

Does current UK research address priorities in palliative and end-of-life care?

The Palliative and end of life care Priority Setting Partnership uncovered 83 unanswered research questions.

Florence Todd Fordham, Bridget Candy, Stevie McMillan and Sabine Best show that, as current UK research starts to address some of these questions, UK open grant data have the potential to encourage collaboration

 **Florence Todd Fordham**
PhD Project Coordinator¹

Bridget Candy
PhD Researcher²

Stevie McMillan
BA (Hons) Research Grants Officer^{1,3}

Sabine Best
PhD Head of Research¹

¹ Marie Curie UK, London

² Marie Curie Palliative Care Research Department, University College, London

³ Pancreatic Cancer UK, London

The Palliative and end of life care Priority Setting Partnership (PeolcPSP) and the James Lind Alliance (JLA) sought to identify the research priorities that are most important to patients, carers, and health and social care professionals involved at the end of life.^{1,2} The PeolcPSP identified 83 questions that were not shown to be answered by an up-to-date systematic review (through Cochrane or identified via the Database of Abstracts of Reviews of Effects³). Carers, patients and clinicians highlighted a top ten list from the 83 questions at a prioritisation workshop.

Palliative and end-of-life care research is underfunded

This project used the UK Clinical Research Collaboration's Health Research Classification System (HRCS) dataset, composed of £2 billion of funding in 2014 from 64 governmental and charitable funders across the UK.⁴ This dataset shows that end-of-life research represents only 0.16% of the total health-related research active in 2014. The 2014 dataset is the third to be conducted but the first to be made publicly available. Using these publicly available data, we set out to discover whether there is currently ongoing research that already addresses any of the questions put forward by the PeolcPSP.

The aims of this project were to:

- help researchers 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.

Interventions are treatments, care and other actions that are designed to make a difference to patients, carers and families and that can be tested and evaluated by research.

Box 1. What is an intervention?

Methodology

Keywords for each of the 83 PeolcPSP questions were identified, and the HRCS 2014 dataset of 14,394 grant abstracts was searched for links. The resulting abstracts were screened for relevance to the individual PeolcPSP questions and divided into:

- interventional grants: projects that proposed an intervention (see Box 1) to address the question
- direct grants: projects that had a direct link to the question but did not propose an intervention.

For the purposes of this research, these are referred to together as 'strong funding'. Detailed results for all 83 questions are due to be published in a forthcoming report.⁵ Table 1 shows the number of strong grants and the total funding allocated in 2014 for the top ten PeolcPSP priorities.

All top ten research questions are already attracting some research interest

Our analysis shows that the top ten research priorities for palliative and end-of-life care, as highlighted by patients, carers and clinicians, are all already attracting some research interest and funding, even though at very different levels (see Table 1). The table

Table 1. Results of the grant mapping exercise in relation to the top ten PeolcPSP priorities in 2014, ranked by funding amount⁵

Top ten priority questions	Strong UK funding amount (of which proposed interventions)	Number of strong UK grants addressing the question (of which proposed interventions)	Systematic review but question remains unanswered*	Top ten rank position
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)?	£4,307,040 (£758,347)	31 (6)	NO	6
How can access to palliative care services be improved for everyone, regardless of where they are in the UK?	£1,915,340 (£528,256)	16 (4)	NO	2
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?	£1,565,916 (£45,820)	11 (1)	YES ⁶	8
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? Does increasing the number of staff increase the quality of care provided in all settings? To what extent does funding affect these issues?	£1,414,488 (£321,796)	11 (1)	NO	5
What are the benefits of Advance Care Planning and other approaches to listening to and incorporating patients' preferences? Who should implement this and when?	£1,225,808 (£234,801)	13 (3)	YES ⁷	3
What are the best ways to assess and treat pain and discomfort in people at the end of life with communication and/or cognitive difficulties, perhaps due to motor neurone disease (MND), dementia, Parkinson's disease, brain tumour (including glioblastoma) or head and neck cancer, for example?	£1,003,763 (£399,855)	4 (2)	NO	10
What are the core palliative care services that should be provided, no matter what the patient's diagnosis is?	£628,219 (£0)	5 (0)	NO	7
What are the best ways to make sure that 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?	£528,015 (£0)	5 (0)	NO	9
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?	£516,924 (£0)	4 (0)	NO	1
What information and training do carers and families need in order to provide the best care for their loved one who is dying?	£343,410 (£265,383)	9 (5)	YES ⁸	4

