Marie Curie Research Grants Scheme

Themes of call: 2016 call for applications

Contents

1. Aim

Marie Curie, the Chief Scientist Office (CSO) and the Motor Neurone Disease Association (MND Association) recognise that there is a paucity of high quality research to increase the evidence base for palliative and end of life care. The aim of this funding initiative is to improve the care of people with terminal illnesses through research.

2. Background and scope of the call

2.1. The Palliative and end of life care Priority Setting Partnership with the James Lind Alliance

The Palliative and end of life care Priority Setting Partnership (PeolcPSP) with the James Lind Alliance (JLA) was initiated in 2013 by Marie Curie to give patients, carers and clinicians the chance to have their say in setting research priorities for palliative and end of life care. More than 30 organisations were involved as co-funders or stakeholders, including the CSO and MND Association who both contributed financially to the project.

By using the JLA methodology, the PeolcPSP identified **83 research questions or evidence uncertainties** which were further prioritised by patients, carers and health and social care professionals.

2.2. Systematic reviews

As part of the JLA process to determine whether a research question/priority had already been addressed, questions were checked against existing systematic reviews and current protocols. For a number of the 83 questions, there were no systematic reviews identified (see appendix 2). Therefore, this call particularly welcomes proposals for systematic reviews for any of the questions that are currently not addressed.

Appendix 2 lists all 83 questions and states which questions are not currently addressed by an up to date systematic review. Further details can be found in the **UK Database of Uncertainties about the effects of treatments** (DUETs, http://www.library.nhs.uk/duets/SearchResults.aspx?tabID=294&catID=15620) where all PeolcPSP-derived uncertainties are listed with additional background information.

2.3. MND-relevant PeolcPSP research priorities

The PeolcPSP survey was well disseminated by the MND Association and as a result, 65 (of 1403) MND-related survey responses were received: 6 from people with MND, 26 current or bereaved carers/family/friends of people with MND, 4 volunteers working with people with MND, 5 members of the public and 24 health care professionals.

There are eight research priorities that directly refer to issues of relevance to people with MND.

'Managing symptoms and medications' theme

- 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? (priority 2.3 in appendix 2)
- 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? (priority 2.4 in appendix 2)
- 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? (priority 2.5 in appendix 2)
- What are the best ways of managing cachexia (weight loss) in palliative care patients, including people with cancer or Motor Neurone Disease (MND)? (priority 2.15 in appendix 2)
- 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? (priority 2.10 in appendix 2)
- 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 research priority was number 10 in the top 10 and resulted from a combination of more than one of the 83 questions at the prioritisation stage (including priority 2.3).*

'Service use' theme: place and type of care

- 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 research priority was number 6 in the top 10 and resulted from a combination of more than one of the 83 questions at the prioritisation stage (including priority 4.3.1).*

'Understanding dying' theme

- 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? (priority 5.1 in appendix 2)

The MND-relevant section of the call will consider the following:

- Applications directly addressing questions that are raised with MND relevance (see above)

- Applications addressing questions that do not mention MND specifically in the question, but where the suggested project / intervention / proposal addresses such a question in the context of people with MND

3. Funding for the 2016 call

The 2016 call is a joint call of Marie Curie, the CSO and the MND Association with a **total of £1.425 million available for high quality proposals addressing one or more of the research priorities identified by the PeolcPSP**. Marie Curie will contribute the usual £1million to this call.

3.1. CSO with Marie Curie

The **CSO** is contributing £225,000. Funds from the CSO will be matched by Marie Curie (total fund of up to £450,000) from the £1million that Marie Curie has allocated to this call. **To be eligible for CSO funding, projects must be led by a Principal Investigator (PI) who is based in Scotland and address one or a combination of PeolcPSP research priorities, applicable to the care of people with any terminal illness.** Collaborative applications from within Scotland are welcome, although the contracted grant will be with the PI's institution. Named academic and/or clinical collaborators are permitted from outside Scotland, but the lead applicant must be a permanent salaried member of staff at a Scottish Higher Education Institution or NHS Health Board. The maximum amount which any individual application can request is £450,000.

3.2. MND Association with Marie Curie

The **MND Association** is contributing £200,000. Funds from the MND Association will be matched by Marie Curie (total fund of up to £400,000) from the £1million that Marie Curie has allocated to this call. **To be eligible for MND Association funding, proposals must show relevance to people living with MND and draw on the associated priorities from the PeolcPSP.** Section 2.4 highlights relevant research priorities. **PIs can apply from anywhere in the UK.** The maximum amount which any individual application can request is £400,000.

3.3. Marie Curie

The remaining £575,000 of the fund, provided by **Marie Curie, will be awarded to proposals that focus on any one or combination of the 83 research priorities identified by the PeolcPSP, applicable to the care of people with any terminal illness. PIs can apply from anywhere in the UK.**

