole endeavour. In a pertinent example, 23% of funding coded as end of life care [Health Research Classification System (HRCS) Research Activity 7.2] comes from organisations

new to the analysis, demonstrating that these organisations make critical contributions to the UK research landscape.

In our recent paper discussing the UKCRC analysis series[1], we were keen to emphasise that availability of portfolio information and sharing funding data can be of great benefit to research organisations. For example it allows areas of interest to be studied in greater detail than can be addressed in a single nationwide report.

This report highlights the advantage of making more detailed data from these analyses freely and publicly available. We are delighted that Marie Curie has been able to use the 2014 data so effectively, and we encourage others to do likewise.

Dr James Carter
Project Manager, UK Health Research Analysis 2014, Medical Research Council

[1] Carter, Sherbon & Viney (2016). United Kingdom health research analyses and the benefits of shared data. Health Research Policy and Systems 14:48 DOI: 10.1186/s12961-016-0116-1

We have as much right to die well as we do to live well. Research has the potential to make a significant difference to how palliative and end of life care can help us, and those we care for, die with dignity and live as well as possible until death. Research can only do this if we focus on the right questions and make the findings available, so we can implement what we know. This report will help the research community do this.

We should be proud that, in our society, funding for research remains a priority – whether that is from the public purse through taxation or from public purses into the charity box. However, funding is limited, which means that deciding on the right questions and allocating research funding is a challenge.

You will see from this report that uncertainties about how to provide the best care, identified through the Palliative and end of life care Priority Setting Partnership (PeolcPSP) with the James Lind Alliance, are among the most challenging questions we put to the research community and are often not well-addressed by current research.

The James Lind Alliance brings together patients, carers and health-related professionals in an equal partnership to identify and prioritise the most important unanswered research questions. The National Institute for Health Research (NIHR) is proud to support the James Lind Alliance by hosting and funding its infrastructure. The real credit, of course, goes to the donors, charities and participants of each partnership. Their financial, emotional, intellectual and time commitment deserves appropriate attention from researchers and funders of research.

This reports highlights that while important uncertainties remain, good research is already underway. Identifying what research is currently being undertaken is as important as deciding what further research is needed, to avoid duplication and facilitate collaboration. Using the Health Research Classification System (HRCS) 2014 dataset to identify in which of the PeolcPSP questions research is underway, and which are much less addressed, will help the research community build on what is already known, or is ongoing, under each of the palliative and end of life care research priorities. This is an important report that all of us involved in palliative and end of life care research should take note of.

Dr Matthew Westmore
Director of NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC)

1. Report at a glance

1.1. Aims of the report

This report highlights under-researched areas in palliative and end of life care. It provides a snapshot of ongoing and very recent research by mapping research activity in 2014 against 83 questions from patients, carers and health and social care professionals. The questions were identified through the Palliative and end of life care Priority Setting Partnership (PeolcPSP) with the James Lind Alliance (JLA).

The report is for researchers, funders and policy planners. It can help them:

- avoid duplication by highlighting current research.

- foster collaboration by showing who is already active in addressing specific research questions.

- identify and tackle questions that are not currently examined at all.

1.2. Project approach

The project takes a novel approach to identifying gaps in research by mapping publicly available health-related research grant data to the questions identified by the PeolcPSP.

The data is taken from the UK Clinical Research Collaboration's (UKCRC) 2014 Health Research Classification System (HRCS) dataset. In mapping this data, the report distinguishes between grants with strong links (which directly address the PeolcPSP questions through an intervention or more discursive and exploratory projects) and those with weak links (which provide background information relating to the questions). This shows the extent to which current research is addressing the priorities that matter to patients, carers and health and social care professionals.

Why is it useful to know where current research funding is going?

- To highlight gaps in research.

- To show areas where, in the near future, research may be put into practice by highlighting interventions that are currently being researched.

- To reduce waste, cost and patient burden caused by repeating similar research projects.

- To guide future funding calls and encourage funder collaboration.

- To make future research applications more targeted.

- To encourage collaboration between researchers by highlighting current research on specific PeolcPSP questions.

How can this report encourage research and have an impact on palliative and end of life care?

- By highlighting the research priorities identified by patients and carers that continue to be unmet.

1.3. Key messages

- This project confirmed the findings of the PeolcPSP report; further research is needed for all 83 PeolcPSP questions.

- Some questions were in the process of being addressed, while some might need an up-to-date systematic review.

- Of the 83 questions, 49 had no reference to an up-to-date systematic review.

- Figure 1 shows that in 2014, four of the questions were not addressed by any funding, with no strong or even weak connections to current research.

- By stressing the importance of conducting research which has interventional aims and sets out to enhance practice.

- By encouraging systematic reviews for any of the relevant 83 PeolcPSP questions.

- The four questions that received no funding related to patient fluid retention; supporting children following bereavement; providing support when the patient doesn't want the prognosis known; and making bereavement support available to all bereaved people.

- A further 15 questions did not receive any funding with strong links.

- 11 other questions were addressed by less than £50,000 of funding with strong links.

- A sub-theme about bereavement received no direct funding at all.

- The least addressed of the top 10 priorities were about how to provide out-of-hours palliative care, support for carers and how to ensure continuity of care.

- The question to receive the most funding asked about the best way to provide palliative care to patients with dementia.
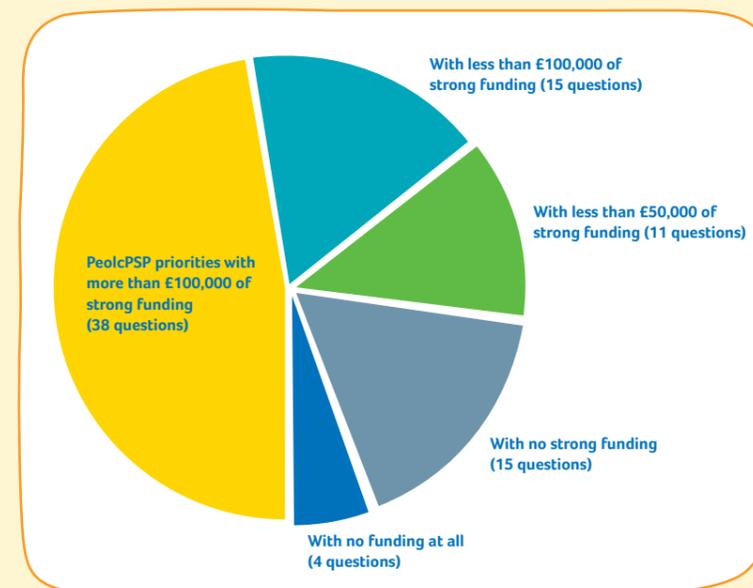

Figure 1: A pie chart showing the amount of funding with strong links to the 83 PeolcPSP questions

2. Introduction

2.1 How do we know these are the questions that matter most to patients, carers and clinicians?

In 2015, the Palliative and end of life care Priority Setting Partnership (PeolcPSP), with the James Lind Alliance (JLA), sought to identify the research priorities that are most important to the end users of palliative and end of life care research – patients, carers and health and social care professionals.

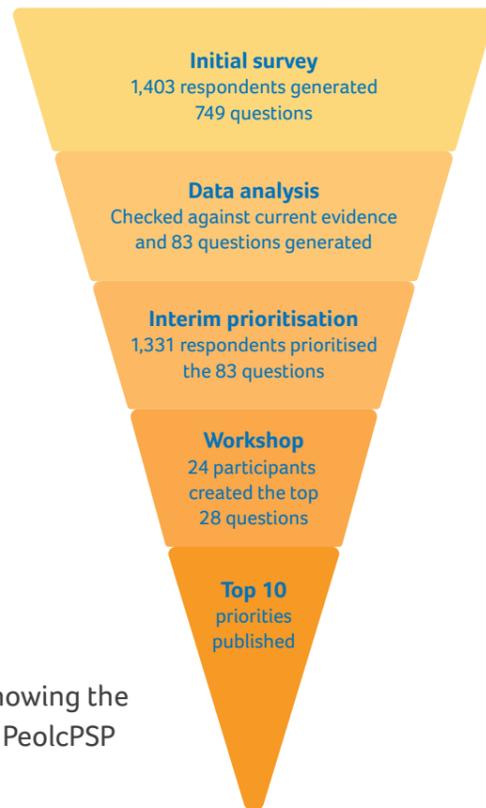The PeolcPSP had the following partners:

Figure 2 shows that the PeolcPSP consulted 1,403 people through an open online and paper-based survey. The responses were then analysed to identify interventional questions on treatments or other forms of care. These questions were checked against systematic reviews of existing trial research to determine whether they were already sufficiently answered. Eighty-three questions were found to be unanswered, as defined by the JLA[1], meaning there is no up-to-date, reliable systematic review (defined in Box 1), or a systematic review shows an uncertainty exists.

A second open survey was undertaken to prioritise the questions by importance. This survey had 1,331 responses from a range of carers,

Initial survey
1,403 respondents generated 749 questions

Data analysis
Checked against current evidence and 83 questions generated

Interim prioritisation
1,331 respondents prioritised the 83 questions

Workshop
24 participants created the top 28 questions

Top 10
priorities published

Figure 2: Diagram showing the methodology of the PeolcPSP

patients and health and social care professionals. The top 28 questions prioritised in this survey were taken to a final priority setting workshop involving the same range of stakeholders. The output was a top 10 list of research questions in palliative and end of life care. The results of this process were published in January 2015 and can be found in the PeolcPSP final report[2].

Box 1: Definitions of key terms in the Priority Setting Partnership process

What is a systematic review?
Systematic review methods in health care are used to summarise the existing clinical research on a topic[3].

The method can be used to critique and summarise the results of available carefully designed healthcare studies (controlled trials). They provide a high level of evidence on the effectiveness of healthcare interventions.

What are interventions?
Interventions are treatments, care and other actions designed to make a difference to patients, carers and families, and which can be tested and evaluated by research[4].

2.2 What do we already know about research funding in palliative and end of life care?

Existing reviews of current research funding

In 2015, the National Cancer Research Institute (NCRI), in collaboration with Marie Curie, highlighted that palliative and end of life care research is an under-represented area[5]. The analysis showed that of the £503 million spent on cancer research by NCRI members in 2013, only £3.08 million (0.61%) was spent on palliative and end of life care research related to cancer.

Also in 2015, the UKCRC published the dataset used in this report, compiled from research carried out in 2014, forming a UK-wide analysis of most governmental and charity-funded
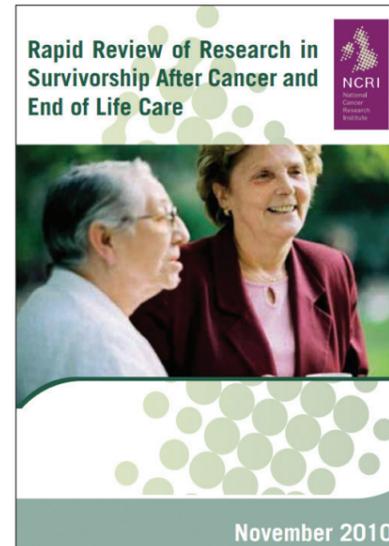

Marie Curie's contribution to palliative and end of life care research funding in the UK
An analysis of the NCRI Cancer Research Database, 2002–13

health research (not just cancer)[6].

According to this analysis, the proportion of research with the main focus on end of life care doubled from 0.08% in 2004/05 to 0.16% in 2014. This still only equates to £3.25 million of the total £2 billion spent on health research in 2014. These two reviews followed very different inclusion and exclusion criteria, which mean the figures cannot be directly compared.

Rapid Review of Research in Survivorship After Cancer and End of Life Care

NCRI National Cancer Research Institute

November 2010

UK Health Research Analysis 2014

UK Clinical Research Collaboration 2015

But they do draw similar conclusions in highlighting that very little is spent on palliative and end of life care research.