* As of January 2015

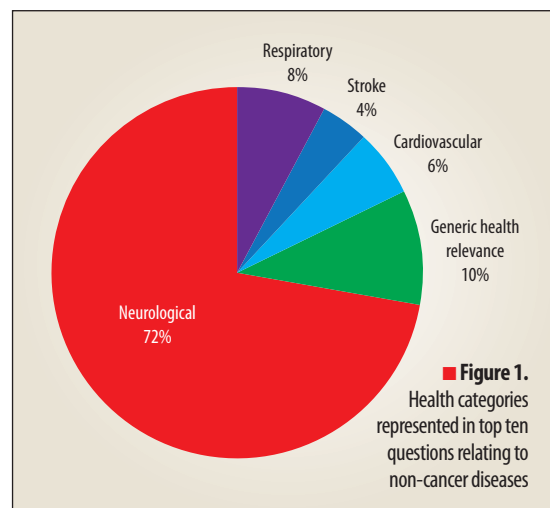
shows that three of the top ten questions received no funding to support interventions in 2014. This contrasts with the question that received the most funding, tackling palliative care in a wide number of non-cancer diseases, which received funding totalling £4.3 million in 2014, 18% of which proposed to test an intervention. This will hopefully help to bring much-needed change to practice in this area in the future.

Research questions that currently attract little attention

The top ten priority that received the least research funding in 2014 addressed the need for further research on support and information for families and carers. The total direct funding to this question amounted to only £343,410. Of this, £265,383 came from five small interventional grants and the rest came from four direct grants. Three-quarters of this funding came from Marie Curie, with most of it funded in a one-off themed research call that focused on informal carers and was co-funded by Dimpleby Cancer Care.⁹

The number one priority, as decided by patients, carers and healthcare professionals, asked how best to provide out-of-hours palliative care. This priority attracted no research proposing interventions and received only £516,924 of direct funding, which is just 0.03% of the total health research funding in 2014.¹⁰ It is clear that there is much need for further research to propose and test interventions to address the issue of out-of-hours palliative care, which is so important to carers, patients and health and social care professionals. The same can be said for the questions relating to continuity of care and the core palliative care services; both questions attracted no research proposing interventions and only a limited amount of direct funding in 2014.

Our wider analysis shows that of the 83 research questions identified in the PeolcPSP, 19 are not addressed by any research projects directly tackling the question.⁵ A further 10 questions were addressed by less than £50,000 of strongly related funding in 2014. The subtheme of bereavement received no strongly related funding in 2014, with no direct or interventional grants addressing any of the four questions in the theme. The details of this analysis are included in a forthcoming full report.⁵



Palliative care beyond cancer: a sizeable research community

The £4.3 million received by the PeolcPSP most funded top ten priority in 2014 – palliative care for people with non-cancer diseases – financed 31 grants, including six that proposed interventions. Research addressing this priority covers a range of conditions (see Figure 1). Neurological conditions take up almost three-quarters of the funding; of this, 80% relates to dementia, of which 82% is government-funded. This highlights the effect of a recent push by the UK government to increase dementia research in 2012.¹¹

Key points

- Published in 2015, the PeolcPSP report is being used to guide palliative and end-of-life care research funding.
- We have reviewed an open database of 2014 UK health research grant data to identify if and how current research is addressing the 83 PeolcPSP questions.
- The aims of this project include helping researchers avoid duplication by highlighting current research and fostering collaboration by showing who is already active in addressing specific questions.
- This project highlights that research spending in palliative and end-of-life care remains low, with pockets of good news. It also highlights the need for more research proposals and testing interventions to tackle the problems encountered in palliative and end-of-life care.
- The number one PeolcPSP priority – how to provide palliative care out of hours – is one of the questions most in need of further research investment.
- Of the 83 questions, 19 are not addressed by any directly related research funding active in 2014.

There is a sizeable community of researchers now looking at non-cancer conditions, such as heart failure,¹² non-cancer lung diseases such as chronic obstructive pulmonary disease¹³ and interstitial lung disease,¹⁴ stroke,¹⁵ organ failure¹⁶ and dementia.¹⁷ This is very encouraging, though clearly the overall amount spent on this question is split between many disease areas.

Next steps

This project shows only a snapshot of UK research addressing the questions identified by patients, carers and clinicians. There will be research not included in this dataset that might be active now or have finished before 2014. It is clear, however, that as none of the 83 questions have been answered in a systematic review, the need for more research in palliative and end-of-life care remains. In particular, it is necessary to develop and test interventions that address patient and carer needs in this area.

The PeolcPSP project has shown that some areas of palliative and end-of-life care research are making progress, and funder initiatives such as the former UK prime minister's 'challenge on dementia', along with smaller themed calls by charities such as Dimpleby Cancer Care and Marie Curie, are clearly having an impact in an area so strongly in need of more research.

Other areas of need, such as bereavement, are not currently addressed by research at all or by only a small amount. The full report of this project, which will be released soon, allows researchers and funders to identify currently active projects and, through those, researchers and clinicians already engaged in a particular field. We hope that it might help to identify potential future collaborators since it also includes references to research that is only weakly linked to a particular question.

