

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

Executive summary

www.palliativecarepsp.org.uk

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Palliative and end of life care
Priority Setting Partnership



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Introduction

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

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

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

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

Methodology and findings

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

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

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

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

Conclusions

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

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

1. What are the best ways of providing palliative care **outside of working hours** to avoid crises and help patients to stay in their place of choice? This includes symptom management, counselling and advice, GP visits and 24-hour support, for patients, carers and families.

2. How can access to palliative care services be improved for **everyone regardless of where they are in the UK**?
3. What are the benefits of **Advance Care Planning** and other approaches to **listening to and incorporating patients' preferences**? Who should implement this and when?
4. What **information and training** do carers and families need to provide the best care for their loved one who is dying, including training for giving medicines at home?
5. How can it be ensured that staff, including healthcare assistants, are **adequately trained** to deliver palliative care, no matter where the care is being delivered? Does increasing the number of staff increase the quality of care provided in all settings? To what extent does funding affect these issues?
6. What are the best ways to determine a person's palliative care needs, then initiate and deliver this care for patients with **non-cancer diseases** (such as chronic obstructive pulmonary disease (COPD), heart failure, motor neurone disease (MND), AIDS, multiple sclerosis, Crohn's disease, Parkinson's disease, dementia, and stroke)?
7. What are the **core palliative care services** that should be provided no matter what the patients' diagnoses are?
8. What are the benefits, and best ways, of **providing care in the patient's home** and how can home care be maintained as long as possible? Does good coordination of services affect this?
9. What are the best ways to make sure there is **continuity for patients at the end of life**, in terms of the staff that they have contact with, and does this improve quality of palliative care? Would having a designated case coordinator improve this process?
10. What are the best ways to **assess and treat pain and discomfort** in people at the end of life with communication and/or cognitive difficulties, perhaps due to motor neurone disease (MND), dementia, Parkinson's disease, brain tumour (including glioblastoma) or head and neck cancer, for example?

Next Steps

For research funders...

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

For researchers...

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

For charities...

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

For the PeolcPSP...

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

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

For more information contact:

If you have any queries or comments, please contact the Project Coordinator on peolcsp@mariecurie.org.uk

For more information on the project process, news coverage and partners and to download the full report, go to www.palliativecarepsp.org.uk

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