This adds to the findings of the NCRI's *Rapid Review of Research in Survivorship after Cancer and End of Life Care* (2010). This report stated that: "While some appropriate funding streams are available, it will take more than money to move this field forward in the UK."[7]

Existing reviews of gaps in research

Recently published National Institute for Health and Care Excellence (NICE) guidance for care of the dying adult covered clinical care of those aged 18 years and over who are in their last two to three days of life[8]. The review assessed the current needs of palliative care and identified four recommendations for research. These recommendations are included in the discussion of this paper, with

the PeolcPSP questions and the grant mapping results considered alongside them.

Policy reports have also identified areas where there is a lack of research. Marie Curie's 2014 policy report *Living and Dying with Dementia in England*, which explored the barriers to care, highlighted that there was still much progress to be made in this area[9].

2.3 The UKCRC Health Research Classification System 2014 dataset

HRCS Online
UKCRC Health Research Classification System

This report uses the UKCRC Health Research Classification System (HRCS) 2014 dataset to provide an overview of health-related research.

The HRCS 2014 dataset is a UK-wide dataset of government and charity-funded health research, and is the third published by the UKCRC since 2004[6]. It is the first dataset to make individual grant information (ie grant title, abstract and funding amount) publicly available.

The HRCS dataset provides an overview or snapshot of funding in health research from major UK grant funding bodies including the 48 Association of Medical Research Charities (AMRC) members who took part.

The 2014 HRCS dataset captures information on £3 billion of health funding in the UK. However, only £2 billion corresponds directly to research projects, with £1 billion coded as infrastructural. The publicly available dataset provides information on the £2 billion of research projects only, and is composed of 14,934 individually coded research projects, funded by 64 funding organisations (48 from newly included AMRC member charities, 12 government and other charity funders who had taken part in previous analyses and four new public funders)[6].

Infrastructure grants (such as core funding to the Marie Curie research centres) are not included in the dataset. The funding totals provided in the HRCS dataset represent an annualised figure, showing only the amount spent in 2014.

The HRCS dataset has a series of inclusion and exclusion criteria for a research project:

Included data:
- Must be funded by a partner organisation.

- Should take place within the UK and be of health relevance.

- Should be active in 2014.

- Must have been peer-reviewed.

Excluded data:
- Industry-funded research.

- Research that was funded by organisations that were not participating in the dataset.

- NHS support for clinical academics.

- Research funded by non-UK funders.

- Research on health that was funded by government departments other than health.

- Research funded by the participating organisations, but taking place outside the UK [10].

The HRCS dataset is a useful tool to review the research landscape of palliative and end of life care. It was created to produce a "robust and openly accessible dataset on UK governmental and charity-funded health research"[6]. This enables the results of this report to:

- avoid duplication by highlighting current research

- foster collaboration by showing who is already active in addressing specific research questions

- encourage researchers to tackle questions that are not currently examined at all

3. Methodology

This grant mapping project used a novel approach which, to our knowledge, has not been reported before. It used a publicly available dataset of 2014 research grant data to identify gaps in research. To make sure the project could be replicated, it followed a structured methodology using a system similar to systematic reviews.

A keyword system identified research that was potentially relevant to the 83 PeolcPSP priorities within the HRCS dataset. Keywords were designated to each of the 83 PeolcPSP questions with the help of an independent systematic reviewer and a palliative care physician. A systematic search was then conducted to ensure that all relevant grants were included in the project (see Appendix 2 for a list of keyword searches).

The searches generated 4,420 research grant abstracts (see Figure 3). These were reviewed against the full list of 83 questions. Abstracts of grants that matched keywords were checked for relevance to the PeolcPSP questions.

Two members of the Marie Curie research management team independently reviewed the abstracts of the selected grants and coded the grants in relation to the PeolcPSP questions. These were coded using a colour system to make the differentiation between the strength of the relationship easier to read (see Box 3). One in every 50 grants was checked by a third member of the research management team to ensure accuracy and consistency in the mapping.
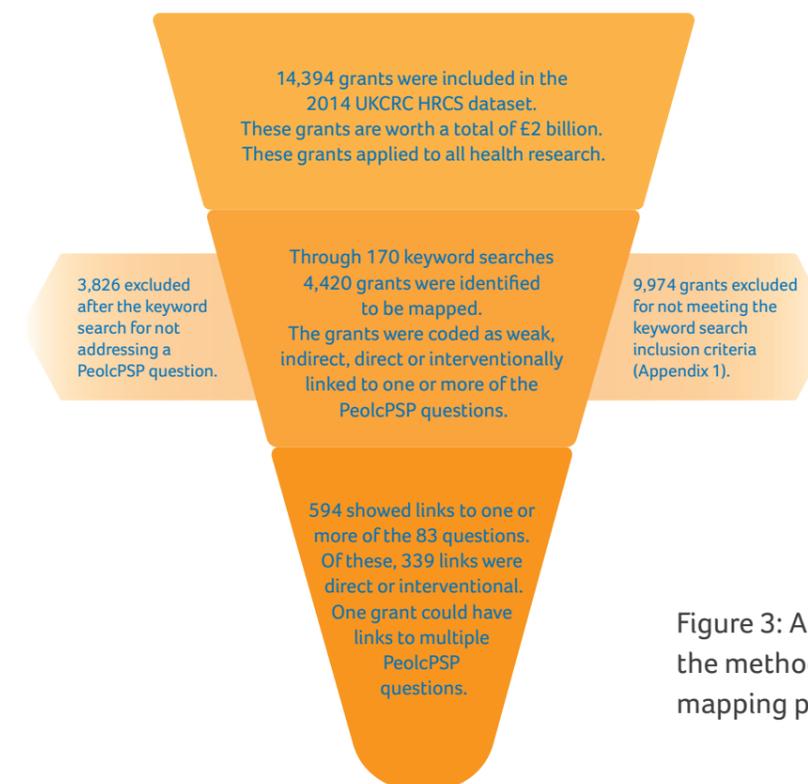

14,394 grants were included in the 2014 UKCRC HRCS dataset. These grants are worth a total of £2 billion. These grants applied to all health research.

3,826 excluded after the keyword search for not addressing a PeolcPSP question.

Through 170 keyword searches 4,420 grants were identified to be mapped. The grants were coded as weak, indirect, direct or interventionally linked to one or more of the PeolcPSP questions.

9,974 grants excluded for not meeting the keyword search inclusion criteria (Appendix 1).

594 showed links to one or more of the 83 questions. Of these, 339 links were direct or interventional. One grant could have links to multiple PeolcPSP questions.

Figure 3: A diagram showing the methodology of the grant mapping process

3.1 **Example of grant mapping**

In 2012, Marie Curie awarded about £1 million to fund a three-year programme grant to improve end of life care for people with advanced dementia, led by the Marie Curie Palliative Care Research Department, University College London.

The grant abstract was entered into the HRCS dataset and mapped against the PeolcPSP questions as it was flagged in many of the keyword searches. The abstract is shown in Box 2.

Box 2: The abstract submitted to the HRCS dataset for the Marie Curie Dementia Research Programme

The Marie Curie Dementia Research Programme: developing an intervention to improve end of life care in advanced dementia

Background: In the United Kingdom (UK) 600,000 people have dementia, and a third of people aged over 65 will die with dementia. Detailed research on the symptom burden and needs of people with advanced dementia at the end of life, and their carers, is lacking in the UK; access to good end of life care is poor.

Aim: To develop and pilot a complex intervention to improve end of life care for people with advanced dementia.

Objectives: 1. To understand in-depth the symptoms, health and social care needs of people with advanced dementia; current pathways of care at the end of life, and needs of informal carers at this time and in bereavement.
2. To develop a complex intervention to improve care including: explanations of its core components; how it may operate in different settings (transferability); cost effectiveness; what works for whom in what circumstances and why.
3. To pilot the intervention in one site, collecting data to inform a future definitive trial.

Methods: We shall work within a realistic evaluation framework to develop and pilot a feasible intervention, in three closely linked workstreams.

In Workstream One (0-12 months) a cohort study of people with advanced dementia and their carers will provide data on clinical and social needs. This will indicate the potential interventions required and inform case studies and vignettes for use in an iterative cycle of workshops and interactive interviews with carers and professional stakeholders. We shall define the core components of the intervention, including an understanding of context and mechanisms, and potential outcomes.

In Workstream Two (9-15 months) we shall refine our intervention, considering adaptation of existing care models. Our intervention, and the team needed, will be described in a manual. We shall consider training and support needs and the costs incurred.

In Workstream Three (15-36 months) we shall pilot our intervention in one setting to understand the interactions required for it to work, how its components influence care pathways, patient and carer outcomes, and assess our training and support programme. We shall check for long term effects, potential for transferability, and describe the cost-effectiveness of its components.

How the results will be used
An in-depth understanding of an intervention to improve care, what works for whom in what circumstances and why, will inform provision of good end of life care in advanced dementia, and also the design of a definitive trial.

This abstract in Box 2 was coded to 11 of the priorities, with a range of intensity mapped. A few of these codes are explained below.

This abstract shows interventional links to PeolcPSP question 5:

What is the best way to give palliative care to patients with dementia and their carers and families? This includes communicating about their diagnosis when they are being cared for at home or elsewhere.

This is mapped as 'interventional' as it clearly aims to develop an intervention to improve palliative care for patients with dementia.

This abstract also has direct links to PeolcPSP question 52:

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?

This is mapped as 'direct' as the abstract considers training and support needs in delivering specialist palliative care and the costs incurred, though this is not the main purpose of the intervention.

The abstract is also indirectly linked to issues surrounding support for carers and families, including bereavement support.

4. Results

4.1 Which of the PeolcPSP questions could be cross-referenced to a systematic review?

Of the 83 unanswered questions, 49 had no reference to an up-to-date systematic review. This is significant given the importance of systematic reviews in summarising the evidence base of all known and robust research in a specific area. The remaining 34 questions had systematic reviews, which highlighted that an uncertainty exists, showing that the questions need further research.

4.2 What has the grant mapping project shown?

Funding by themes

The results of the grant mapping can be split by the five themes of research questions identified in the PeolcPSP process[2].

Table 1 shows that most funds were spent on research relating to service use, with the least spent on the theme of communication. Most of the interventional funding was spent on research around managing symptoms, which includes: research on pain, difficulties swallowing, drooling, respiratory secretions, breathlessness, sedation, delirium, agitation, distress, restlessness, artificial hydration and nutrition, diet, cachexia, nausea and vomiting, incontinence, fluid retention, blood clots, constipation, depression, anxiety, dry mouth and mental health.

However, considering the high costs of clinical trials and the multitude of symptoms experienced at the end of life and addressed in research projects, this still is a small amount and more interventional research is needed.

Funding for individual questions

The grant mapping results can also be used to explore the funding to individual PeolcPSP questions. Table 2 shows the funding amounts for each of the 83 PeolcPSP questions. Projects can map to multiple questions, so the total is for each question only. Questions that correspond with a NICE guidance research recommendation are highlighted in blue in the first column. The PeolcPSP question number in the table corresponds to the full list of PeolcPSP questions in Appendix 2 (complete with the full keyword search list for each question). These numbers are not in priority order, but in the order in which they were published in the final PeolcPSP report.

More detail in full report

The grant mapping exercise provided more detail than can be shown in this report, which mainly shows summaries of total research funds spent in 2014, relating to particular PeolcPSP questions. Appendix 3 shows an example of the detail available for each PeolcPSP question in the full list of results, which includes numbers and titles of grants for all strong funding links and numbers and funding amounts for weak links. The full report is available on the PeolcPSP website: https://palliativecarepsp.org.uk/

Table 1: Summary of the interventional and direct funding in 2014 to each of the five PeolcPSP themes

Theme	Interventional Funding	Direct Funding
Communication	£234,801	£1,070,355
Managing Symptoms	£4,786,860	£9,144,167
Support	£836,601	£1,635,441
Service Use	£1,276,345	£13,428,586
Understanding Dying	£758,347	£4,403,482

Box 3: Coding guide to grants in relation to PeolcPSP questions

• One colour, which increased in intensity, expressed the strength of the relationship to the question.
• All 4,420 grants were read and coded individually to each of the 83 PeolcPSP questions, so one grant could be coded to more than one question.

