

# Current palliative care research neglects out of hours care which is ranked the top end-user research priority

Palliative and end of life care  
Priority Setting Partnership



Authors: Florence Todd Fordham, Sabine Best, Sanjay Thakrar and Bill Noble, Marie Curie

## 1,403

responses to our initial survey

**48% professional; 35% bereaved carers; 13% current carers; 4% patients**

From the survey responses,

## 83

unanswered interventional questions were formulated

PRIORITISATION

The **Top Ten** unanswered questions in palliative and end of life care were published on **15th January 2015**<sup>1</sup>

**TOP PRIORITY**  
What are the best ways of providing **out of hours palliative care** to avoid crises and help patients to stay in their place of choice?

## INTRODUCTION AND AIM

In 2013/14 the Palliative and end of life care Priority Setting Partnership (PeolcPSP) used the James Lind Alliance (JLA) methodology to establish the top ten list of unanswered questions relating to palliative and end of life care research. These were ranked in accordance with responses from current and bereaved carers, healthcare professionals and people in the last years of life. The JLA methodology identifies questions that are either not answered by a current systematic review or for which no systematic review exists. Nevertheless, there might be current research projects in process which look into the question, either directly or in a way in which the results might be relevant to the question in an indirect way.

This aim of this paper is to review the ways in which current research is addressing the top research priority through a grant mapping exercise.

## METHODS

**Grant mapping** facilitates the visualisation of the current research landscape in palliative and end of life care, highlighting the research questions that are currently being addressed and those where there is less or no attention/funding. To conduct the mapping project, the recently published UKCRC's Health Research Classification System database was used<sup>2</sup>. This dataset, which is composed of £2 billion of UK health relevant research funding for 2014, was analysed for links between the abstracts and the PSP questions.

The following analysis specifically looks at the results relating to the top priority:

**Out of hours palliative care.**



## OUT OF HOURS PALLIATIVE CARE

The out of hours period covers from 18.30 to 08.00 on weekdays, and from 18.30 on a Friday through to 08.00 on a Monday, and on bank and public holidays<sup>3</sup>. Out of hours palliative care is just one component, albeit an important one, of the out of hours services needed by patients in the last years of life living at home.

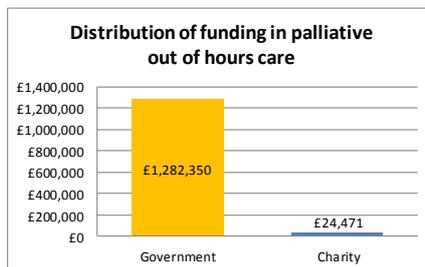
Using keyword searches, the HRCS dataset was searched for relevant grant abstracts. The keywords brought up 4,420 grants of which 594 were manually mapped. The keyword searches that were specific to the out of hours palliative care priority were: **palliative, end of life, end-of-life, EOL, terminal, dying, end stage, advanced disease, working hours, out of hours, out-of-hours, OOH, 24 hour, 24-hour, 24hr, place of choice, famil\*, carer.**

## LIMITATIONS

- Using the HRCS 2014 dataset of health research, this grant mapping process only considered research grants which were active in 2014, so shows a **snapshot** of the research landscape in palliative and end of life care.
- The dataset looks at £2 billion of project grants. A further £1 billion of infrastructural funding is not included (eg. Marie Curie centres are not included).
- The HRCS 2014 dataset includes most governmental and charitable researcher funders, but not all.

## RESULTS AND ANALYSIS

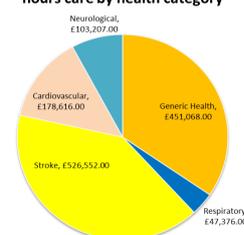
14,934 grant abstracts were searched using keyword searches for all 83 priorities. Of these, only 12 related to the priority on out of hours palliative care. These 12 grants amount to £1,306,820 of funding, which is 0.06% of the total health research spend in the 2014 HRCS dataset. The distribution of this funding is displayed in the graph below.



However, of these 12 grants, only 4 are considered "directly" related to the out of hours palliative care priority, with a specific link to 24 hour support for patients at the end of life and their carers and families, reducing the amount to only £516,924, which is just 0.03% of the health spend in 2014.

Of this directly related amount, 3.8% comes from Marie Curie (£19,483), and the rest is governmental funding. There only two other funders, direct and indirect, with a combined research funding of £18,932.

## Distribution of grant funding relating to out of hours care by health category



As is highlighted above, the **stroke** health category received the highest proportion of the total funding relating to out of hours palliative care.

## DISCUSSION

Out of hours palliative care has been identified as the top priority for research by carers, patients and clinicians. The 2014 HRCS research snapshot shows that there is little ongoing research in out of hours palliative care.

In addition, it has been found that the specific need for out of hours palliative care has not been systematically explored in research to date<sup>4</sup>. There is a lack of high quality research evaluating existing out of hour palliative services. High quality implementation and evaluation studies into out of hours palliative care are required to establish national standards.

## CONCLUSIONS AND NEXT STEPS

- Current palliative and end of life care research neglects out of hours palliative care despite it being ranked as the top research priority by carers, patients and clinicians.
- To address this unmet need, Marie Curie recently announced its seventh funding call addressing the PeolcPSP priorities. NIHR has recently announced an HS&DR researcher-led funding call with a specific highlight on the PeolcPSP questions.
- The Marie Curie conference on 19th October 2016 will look at the issue; conference theme: **Round the clock – making 24/7 palliative care a reality.**
- High quality implementation and evaluation studies into out of hours palliative care are required to establish national standards.

## References

- Palliative and end of life care Priority Setting Partnership (PeolcPSP) Final Report, January 15th 2015, <http://www.palliativecarepssp.org.uk/finalreport/>
- "UK Health Research Analysis 2014 (UK Clinical Research Collaboration, 2015) ISBN 978-0-903730-20-4 <http://www.hrcsonline.net/pages/uk-health-research-analysis-2014>"
- Addinton-Hall, J., Gerard, K. Brien, S. B., Brailsford, S., Salisbury, C., Heaney, D., Todd, C., Moore, M., Leydon, G., England, H., Lattimer, V. (2011) Variations in Out of Hours end of life care provisions across primary care organisations in England and Scotland. Final Report. NIHR Service Delivery and Organisation Programme, 2013.
- Godwin JV, Anagnostou D, Morgan F, Skell S, Baillie J, Byrne A, and Nelson A. (2016) Exploring experiences of out of hours palliative and end of life care: a supplementary thematic analysis of the PeolcPSP data, in preparation



Marie Curie  
Care and support  
through terminal illness



James Lind Alliance  
Priority Setting Partnerships