We hope that highlighting the questions with little current funding will encourage researchers and funders to endeavour to look into these further. Some questions, in particular in the top ten, are broad research priorities and might require further work to identify more focused research questions. A recent local initiative from the Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Greater Manchester has demonstrated a method of achieving 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 ten questions.¹⁸

Research funders can help by providing 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 will help to make better use of limited research funds and avoid unnecessary duplication. In the UK, a group of funders with an interest in palliative and end-of-life care meets regularly as the UK end of life care Research Interest Group (UKeolcRIG).¹⁹

Acknowledgements

The authors are grateful to Dr Sanjay Thakrar and Professor Bill Noble for advice on the search terms used to conduct the grant mapping project.

References

1. PeolcPSP. *Palliative and end of life care Priority Setting Partnership (PeolcPSP) – final report*. London: PeolcPSP, 2015. https://palliativecarepssp.files.wordpress.com/2015/01/peolcsp_final_report.pdf (last accessed 22/08/16)
2. Smith R, Best S, Noble B. Identifying palliative and end of life care research priorities: a UK approach to consult end users. *Eur J Pall Care* 2015; **22**: 114–7.
3. DARE: www.crd.york.ac.uk/crdweb/; Cochrane: www.cochranelibrary.com/cochrane-database-of-systematic-reviews/ (last accessed 01/09/16)
4. UK Clinical Research Collaboration. *UK Health Research Analysis 2014*. London: UK Clinical Research Collaboration, 2015. www.hrcsonline.net/pages/uk-health-research-analysis-2014 (last accessed 01/09/16)
5. Todd Fordham F, Candy B, Noble B *et al*. *How is current palliative and end of life care research addressing the priorities of patients, families and clinicians?* London: Marie Curie, 2016 (in press)
6. Gomes B, Calanzani N, Curiale V *et al*. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *Cochrane Database Syst Rev* 2013; **6**: CD007760.
7. Houben CH, Spruit MA, Groenen MT *et al*. Efficacy of advance care planning: a systematic review and meta-analysis. *J Am Med Dir Assoc* 2014; **15**: 477–489.
8. Capurro D, Ganzinger M, Perez-Lu J, Knaup P. Effectiveness of ehealth interventions and information needs in palliative care: a systematic literature review. *J Med Internet Res* 2014; **16**: e72.
9. Dimpleby Marie Curie Research Fund. www.mariecurie.org.uk/research/funding-research/dimpleby-marie-curie-research-fund (last accessed 19/08/16)
10. UK Clinical Research Collaboration. *UK Health Research Analysis 2014*. London: UK Clinical Research Collaboration, 2015. www.hrcsonline.net/sites/default/files/UKCRHealthResearchAnalysis2014%20WEB.pdf (last accessed 23/08/16)
11. Department of Health. *Prime Minister's challenge on dementia 2020*. www.gov.uk/government/uploads/system/uploads/attachment_data/file/14344/pm-dementia2020.pdf (last accessed 19/08/16)
12. Denvir, M. Murray, S. and Boyd, K. Future care planning: a first step to palliative care for all patients with advanced heart disease. *Heart* 2015; **101**: 1002–7.
13. Javadzadeh S, Chowienczyk S, Booth S, Farquhar MC. Comparison of respiratory health-related quality of life in patients with intractable breathlessness due to advanced cancer or advanced COPD. *BMJ Support Palliat Care* 2016; **6**: 105–8.
14. Boland J, Reigada C, Yorke J *et al*. The adaptation, face, and content validation of a needs assessment tool: progressive disease for people with interstitial lung disease. *J Palliat Med* 2016; **19**: 549–5.
15. Burton C, Payne S, Turner M *et al*. The study protocol of: 'Initiating end of life care in stroke: clinical decision-making around prognosis', *BMC Palliat Care* 2014; **13**: 55.
16. Kendall M, Carduff E, Lloyd A *et al*. Different experiences and goals in different advanced diseases: comparing serial interviews with patients with cancer, organ failure, or frailty and their family and professional carers. *J Pain Symptom Manage* 2015; **50**: 216–224.
17. Jones L, Candy B, Davis S *et al*. (2016). Development of a model for integrated care at the end of life in advanced dementia: A whole systems UK-wide approach. *Palliat Med* 2016; **30**: 279–295.
18. NHS NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC) for Greater Manchester. *Next steps for end-of-life research: Research priorities defined for Greater Manchester*. Salford: Salford Royal NHS Foundation Trust, 2016.
19. Marie Curie. UK end of life care Research Interest Group (UKeolcRIG). www.mariecurie.org.uk/research/end-of-life-care-research-interest-group (last accessed 01/09/16)