• Grants could have a variety of links of different strength. For instance, a grant proposing a direct intervention to help answer one PeolcPSP question might also weakly address aspects of other questions.

Interventional grants

Grants coded as 'interventional' use some of the specific wording of the PeolcPSP question as the primary aim of the project with the intention of enhancing practice through an intervention. The intervention proposed must be directly linked to a PeolcPSP question to be coded as interventional for this particular question. These grants should lead to ways in which the specific PeolcPSP question could be addressed in future practice.

Direct grants

Grants coded as 'direct' incorporate some of the specific wording of the PeolcPSP question as the primary aim of the project. However, these grants do not propose an intervention which will directly address the specific wording of the PeolcPSP question. A good example of a direct grant is a systematic review, as it can directly address a question but does not propose an intervention. Some grants with clear interventional outcomes may be coded as direct if the intervention does not specifically address the PeolcPSP question in hand, but nonetheless addresses the subject matter.

Indirect connection

Grants are coded as 'indirect' when similar wording to the question is used, but not as a primary objective of the project. Clear connections are made, but the question is not the intended focus of the grant.

Weak connection

Grants are coded as 'weak' when the wording of the question is not specifically mentioned and it is not a primary aim of the project. These grants are still linked to a PeolcPSP question as knowledge relevant to the PeolcPSP might result from the grant, but only as background information.

Weak and indirect links are coded to each grant abstract but are not included in the following analysis as, by definition, they do not directly address the PeolcPSP questions in their primary aims.

Direct and interventional grants are together referred to as 'strong links'.

Kieran Dodds/Marie Curie

Table 2: Number of grants and funding amounts for grants with strong links to PeolcPSP questions.

For indirect and weak links, only the number of grants is shown. Grants can be linked to more than one question in different ways.

Theme	Question number NICE research recommended in blue	Number of interventional projects	Amount of funding to interventional grants	Number of direct projects	Amount of funding with direct links	Total funding with strong links	Indirect	Weak
Communication	1	0	£0	1	£78,829	£78,829	12	5
	2	0	£0	1	£5,519	£5,519	1	4
	3	3	£234,801	10	£991,007	£1,225,808	24	28
Managing symptoms and medications	4	1	£99,274	3	£527,376	£626,650	7	1
	5	4	£790,346	19	£3,888,382	£4,678,728	22	6
	6	2	£399,855	2	£603,908	£1,003,763	3	6
	7	4	£283,563	2	£72,370	£355,933	12	5
	8	1	£49,362	0	£0	£49,362	1	0
	9	0	£0	1	£29,685	£29,685	0	0
	10	2	£399,855	1	£526,063	£925,918	4	7
	11	4	£871,292	4	£169,960	£1,041,252	14	16
	12	4	£232,539	5	£179,682	£412,221	17	12
	13	0	£0	0	£0	£0	0	2
	14	1	£6,000	1	£26,685	£32,685	0	1
	15	3	£927,069	6	£1,140,213	£2,067,282	20	18
	16	0	£0	1	£526,063	£526,063	3	1
	17	1	£29,685	0	£0	£29,685	5	5
	18	2	£63,647	2	£62,200	£125,847	3	3
	19	0	£0	0	£0	£0	2	0
	20	0	£0	1	£18,475	£18,475	1	2
	21	1	£39,116	0	£0	£39,116	5	11
	22	0	£0	0	£0	£0	4	1
	23	0	£0	1	£26,685	£26,685	4	1
	24	0	£0	2	£86,632	£86,632	1	4
	25	0	£0	0	£0	£0	0	0
	26	0	£0	1	£291,189	£291,189	5	1
	27	0	£0	2	£84,190	£84,190	6	7
	28	0	£0	1	£95,853	£95,853	14	26
	29	0	£0	1	£65,582	£65,582	0	0
	30	0	£0	0	£0	£0	3	1
	31	2	£520,446	7	£458,221	£978,667	25	34
	32	1	£73,144	0	£0	£73,144	0	1
	33	1	£1,667	1	£77,844	£79,511	2	2
	34	0	£0	1	£90,000	£90,000	3	4
	35	0	£0	1	£96,909	£96,909	4	14
	36	0	£0	0	£0	£0	4	2
Support: Carers and families	37	1	£63,905	4	£130,557	£194,462	11	20
	38	5	£265,383	4	£78,027	£343,410	29	30
	39	0	£0	0	£0	£0	0	1
	40	0	£0	0	£0	£0	0	1
	41	0	£0	2	£243,476	£243,476	9	7
Support: Carers and families	42	0	£0	0	£0	£0	3	5
	43	0	£0	0	£0	£0	3	2
	44	0	£0	0	£0	£0	0	0
	45	1	£139,696	1	£54,002	£193,698	11	12
	46	0	£0	0	£0	£0	0	0
Support: Bereavement	47	0	£0	0	£0	£0	0	0
	48	0	£0	0	£0	£0	0	3
	49	0	£0	0	£0	£0	2	2
	50	0	£0	0	£0	£0	1	0
Support: Training and staff support	51	1	£45,821	1	£36,687	£82,508	5	0
	52	1	£321,796	10	£1,092,692	£1,414,488	19	12
	53	0	£0	0	£0	£0	1	0
Service use: Care coordination	54	1	£4,988	6	£464,649	£469,637	10	10
	55	0	£0	1	£1,415	£1,415	1	3
	56	1	£37,066	1	£68,119	£105,185	8	22
	57	1	£68,119	0	£0	£68,119	6	7
	58	3	£89,263	8	£1,076,273	£1,165,536	25	18
	59	0	£0	5	£528,015	£528,015	6	5
	60	1	£180,104	3	£213,463	£393,567	16	28
	61	0	£0	3	£131,757	£131,757	2	3
	62	0	£0	3	£50,068	£50,068	6	3
	63	0	£0	1	£52,469	£52,469	3	1
Service use: Accessing services	64	0	£0	1	£208,404	£208,404	0	1
	65	0	£0	1	£39,619	£39,619	1	2
	66	4	£528,256	12	£1,387,084	£1,915,340	34	41
	67	0	£0	4	£516,924	£516,924	9	0
	68	0	£0	3	£82,961	£82,961	11	17
	69	0	£0	0	£0	£0	1	0
Service use: Place and type of care	70	1	£95,581	13	£1,762,238	£1,857,819	47	29
	71	1	£190,082	3	£287,007	£477,089	18	22
	72	0	£0	5	£628,219	£628,219	17	9
	73	0	£0	8	£1,520,480	£1,520,480	17	26
	74	1	£45,820	10	£1,520,096	£1,565,916	21	13
	75	0	£0	6	£750,107	£750,107	19	14
	76	0	£0	4	£557,499	£557,499	22	34
	77	0	£0	1	£12,955	£12,955	2	1
	78	1	£37,066	5	£478,209	£515,275	10	6
	79	0	£0	11	£1,090,556	£1,090,556	7	15
	80	0	£0	0	£0	£0	3	4
Understanding dying	81	6	£758,347	25	£3,548,693	£4,307,040	93	72
	82	0	£0	8	£786,843	£786,843	26	15
	83	0	£0	1	£67,946	£67,946	0	1

5. Key findings

5.1 How are the top 10 PeolcPSP research priorities being addressed?

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.

The grant mapping project shows that this priority received no interventional funding, with no abstracts stating they would test ways to provide out-of-hours palliative care. The topic has only received £516,924 of direct funding from four grants, detailed in Figure 4. This is just 0.03% of the health research funding in 2014, making **priority number 1 the second-lowest funded of the top 10**.

2 How can access to palliative care services be improved for everyone regardless of where they live in the UK?

Four interventional grants totalling £528,256 and 12 direct grants with £1,387,084 of funding addressed this priority, making it the second-highest funded priority in the top 10.

Government
£497,441
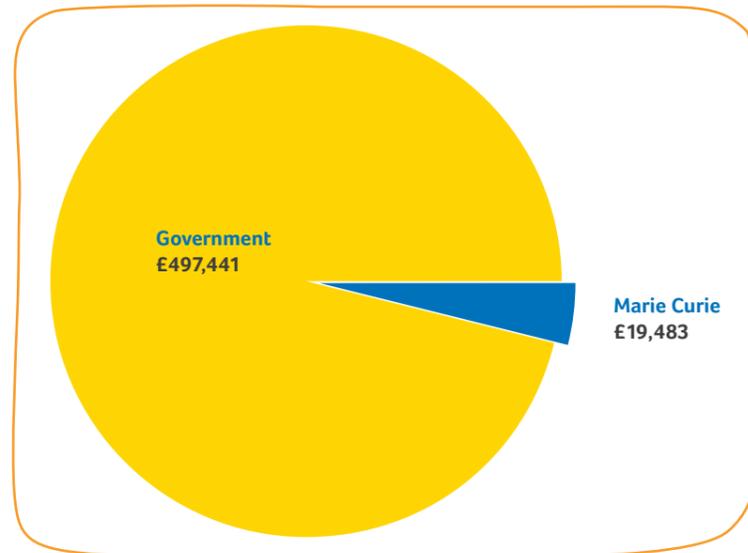
Marie Curie
£19,483

Figure 4: Graph showing split of funding between Marie Curie and government funders for top 10 question 1

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?

This priority was addressed by total funding of £1,225,808 with strong links. There are three interventional grants and 10 direct grants. Many of the non-interventional grants relating to the priority were qualitative in design.

4 What information and training do carers and families need to provide the best care for their loved one who is dying?

This priority was the least funded of the top 10 questions. The total funding with strong links amounted to only £343,412. Of this, £265,383 came

from five small interventional grants and the rest from four direct grants. The majority of this funding was from Marie Curie, as detailed in Figure 5, with most funded by a themed research call,
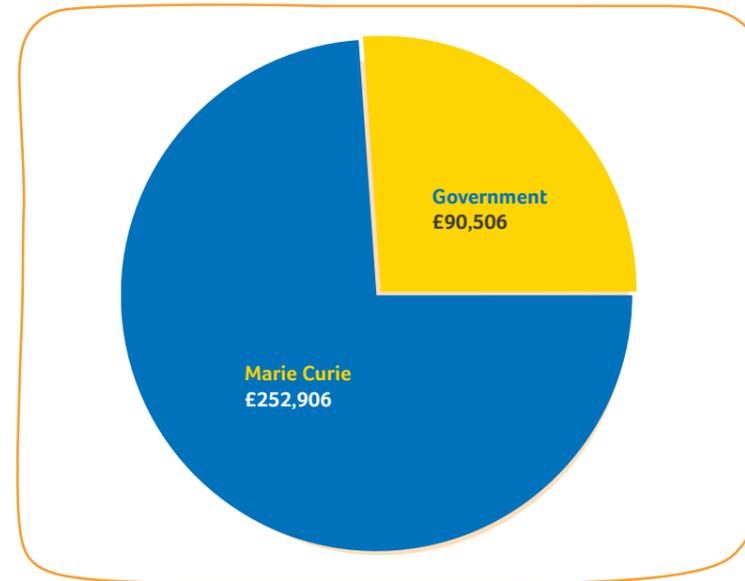
Government
£90,506

Marie Curie
£252,906

Figure 5: Graph showing split of funding to top 10 question 4 between Marie Curie and government funders

Neurological 72%

Generic health relevance 10%

Respiratory 8%

Cardiovascular 6%

Stroke 4%

Figure 6: Graph showing health categories represented in top 10 question 6

which focused on informal carers. This call was co-funded by Dimbleby Cancer Care[11]. Seventy-six per cent of the interventional funding to this question was funded by this call.

5 How can it be ensured that staff, including health care assistants, are adequately trained to deliver palliative care, no matter where the care is being delivered?

This priority had an interventional grant totalling £321,796, and further direct funding amounting to £1,092,692 from 10 grants.

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)?

This priority had 31 grants which addressed it strongly, with £4,307,040 of funding. Of these grants, six were interventional and totalled £758,347. The priority covers a range of conditions. However, as shown in Figure 6, neurological conditions take up almost three quarters of the funding and, of this, most relates to dementia with the majority government-funded. This is likely to be an effect of a UK governmental push to increase dementia research in 2012[12]. This is explored in more detail in section 5.4, which focuses specifically on dementia.
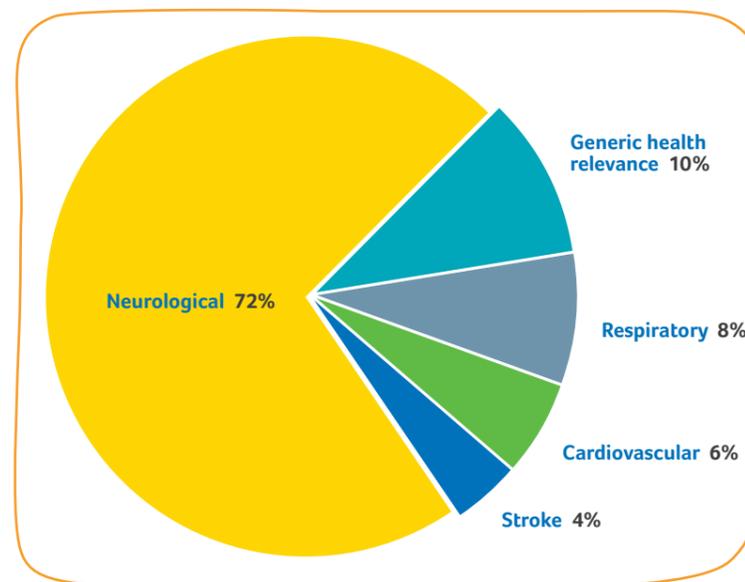
7 What are the core palliative care services that should be provided no matter what the patient's diagnosis is?

This priority was not addressed by any interventional grants and was linked to only five direct grants totalling £628,219.

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?

This priority received the third-highest amount of funding for the top 10 questions, with £1,565,916 of funding with strong links. Only one grant was interventional, totalling £45,820. The rest of the funding with strong links came from 10 direct grants.

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?

The priority was addressed by no interventional funding and had only £528,015 of direct funding, making it **the third-lowest funded priority in the top 10**.

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?

This priority was addressed by a total funding of £1,003,763 with strong links from four government-funded grants. Figure 7 shows that the majority of this funding related to neurological conditions, with the remainder addressing mental health, from one large grant creating a decision tool for managing pain.
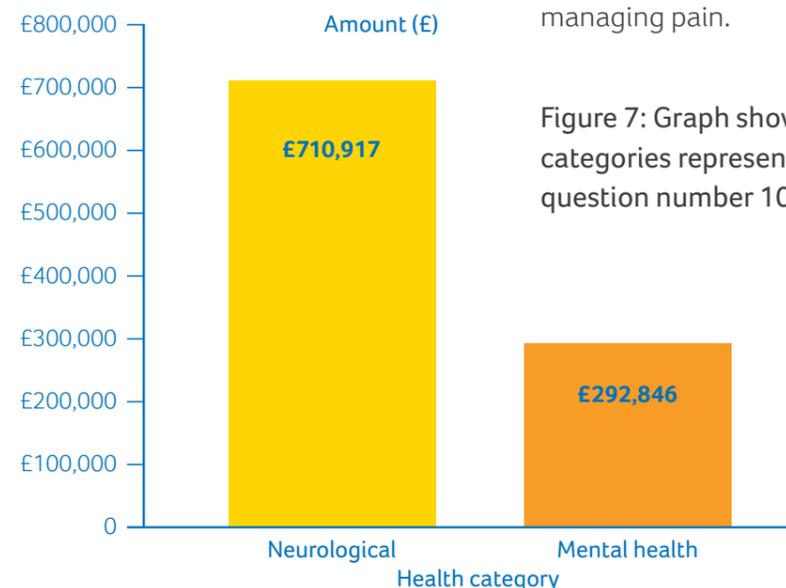
Figure 7: Graph showing health categories represented in top 10 question number 10

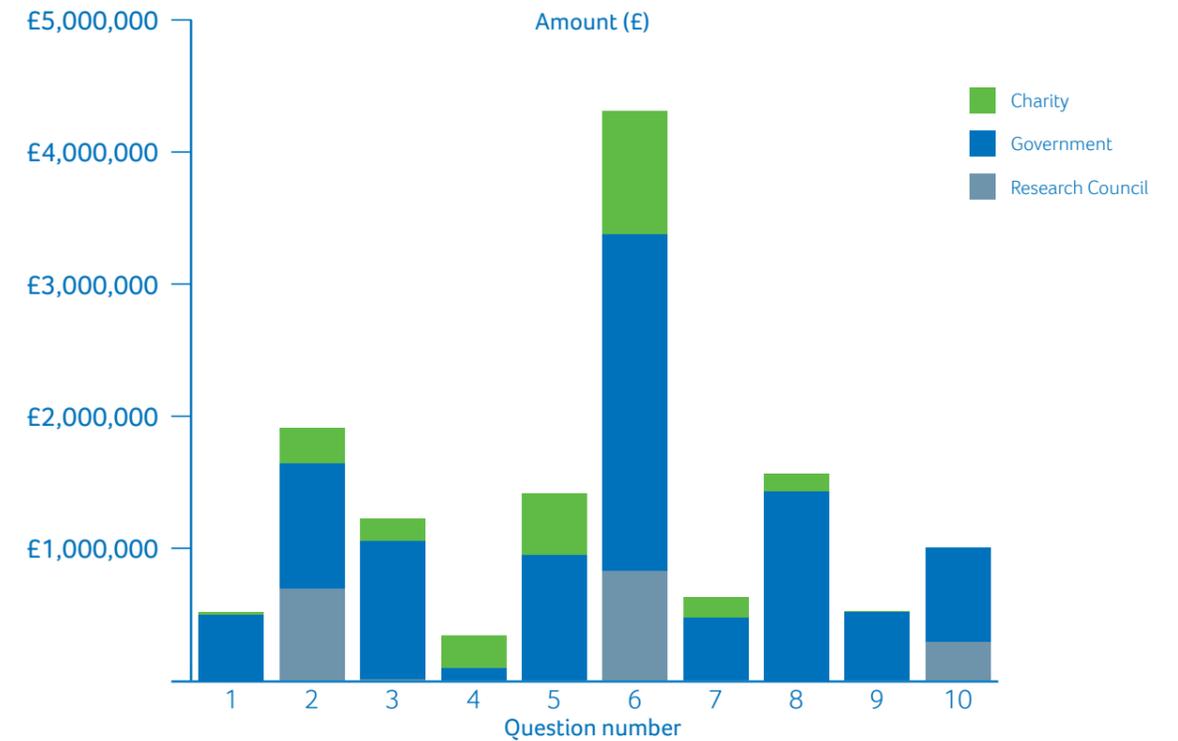**Who is addressing the top 10 priorities?**

Figure 8: The distribution of funding with strong links, by funding body, to the top 10 PeolcPSP priorities

Figure 8 shows the differentiation between governmental, charitable and research council funding as split by the HRCS dataset. Governmental funding includes the main government health research funders from the devolved nations (NIHR (England), CSO (Scotland), HCRW (Wales) and HSCNI (Northern Ireland)) but not the research councils. The graph shows that research councils have their greatest impact with regards to non-cancer diseases (top 10 priority number 6) and the geographic spread of care (top 10 priority number 2). Governmental funding covers all the top 10, while charitable funding makes up the biggest proportion of the support for carers and families (top 10 priority number 4).

When this is split by funder, as in Figure 9, it is clear that the Department of Health and Marie Curie fund the widest variety of top 10 questions, while more specific charities, such as the British Heart Foundation and the Motor Neurone Disease Association understandably only fund questions from the top 10 relating to non-cancer diseases (top 10 priority number 6).
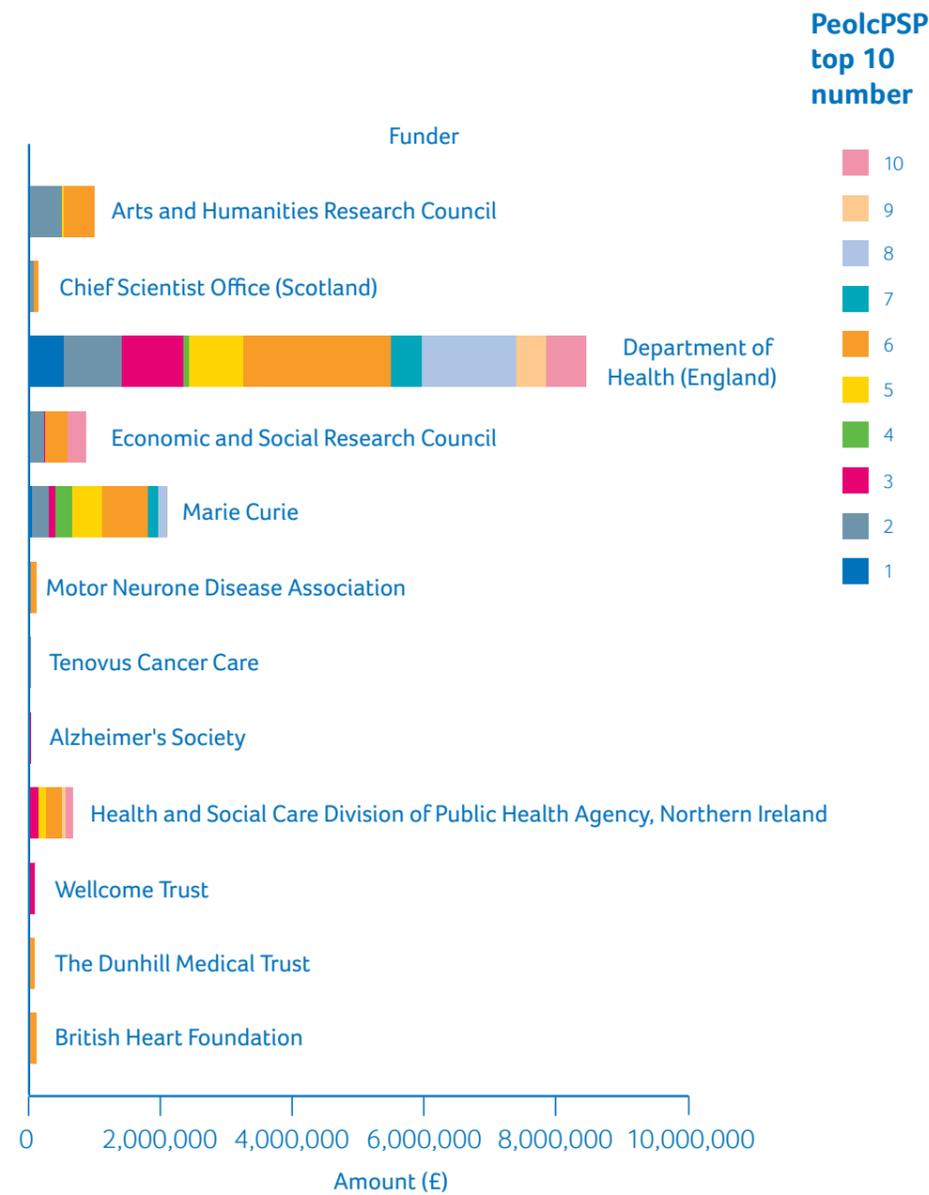
PeolcPSP top 10 number

Figure 9: Funding with strong links by research funder to the top 10 PeolcPSP priorities

What types of research are addressing the top 10?

Each grant included in the HRCS dataset is assigned to a group by type of research activity. The research activities are defined in Table 3.

Research activity group	Includes:
1 Underpinning Research	Research that underpins investigations into the cause, development, detection, treatment and management of diseases, conditions and ill health
2 Aetiology	Identification of determinants that are involved in the cause, risk or development of disease, conditions and ill health
3 Prevention of Disease and Conditions, and Promotion of Wellbeing	Research aimed at the primary prevention of disease, conditions or ill health, or promotion of wellbeing
4 Detection, Screening and Diagnosis	Discovery, development and evaluation of diagnostic, prognostic and predictive markers and technologies
5 Development of Treatments and Therapeutic Interventions	Discovery and development of therapeutic interventions and testing in model systems and preclinical settings
6 Evaluation of Treatments and Therapeutic Interventions	Testing and evaluation of therapeutic interventions in clinical, community or applied settings
7 Management of Diseases and Conditions	Research into individual care needs and management of disease, conditions or ill health, including research activity code relating to end of life care (Code 7.2)
8 Health and Social Care Services Research	Research into the provision and delivery of health and social care services, health policy and studies of research design, measurements and methodologies

Table 3: Definitions of the HRCS Research activity groups[10]

Figure 10 shows the distribution of the research activity group in relation to each of the top 10 priorities. For all these priorities, most funding sits in research activity groups 7 and 8. There are also interesting links to aetiology (linked to training for staff, top 10 question 5), treatment development (within the pain management priority, top 10 question 10) and prevention (in the care at home priority, top 10 question 8).
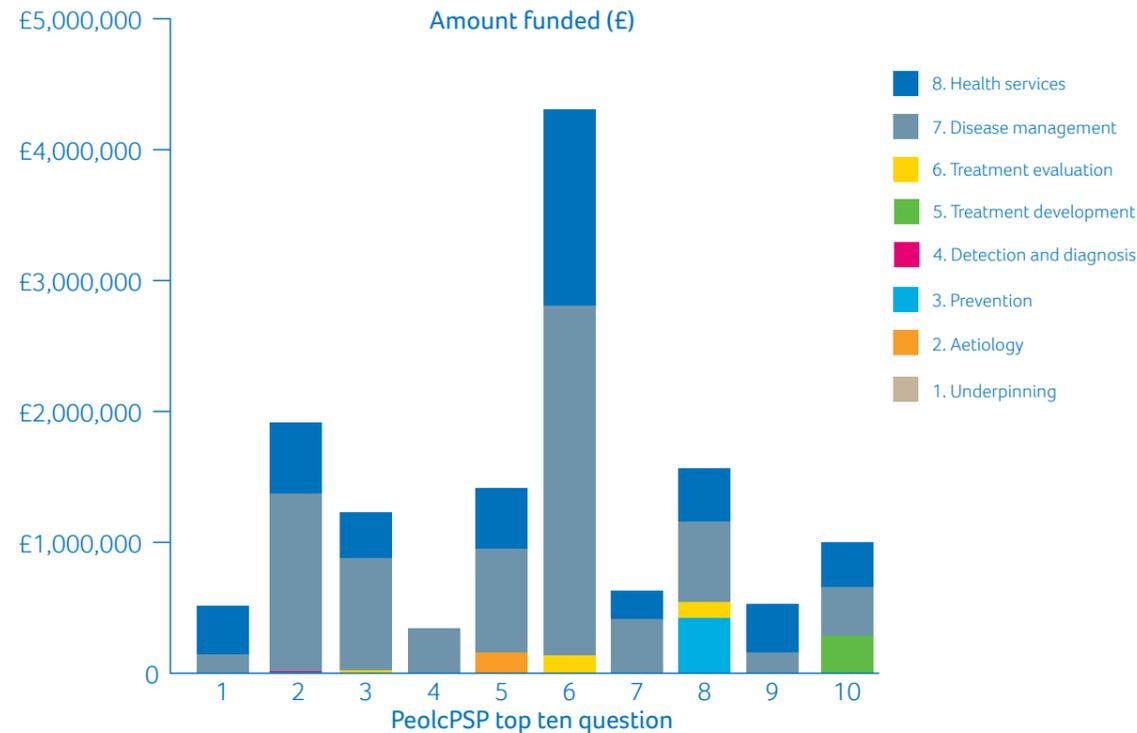

Amount funded (£)

- 8. Health services
- 7. Disease management
- 6. Treatment evaluation
- 5. Treatment development
- 4. Detection and diagnosis
- 3. Prevention
- 2. Aetiology
- 1. Underpinning

PeolcPSP top ten question

Figure 10: The distribution of funding by research activity code to the top 10 PeolcPSP priorities

5.2 Which of the 83 PeolcPSP questions received little or no funding?

PeolcPSP questions with no funding identified in 2014

A key finding from this project is that four PeolcPSP questions may not be receiving any current research funding in the UK at all. This means that four PeolcPSP questions received no interventional, direct, indirect or weak funding in 2014 (detailed below).

- Question 25 (theme – managing symptoms and medications): What are the best treatments for fluid retention in patients approaching the end of life?

- Question 44 (theme – support; sub-theme – carers and families): 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**

- Question 46 (theme – support; sub-theme – carers and families): How can patients, carers and families be supported when the patient does not want their carers and families to know their prognosis?*

- Question 47 (theme – support; sub-theme – bereavement): Should bereavement support be made available to all bereaved people and, if so, how? Should GPs or other professionals provide bereavement visits?

Systematic reviews identified when the final report was published

Of the four PeolcPSP questions that received no funding at all in 2014, only question 46 had an in-date (undertaken within last three years) systematic review[13]. It also had one related review, which addressed the question but not as the main focus of the review[14]. These reviews do not provide definite answers and show that an uncertainty regarding the research question still exists. Question 44 had an out-of-date systematic review[15]. No systematic reviews were identified for the other two unfunded PeolcPSP questions.

* had reference to an in-date systematic review.

** refers to PeolcPSP questions with only out-of-date systematic reviews.

Kieran Dodds/Marie Curie

PeolcPSP questions without strong funding links

A further 15 PeolcPSP questions did not receive strong funding, as shown in Box 4:

Box 4: Full wording of the PeolcPSP questions which did not receive any strong funding links in 2014

Theme: Managing symptoms and medication

Question 13 – What are the pros and cons of withdrawing MST (morphine sulphate) in people at the end of life?

Question 19 – Is it ever necessary to withdraw food and water (non-artificial hydration/nutrition)?*

Question 22 – 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?*

Question 30 – What are the benefits and limitations (physical, social, psychological) of blood transfusions at the end of life?

Theme: Support – carers and families

Question 36 – 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?**

Question 39 – Do people who are dying and their carers and families fare better if domestic support with shopping, washing up, laundry, etc, is provided?**

Question 40 – 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?

Question 42 – Does practical advice for concerns about housing, finance and transport, etc, reduce anxiety for carers and families and increase their wellbeing?**

Question 43 – 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?

Theme: Support – bereavement

Question 48 – How can the risk of intense and long-lasting grief best be assessed and treated? Can this be prevented through early bereavement support?

Question 49 – What are the benefits of bereavement support, including preventing depression and other illness?

Question 50 – 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?

Theme: Support – training and staff support

Question 53 – What are the benefits of all health and social care staff having training in bereavement awareness and support? Is this possible?

Theme: Service use – accessing services

Question 69 – 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.

Theme: Service use – place and type of care

Question 80 – 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?**

Of the 15 PeolcPSP questions which received no strong links, only two had reference to an in-date systematic review (*). Four had out-of-date systematic reviews (**), and for the remaining nine there was no reference to a systematic review.

PeolcPSP questions with less than £50,000 of strong research funding links

In addition to those mentioned above, an additional 11 PeolcPSP questions were addressed by less than £50,000 of strongly related research grants in 2014, as shown in Box 5.

* had reference to an in-date systematic review.

** refers to PeolcPSP questions with only out-of-date systematic reviews.

* had reference to an in-date systematic review.

** refers to PeolcPSP questions with only out-of-date systematic reviews.

Layton Thompson/Marie Curie

Box 5: Full wording of the PeolcPSP questions which received less than £50,000 of funding with strong links in 2014

Theme: Communication
Question 2 – How can carers and families of people at the end of life be supported to communicate better with each other and their loved one?*

Theme: Managing symptoms and medications
Question 8 – What are the best ways to manage drooling and excessive salivation in patients with diseases such as Motor Neurone Disease (MND) who are approaching the end of their life*

Question 9 – What are the best ways to manage respiratory secretions (death rattle) in patients at the end of life?*

Question 14 – Which sedative drugs (such as midazolam, haloperidol and levomepromazine) are most beneficial for managing agitation at the end of life and which are best in terms of side effects? Do these drugs have an effect on other symptoms?*

Question 17 – 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?*

Question 20 – 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?*

Question 21 – 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?*

Question 23 – What are the best treatments for nausea and vomiting (including for people with bowel obstruction and those having palliative chemotherapy)?*

Theme: Service use – care coordination
Question 55 – Since patients are often seen by a variety of professionals and services, would care improve if patients carried their own medical notes?

Theme: Service use – accessing services
Question 65 – How can palliative care information and services be made more accessible to people whose first language is not English?

Theme: Service use – place and type of care
Question 77 – 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?

Of the 11 PeolcPSP questions which received less than £50,000 of strong funding, eight had reference to an in-date systematic review (*), and for the remaining three there was no reference to a systematic review.

* had reference to an in-date systematic review.

** refers to PeolcPSP questions with only out-of-date systematic reviews.

5.3 **Highlighting bereavement**

Bereavement is the only whole theme of the PeolcPSP which has not received any funding with strong links in 2014, with no direct or interventional grants addressing any of the six PeolcPSP questions relevant to research relating to bereavement. Box 6 details these six questions:

Box 6: The PeolcPSP questions which refer to bereavement.

Theme: Support – carers and families
Question 44 – 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.

Theme: Support – bereavement
Question 47 – Should bereavement support be made available to all bereaved people and, if so, how? Should GPs or other professionals provide bereavement visits?

Question 48 – How can the risk of intense and long-lasting grief best be assessed and treated? Can this be prevented through early bereavement support?

Question 49 – What are the benefits of bereavement support, including preventing depression and other illness?

Question 50 – 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?

Theme: Support – training staff and support
Question 53 – What are the benefits of all health and social care staff having training in bereavement awareness and support? Is this possible?

Question 47 (outlined in Box 6) received no grant funding, whether strongly or weakly related, in 2014.

Question 44 (outlined in Box 6), which addressed bereavement support but fell under the theme of support for carers and families, also received no research funding in 2014. Box 7 shows some of the original PeolcPSP survey responses which generated these questions.

Aspects of the responses of the PeolcPSP survey on bereavement issues have been analysed separately[16], and Marie Curie has recently announced funding of a systematic review on a core outcome set for bereavement research in palliative care, conducted by Dr Emily Harrop at the Marie Curie Palliative Care Research Centre, Cardiff University[17].

Box 7: Responses relating to bereavement from the PeolcPSP survey*

"Why is bereavement and my grief a problem for other people?"
Professional working with people in the last few years of life; bereaved carer/family member/friend

"Why does bereavement counselling only kick in after death and why so soon?"
Bereaved carer/family member/friend

"I also think continued support for carers after bereavement is essential as this could possibly prevent depression and illness and increased burden on the health care system at a later stage."
Professional working with people in the last few years of life; bereaved carer/family member/friend

"Is there support for bereaved people if they need it? It can feel like being "cut off" once the caring stops."
Bereaved carer/family member/friend

"I needed to know that our whole family would be cared for. Is bereavement counselling available about three months down the line? I wanted the Hospice to phone me, not the other way around."
Professional working with people in the last few years of life; bereaved carer/family member/friend

*These are the exact responses from the survey
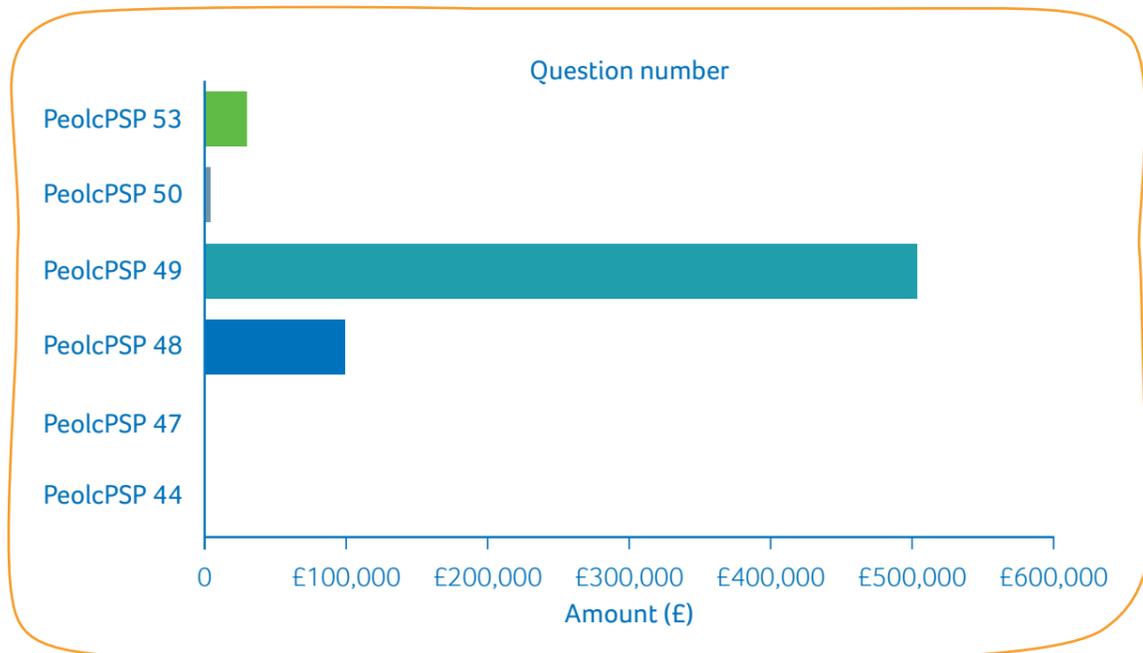
Figure 11a: Distribution of indirect funding to the six PeolcPSP questions relevant to bereavement
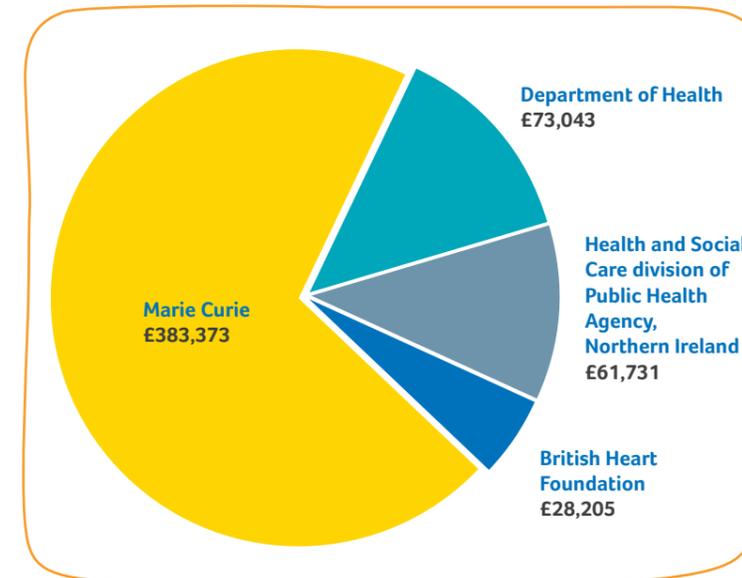
Figure 11b: Pie chart showing the questions which indirectly refer to bereavement

Figures 11 a, b and c show the active funding which is indirectly addressing bereavement (meaning those grants which did not propose interventions or directly focus on bereavement, but still have relevance to the PeolcPSP questions).

The question receiving the most indirect funding focused on preventing depression and other conditions that may be associated with bereavement (PeolcPSP question number 49). This links to the PeolcPSP question number 31:

Figure 11c: Health categories addressed by indirect funding
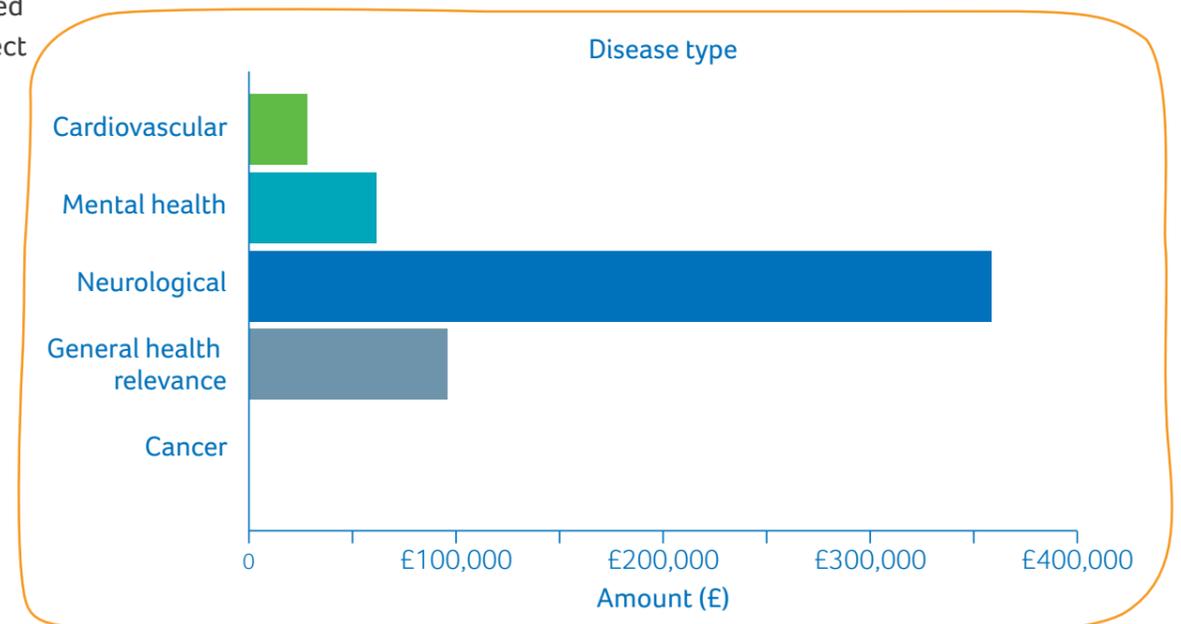
Question 31 – What are the best ways to recognise and treat depression, anxiety and low mood in people who are dying? What are the pros and cons of different psychotherapeutic interventions, including drug therapies, and when is the best time to provide them?

This question received more interventional funding than the question addressing prevention of depression after bereavement, as a number of grants focused on providing support for people at the end of life with depression. This is another example of the lack of research on carers. The pie chart (Figure 11b) shows that the highest proportion of research funding relating to bereavement support is from charitable funders, with governmental funders from England and Northern Ireland making up a quarter of the total. Figure 11c shows that most of the indirect funding addressing bereavement related to neurological conditions such as dementia. In addition, the majority of the grants addressing bereavement were qualitative research projects.

5.4 **Highlighting dementia**

The most funded question in 2014 identified by the grant mapping project addressed the provision of palliative care to patients with dementia:

Question 5 – What is the best way to give palliative care to patients with dementia and their carers and families? This includes communicating about their diagnosis when they are being cared for at home or elsewhere.

This question received £4,678,728 of strongly related research from 23 grants funded by six different funders, as illustrated in Figure 12.
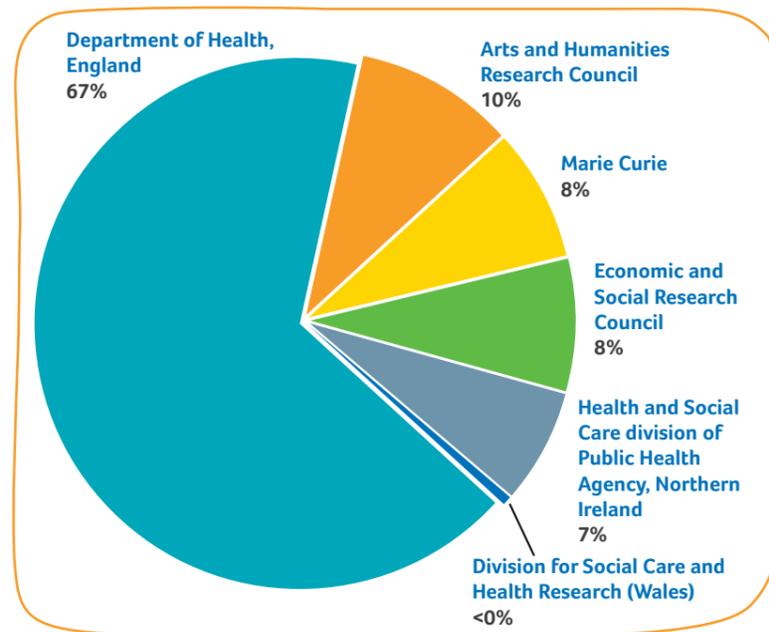
Figure 12: Research by funding bodies with strong links to PeolcPSP question 5 on managing dementia

Table 4: The five highest funded PeolcPSP questions

Question Number	Full wording	Total funding with strong links
5	What is the best way to give palliative care to patients with dementia and their carers and families? This includes communicating about their diagnosis when they are being cared for at home or elsewhere.	£4,678,728
81 (merged with 70 to form top 10, number 6)	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?	£4,307,040
15	What are the best ways to diagnose and treat delirium, agitation, distress and restlessness in people at the end of life?	£2,067,282
66 (top 10, number 2)	How can access to palliative care services be improved for everyone regardless of where they are in the UK?	£1,915,340
70 (merged with 81 to form top 10, number 6)	What are the best ways to begin to deliver palliative care for patients with non-cancer diseases (such as chronic obstructive pulmonary disease (COPD), heart failure, motor neurone disease (MND), AIDS, multiple sclerosis, Crohn's disease and stroke)	£1,857,819

In 2012, former Prime Minister David Cameron launched a national challenge to address the issues surrounding dementia healthcare through research.

Since the launch of the national challenge to 'fight dementia'[18] in 2012, there has been a significant increase in dementia research. This includes research funding on palliative care for patients with dementia. David Cameron stated in a 2015 report that "well over £60 million" was being spent on dementia research each year[12]. Much of this funding was from an NIHR dementia-themed call for research funding in December 2012[18].

An increase in funding does not mean that a PeolcPSP question has been answered. The fact that much of the research funding was deemed interventional (testing a treatment or type of service) gives hope that, in the future, there will be findings leading to improvements in care for people with dementia. For this to be fully analysed, a systematic review would need to be conducted in the near future.

Not all PeolcPSP questions are backed by a personal pledge from the Prime Minister. However, by highlighting the questions most in need of further research, funders and researchers can focus on these areas. This will help the design and testing of interventions that will make a real difference to people with terminal illness and their carers, families and friends.

5.5 **How do these results relate to NICE research recommendations?**

In December 2015, NICE published guidelines involving recommendations for research into the care of dying adults in the last days of life[8]. These recommendations looked specifically at research to improve care in the last few days of life. They were based on reviews of existing research and called for more evidence. The next section reviews the recommendations, comparing how they relate to the questions raised by the PeolcPSP, and how well they were addressed by UK health-related research funding in 2014.

Recognising dying

"What can multi-professional teams do to reduce the impact of uncertainty recognising when a person is entering the last days of life?" (NICE guidance)

This was highlighted by the PeolcPSP, with a theme of the report entitled 'Understanding Dying'. One question in this theme asks:

Question 83 – 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?

This question had no interventional funding and only one direct grant for £67,946.

The NICE guidance also stresses the importance of research in "reducing the impact of uncertainty on clinical care, shared decision-making and communication within multi-disciplinary teams". This was prioritised in the PeolcPSP, in the 13th ranked question:

Question 54 – What are the best ways to facilitate communication across services and between healthcare professionals, including effective IT systems, team meetings and remote technology?

This question has one very small interventional grant (under £5,000), and £464,649 of direct funding.

Agitation and delirium

"What is the best way to control delirium, with or without agitation, in the dying person, without causing undue sedation and without shortening life?" (NICE guidance)

The PeolcPSP generated several priorities which link to this question. Directly addressing delirium and agitation, the PeolcPSP identified this as an unanswered question for palliative care:

Question 15 – What are the best ways to diagnose and treat delirium, agitation, distress, and restlessness in people at the end of life?

This question is currently addressed by almost £1 million of interventional funding, and just over £1 million of direct funding, which will contribute to the evidence base in this area.

Noisy respiratory secretions

"People considered to be in the last few hours and days of life, on whether anti-secretory anti-muscarinic drugs (used alongside nursing interventions, such as repositioning and oropharyngeal suction) are better at reducing noisy respiratory secretions and patient, family and carer distress without causing unwanted side effects, than nursing interventions alone?" (NICE guidance)

A question generated in the PeolcPSP process directly focuses on this:

Question 9 – What are the best ways to manage respiratory secretions (death rattle) in patients at the end of life?

This is a much underfunded question with only £29,685 of direct funding.

The PeolcPSP goes further to address the carer aspect of this question:

Question 1 – What are the best ways for healthcare professionals to tell patients, carers and families that a patient's illness is terminal and also explain the dying process compassionately and honestly? Can literature, including leaflets, be helpful? Who is the best person to provide this information and communication?

This question is also poorly funded, with no interventional funding and only one small direct grant amounting to £78,829.

Anticipatory prescriptions

"What is the clinical and cost effectiveness of anticipatory prescribing for patients dying in their usual place of residence, on patient and carer reported symptoms at end of life?" (NICE guidance)

One PeolcPSP question addresses 'just-in-case kits' (containing anticipatory drugs):

Question 33 – 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?

This question, which looks specifically at Motor Neurone Disease rather than all end of life care patients, has one very small interventional grant (£1,667), and less than £100,000 of direct funding (£77,844).

The PeolcPSP also identified a question which looks at patients dying in their usual place of residence:

Question 74 – 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 co-ordination of services affect this?

This is number eight in the top 10, which was reviewed on page 24.

There is agreement between the priorities highlighted by the PeolcPSP and NICE guidance

The NICE guidance notes that many of the studies that have looked at palliative care are primarily based on cancer patients. Fourteen of the 83 PeolcPSP priorities specifically address the needs of non-cancer patients, with many of the symptoms described in other questions also relevant to a variety of other conditions.

The NICE guidance looks specifically at the last days before death and therefore only highlights questions relating to palliative and end of life care research addressing people judged to be within a few (two to three) days of death.

The PeolcPSP identified a broader range of research questions. NICE methodology is used to identify very specific research questions that can potentially feed directly into NIHR research commissioning streams compared to the often broader questions raised from Priority Setting Partnerships with the James Lind Alliance.

Despite these differences, both sets of recommendations highlight that more research is needed in similar areas of palliative and end of life care provision.

6. Conclusion and recommendations

6.1. What has this project shown?

This report has mapped research activity in 2014 against each of the 83 PeolcPSP questions. In doing so, it highlights the unanswered research questions of importance to patients, carers and clinicians, which are attracting funding and being addressed by current research, and those that are not. In particular it highlights four priority questions that received no funding in 2014, and a further 15 with limited (no interventional or direct) funding.

This report is limited in that it only provides a snapshot of UK research addressing the PeolcPSP questions identified by patients, carers and clinicians. There will be research not listed in the dataset funded by organisations not included in the original HRCS analysis (eg money from pharmaceutical companies or organisations not part of the Association of Medical Research Charities). There is research not included in the HRCS dataset that

might be active now or had finished before 2014.

However, as none of the 83 questions have been answered in a systematic review, it is clear that the need for more research in palliative and end of life care remains. In particular, there is a need to develop and test interventions that address patient and carer need in this area.

It is evident, though, that in some areas of palliative and end of life care research, progress is being made. Funder initiatives such as the former UK Prime Minister's challenge on dementia and smaller themed calls for research applications by charities, such as the Dimbleby Marie Curie Cancer Care Research Fund, are having an impact.

Other areas of need, such as bereavement support, are not currently addressed (at least in 2014) by direct research and more needs to be done.

6.2. Key messages

This report has shown how publicly available grant data, particularly the UKCRC HRCS 2014 dataset, can create an analysis useful to funders in setting research priorities in underfunded areas[20].

- It confirmed the recommendations generated by the PeolcPSP report; that further research is needed for all 83 PeolcPSP questions, specifically highlighting questions with little or no current funding.

- Some questions were in the process of being addressed, while some might need a systematic review.

- Of the 83 questions, 49 had no reference to an up-to-date systematic review.

- The question that asked about the best way to give palliative care to patients with dementia received the most funding of all of the questions.

- In 2014, four of the questions were not addressed by any research funding, with no strong or weak funding linked to current research (see section 5.2).

- A further 15 questions were not addressed by funding with strong links (meaning no research which proposed an intervention or set out to directly explore the topic).

- 11 other questions were addressed by less than £50,000 of funding with strong links.

- The six questions about bereavement had not received any funding with strong links.

- How to provide out-of-hours palliative care, support for carers and how to ensure continuity of care were the top 10 priorities least addressed by current research in 2014.

6.3. What next?

This report helps researchers and funders identify current and recent projects. This has the potential to help facilitate new collaborations.

By highlighting the PeolcPSP questions with low funding, researchers and funders are encouraged to investigate these further. Some PeolcPSP questions, particularly in the top 10, are broad research priorities and might require further work to identify more focused research questions. A recent local initiative in Manchester from the Collaboration for Leadership in Applied Health Research and Care (CLAHRC) has demonstrated a way to achieve this. It used focus groups and workshops with local carers and health care professionals to identify more detailed research questions relevant to local need within the PeolcPSP top 10 questions[21].

Research funders can help by advertising clearer information about funding streams that are open for palliative and end of life care research and by supporting researchers in developing applications in new topic areas. Collaborations between funders in areas of common interest (for instance charities whose interests are in specific chronic and progressive diseases) may help to make better use of limited research funds and avoid unnecessary duplication. A group of funders with an interest in palliative and end of life care, known as the UK end of life care Research Interest Group (UK eolcRIG)[22] meets regularly. This group shares practical advice and expertise and is open to new members. Follow **@UKeolcRIG** for funding opportunities in palliative and end of life care research.

Funders of research calls should strongly promote their opportunities and support researchers to conduct enterprising research in new areas. Partnerships are already happening to encourage new research, such as the joint call by Marie Curie, the Motor Neurone Disease Association and the Chief Scientist Office in Scotland.

It is also important to train new experts and build the capacity of the next generation of palliative and end of life care researchers, who can answer the questions most important to patients, their carers and families, and the healthcare professionals who support them. Highlighting how the PeolcPSP questions are being addressed will help target research and foster collaboration between experts in the field.

The 2016 annual Marie Curie Research Conference, held jointly with the Palliative Care Section of the Royal Society of Medicine, adopted the top PeolcPSP priority as its research theme: "Round the clock: Making 24/7 palliative care a reality". A summary of the Twitter activity at the event highlights the key messages from the day[23].

Marie Curie is committed to continuing to work towards addressing all 83 of these research questions. Its annual research call welcomes research on all areas of palliative and end of life care, and has used the PeolcPSP to structure the call in 2016. Upcoming research calls are widely advertised on the Marie Curie website and on social media. For news on the PeolcPSP questions, follow **@PeolcPSP**.

Appendices
Appendix 1: **Methodology guide**

Coding principles

In order to maintain research process consistency, some principles were developed to guide the grant mapping coding process:

- When reading a grant abstract, only the information provided was used. No external information or knowledge was used to assess the relevance of the grant to the PeolcPSP questions.

- No assumptions were made when reading a grant abstract. It should not be assumed to be relevant to end of life care purely because of the assumed nature of the disease.

- When coding the 'intensity' of the relationship, grants were labelled 'interventionally related' only if they related specifically to a PeolcPSP question and proposed an intervention.

- The full funding amount for a grant was included in the financial analysis, not just the relevant proportion coded to a particular activity.

In order to make the task more manageable and reduce potential error, two team members reviewed the codes and discussed any discrepancies after each 20 grants were reviewed. If the two team members could not achieve consensus, the abstracts were further reviewed and coded by another team member. In order to ensure quality control and validate the coding system, one in every 50 grants was randomly selected and cross-checked by a third

member of the research management team. The coding system ensured that the abstracts of grants not directly relating to palliative care were not eliminated from the project despite their weaker relationship.

Inclusion and exclusion criteria

- Grants were excluded if both coders felt that an abstract was not related to the PeolcPSP questions. These abstracts were included in the randomised searches for quality control.

- Grants that showed only indirect or weak links were not included in the following analysis, but were included in a more general analysis. They are important aspects of the research landscape in palliative care and might lead to the identification of researchers interested in each PeolcPSP question.

Secondary exclusions and limitations

- Infrastructure grants (such as those for the Marie Curie research centres) were not included in the publicly available data and are therefore not included in the analysis.

- Grants from most, but not all, government and charity research funders are included in the UKCRC HRCS dataset. There will be projects that are not included in this analysis.

- Industry-funded research and research ongoing outside of the UK is not included in the dataset, so the

analysis does not take account of such activity.

- Some grants did not provide an abstract, which made coding difficult.

- The grants that only provided short or incomplete abstracts were often coded to fewer questions, or given less strong links. This may not be representative of the study, but reflects the fact that limited information was available.

- Some of the titles and abstracts had poor spelling and grammar. This may have impacted whether the key search terms showed up in the searches.

Appendix 2: Full wording of PeolcPSP questions with keyword searches

Communication	
1 What are the best ways for healthcare professionals to tell patients, carers and families that a patient's illness is terminal and also explain the dying process compassionately and honestly? Can literature, including leaflets, be helpful? Who is the best person to provide this information and communication?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, carer, family, famil*, relative, caregiver, compassion*, communicat*, honest*, leaflet*, pamphlet*, booklet*, breaking bad news*
2 How can carers and families of people at the end of life be supported to communicate better with each other and their loved one?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, carer, famil*, close person, loved one, communicat**
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?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, advance care planning, ACP, Patient preference, right to die, attorney, living will*

Managing symptoms and medications	
4 What are the best approaches to giving medicines, such as morphine, in a patient's home, for example using different cannulas such as BD-saf-T-intimaTM? What are the pros and cons of training carers, families and non-palliative professionals, such as healthcare assistants, to give these medicines?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, morphine AND home, home care, cannulas, carers, families, healthcare assistants, intravenous*
5 What is the best way to give palliative care to patients with dementia and their carers and families? This includes communicating about their diagnosis when they are being cared for at home or elsewhere.	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, carer, family, famil*, home care, hospice, communicat*, dementia AND care, alzheimer AND care*
6 What are the best approaches to providing pain relief for people who have communication difficulties, perhaps as a result of their disease, such as motor neurone disease (MND), dementia, brain tumour (including glioblastoma) or head and neck cancer?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, pain relief, communication difficult*, motor neuron*, MND, ALS, amyotrophic lateral sclerosis, dementia, alzheimer, brain tumour, glioblastoma, pain AND head and neck cancer, algiatry*

#	Question	Keywords
7	What are the best ways to manage the problems associated with difficulty in swallowing, including for patients with Parkinson's disease, motor neurone disease (MND) and dementia who are at the end of their life?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, swallow, dysphagia, MND, motor neuron, ALS, amyotrophic lateral sclerosis, dementia, alzheimer*
8	What are the best ways to manage drooling and excessive salivation in patients with diseases such as motor neurone disease (MND) who are approaching the end of their life?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, drooling, excessive salivation, hypersalivation, ptyalism, sialorrhea, MND, motor neuron*, ALS, amyotrophic lateral sclerosis*
9	What are the best ways to manage respiratory secretions (death rattle) in patients at the end of life?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, death rattle, respiratory secretion*
10	What are the best ways to assess and treat pain and discomfort in people at the end of life with advanced dementia, Parkinson's disease and other diseases that affect cognition and communication?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, assess AND pain, assess AND discomfort, cognition, communication difficult*, discomfort AND dementia, alzheimer, parkinson, discomfort AND communication, pain AND dementia, communicat**
11	What are the best ways to make sure that palliative care patients receive adequate pain and symptom relief and which drugs for pain management are best in terms of side-effects, such as drowsiness?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, symptom relief, pain relief, pain AND drug*, painkiller, drowsiness*
12	What are the best ways to manage acute and/or chronic breathlessness in patients with cancer and non-cancer terminal illnesses?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, breathlessness, breathless*, dsypnoea*
13	What are the pros and cons of withdrawing MST (morphine sulphate) in people at the end of life?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, withdraw* AND MST, withdraw* AND morphine sulphate*
14	Which sedative drugs (such as midazolam, haloperidol and levomepromazine) are most beneficial for managing agitation at the end of life and which are best in terms of side-effects? Do these drugs have an effect on other symptoms?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, sedat*, agitation*
15	What are the best ways to diagnose and treat delirium, agitation, distress, and restlessness in people at the end of life?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, delirium, distress, restlessness, agitation*
16	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?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, dementia, alzheimer, distress, parkinson, communicat**
17	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?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, artificial hydration, artificial nutrition, nutritional support, parenteral nutrition, feeding tube, bowel obstruction*
18	What are the best ways of managing cachexia (weight loss) in palliative care patients, including people with cancer or motor neurone disease (MND)?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, cachexia, weight loss, MND, motor neuron, ALS, amyotrophic lateral sclerosis*
19	Is it ever necessary to withdraw food and water (non-artificial hydration/nutrition)?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, withdraw, nil by mouth*
20	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?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, withdraw, artificial hydration, artificial nutrition, communicat*, famil*, carer*
21	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?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, healthy weight*
22	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?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, sedat*, carers, famil*, communicat**
23	What are the best treatments for nausea and vomiting (including for people with bowel obstruction and those having palliative chemotherapy)?	*Palliative [inc. chemotherapy], end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, nausea, vomit*, bowel obstruction, anti-emetic, antinauseants*
24	How is incontinence best managed in people who are approaching the end of life (including those with Parkinson's disease)?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, incontinence, parkinson*
25	What are the best treatments for fluid retention in patients approaching the end of life?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, fluid retention*

26 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)?

palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, blood clot*, deep vein thrombosis, DVT, embolism, low molecular weight heparin, LMWH

27 How are steroids best used in palliative care (dose, duration, etc) for patients with different conditions, including those with brain tumours?

palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, steroid

28 What are the benefits and limitations of chemotherapy and radiotherapy for patients approaching the end of life, including those with brain tumours? How can health care professionals best communicate this?

Palliative [inc. palliative radiotherapy and chemotherapy], end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, brain tumour, communicat*

29 What are best ways of managing constipation, including when caused by medication, such as opioids?

palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, constipation, opioids

30 What are the benefits and limitations (physical, social, psychological) of blood transfusions at the end of life?

palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, blood transfusion

31 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?

palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, depression, depress*,

32 What are the best ways to treat dry mouth in patients at the end of life, including medications and foods, such as pineapple?

anxiety, distress, low mood, psychotherapeutic intervention, drug therap*, antidepressant*

33 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?

palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, dry mouth, xerostomia, pineapple

34 What are the best models of palliative care for people who have learning difficulties?

palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, MND, motor neuron, ALS, amyotrophic lateral sclerosis

35 What are the best models of palliative care for people who have mental health issues?

palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, learning difficulties

palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, mental health AND care

Support: Carers and families

36 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?

palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, respite, carers, famil*

37 How can carers and families be encouraged to seek support for themselves at the right time?

palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, carer, famil*, carer AND support

38 What information and training do carers and families need to provide the best care for their loved one who is dying?

palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, carer, famil* [training grants included in these searches]

39 Do people who are dying and their carers and families fare better if domestic support with shopping, washing up, laundry, etc, is provided?

palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, carer, famil*, domestic, laundry, shopping, washing up

40 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?

palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, carer, famil*, privacy, visiting hours, care home, hospice

41 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?

palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, carer, famil*, spiritual, emotional, symptom relief, care home

42 Does practical advice for concerns about housing, finance and transport, etc, reduce anxiety for carers and families and increase their wellbeing?

palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, carer, famil*, housing, finance , transport, anxiety, wellbeing

43 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?

palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, carer, famil*, alcohol addiction, alcoholism, domestic violence, drug/substance misuse

44 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.

palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, bereav*, child* AND support, communicat*

#	Question	Keywords
45	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?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, carer, famil*, peer support, support groups, professional counselling, counselling, one-on-one*
46	How can patients, carers and families be supported when the patient does not want their carers and families to know their prognosis?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, famil*, carer, secret*

Bereavement

#	Question	Keywords
47	Should bereavement support be made available to all bereaved people and, if so, how? Should GPs or other professionals provide bereavement visits?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, carer, famil*, bereav**
48	How can the risk of intense and long-lasting grief best be assessed and treated? Can this be prevented through early bereavement support?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, carer, famil*, bereav*, grief [including grief bereavement support, prolonged grief disorder] PGD*
49	What are the benefits of bereavement support, including preventing depression and other illness?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, carer, famil*, bereav*, depression*
50	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?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, carer, famil*, bereav* 24hr/24-hour support*

Training and staff support

#	Question	Keywords
51	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?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, carer, famil*, volunt*, unpaid, complementary therapist*
52	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?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, staff AND train**
53	What are the benefits of all health and social care staff having training in bereavement awareness and support? Is this possible?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, staff AND train*, bereav* [including awareness and support]*

Service use: care coordination

#	Question	Keywords
54	What are the best ways to facilitate communication across services and between healthcare professionals, including effective IT systems, team meetings and remote technology?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, communic*, IT system, remote technology, telemedicine, telehealth, ehealth, team meeting*
55	Since patients are often seen by a variety of professionals and services, would care improve if patients carried their own medical notes?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, medical notes, medical records, passport*
56	What are the benefits of increasing the numbers of palliative clinical nurses/nurse specialists in hospitals, GP surgeries, nursing homes and other settings?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, clinical nurses, nurse specialist, hospital, hospice, care home, nursing home, increase AND staff**
57	Who should be part of the care team (such as chaplains, occupational therapists, GPs, etc)?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, care team, chaplain, occupational therapist*
58	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?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, virtual AND care, skype, video-phone, face-time, carer, famil*, telemedicine, telehealth, ehealth*
59	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?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, continuity, continuity AND staff, staff AND contact, case-coordinator, continuity AND quality, designated AND care/staff*
60	What are the best care packages for patients, carers, family and staff which combine health care and social care and take individual prognosis into consideration?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, care package, health care AND social care, health AND social care, carer, famil**
61	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?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, charit*, volunt**
62	Is there evidence that some volunteer services that provide support for patients, carers and families reduce the need for paid trained staff?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, volunt*, unpaid, famil*, staff AND train**

63	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?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, volunt*, unpaid carer, famil*, friend*, support*

Service use: Accessing services

64	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?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, carer, famil*, access AND care, care services, care AND welfare, benefits, welfare benefits*
65	How can palliative care information and services be made more accessible to people whose first language is not English?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, language*
66	How can access to palliative care services be improved for everyone regardless of where they are in the UK?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, UK AND access, UK AND care*
67	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.	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, working hours, out of hours, OOH, 24 hour, 24-hour, 24hr, place of choice, famil*, carer, counseling, counselling*
68	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?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, outcome AND early, early AND access*
69	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?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, alone, home care, friend, famil*, adequate AND care*

Place and type of care

70	What are the best ways to begin to deliver palliative care for patients with non-cancer diseases (such as chronic obstructive pulmonary disease (COPD), heart failure, motor neurone disease (MND), Aids, multiple sclerosis, Crohn's disease and stroke)?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, begin AND deliver, begin AND care, COPD, chronic obstructive pulmonary disease, heart failure, motor neurone, MND, AIDs, acquired immune deficiency syndrome, multiple sclerosis, Crohn's disease, stroke, non-cancer*

71	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?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, exercise tolerance, chronic obstructive pulmonary disease, COPD, pulmonary rehabilitation*
72	What are the core palliative care services that should be provided no matter what the patients' diagnosis is?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, diagnosis AND care services, core AND services*
73	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?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, carer, famil*, day hospice, day therap*, complementary therap*, rehabilitation, physical exercise, exercise, therap* AND independen**
74	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?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, Home care, coordination AND service*
75	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?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, home care, hospice, hospital, care home, care AND environment*
76	What are the best models of palliative care in an acute setting, such as a hospital?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, acute AND care, hospital AND care, acute setting*
77	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?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, carers, famil*, spiritual*, Relig**
78	Are some palliative care approaches better than others (eg holistic support, coordinated care, nurse-led care, early intervention) and for whom?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, holistic, nurse-led, coordinated care, early intervention AND care*
79	What are the benefits of occupational, beauty, diversion therapies (such as mindfulness, meditation, art, dance and gardening) for palliative care patients? How and where are these best provided?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, occupational therap*, beauty therap*, diversion therap*, dance therap*, garden*, mindfulness, meditation, art therap**

80	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?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, homeopathy, alternative therap*, acupuncture, complementary therap**
Understanding dying		
81	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?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, non-cancer, motor neuron, MND, ALS, amyotrophic lateral sclerosis, parkinson, alzheimer, dementia, heart failure, COPD, chronic obstructive pulmonary disease*
82	Do people with various types of terminal cancer have different palliative care needs? If so, what are the best ways of managing their symptoms?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, terminal AND cancer, terminal AND symptom*
83	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?	*palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, die AND detection, dying AND detection, carer, famil**

Appendix 3: **Example of detail provided in the full report**

The table below shows an example of the detail provided in the full report, acting as a guide for how to use the report which can be found here: https://palliativecarepsp.files.wordpress.com/2016/12/full-results.pdf

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Acknowledgements

Glossary

CSO	Chief Scientist Office, Scotland
HCRW	Health and Care Research Wales
HRCS	Health Research Classification System
HSCNI	Health and Social Care, Northern Ireland
JLA	James Lind Alliance
NCRI	National Cancer Research Institute
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research
PeolcPSP	Palliative and end of life care Priority Setting Partnership
UKCRC	UK Clinical Research Collaboration

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