The final distribution of funds will depend on the number and size of proposals that are received. Joint funding can be for one or a number of projects. Figure 1 shows the relative contributions of the three components of funding for call 7.
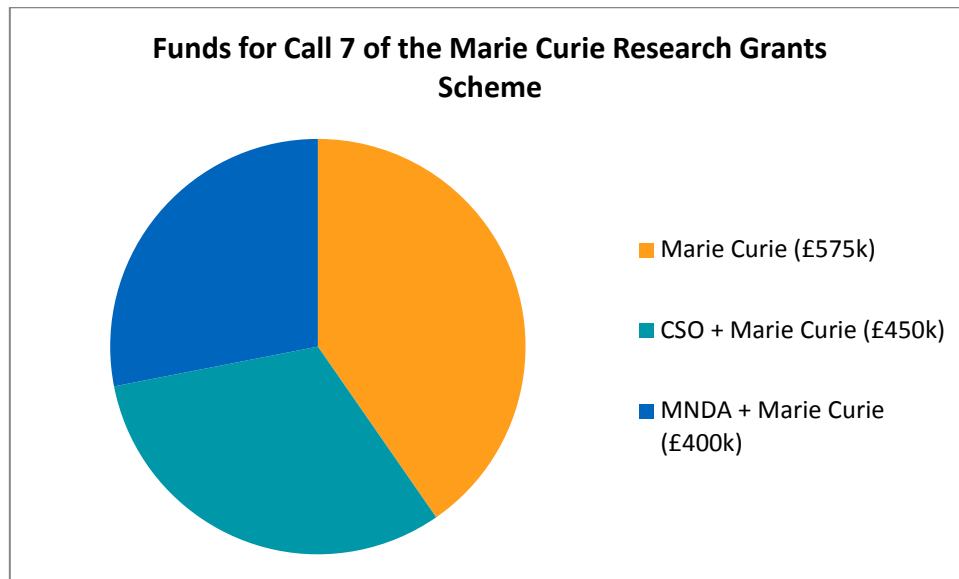
Figure 1. **Distribution of funds for joint call, the total funds available are £1,425,000**

4. Eligibility

The following criteria apply in addition to those outlined in Section 3:

- Outline applications are invited from Principal Investigators at recognised Universities, NHS hospitals, hospices or research institutes within the UK. The lead applicant must have a post which covers the **entire duration** of the proposed study.

- Please note that applications are welcome from **hospices** providing they are able to comply with all clauses within the Marie Curie Terms and Conditions (available on the Marie Curie website). In addition, it is essential that hospices form links with an academic institution or NHS partner organisation to build collaborations and obtain support for their project.

- **Early career researchers** are particularly encouraged to apply.

- **Collaborative applications are welcome** and named academic/clinical collaborators are permitted – although, if successful, the contracted grant (and associated funding arrangements) will be with the lead applicant's institution in the UK.

- Applicants are strongly advised to determine if their proposal is 'research' as defined by the National Research Ethics Service (NRES). **Proposals focussing on pure service evaluation and audits will NOT be accepted**. However, implementation studies will be considered. The HRA leaflet 'Defining Research' would be helpful to provide further guidance.

5. Funding criteria

Applicants will also be expected to outline how their application will address the following funding criteria for this call:

1) The potential to improve palliative and end of life care for people with a terminal illness and/or their carers, families and friends

2) Evidence of a demonstrable need for research in this area. Please highlight any relevant systematic reviews, if applicable.

3) The potential national/international impact of the proposed research.

4) The active engagement of Patient and Public Involvement (PPI) principles and processes in all stages of the research from planning through to dissemination.

5) The potential of study results or interventions to be generalisable and applicable throughout the UK.

6) A clear research plan and description of methodology to be employed. For feasibility studies, include the outcome measures and describe how and from whom the full trial could be funded.

7) Dissemination and knowledge transfer plan, including and beyond peer reviewed publications.

8) Which of the PeolcPSP research priorities are addressed in the proposal and how are they addressed.

Appendix 1

Top 10 PeolcPSP research priorities

Priority number	Research Priority
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?
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? 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' diagnosis is?
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 co-ordination 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?

Appendix 2

Table 2. Full list of 83 PeolcPSP research priorities, by theme

Unmarked boxes denote that a Systematic Review (SR) has identified evidence uncertainties within the associated topic.

	Theme 1: Communication	**SYSTEMATIC REVIEW?**
1.1	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?	
1.2	How can carers and families of people at the end of life be supported to communicate better with each other and their loved one?	
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?	
	Theme 2: Managing symptoms and medications	
2.1	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?	
2.2	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?	
2.3	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?	NO
2.4	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?	
2.5	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?	
2.6	What are the best ways to manage respiratory secretions (death rattle) in patients at the end of life?	
2.7	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?	
2.8	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?	
2.9	What are the best ways to manage acute and/or chronic breathlessness in patients with cancer and non-cancer terminal illnesses?	
2.10	What are the pros and cons of withdrawing MST (morphine sulphate) in people at the end of life?	NO (has protocol)
2.11	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?	
2.12	What are the best ways to diagnose and treat delirium, agitation, distress, and restlessness in people at the end of life?	
2.13	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?	YES (but out of date)
2.14	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?	
2.15	What are the best ways of managing cachexia (weight loss) in palliative care patients, including people with cancer or Motor Neurone Disease (MND)?	
2.16	Is it ever necessary to withdraw food and water (non-artificial hydration/nutrition)?	
2.17	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?	
2.18	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?	
2.19	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?	
2.20	What are the best treatments for nausea and vomiting (including for people with bowel obstruction and those having palliative chemotherapy)?	
2.21	How is incontinence best managed in people who are approaching the end of life (including those with Parkinson's disease)?	
2.22	What are the best treatments for fluid retention in patients approaching the end of life?	NO
2.23	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)?	NO (reference to an up-to-date SR, but could be extended)
2.24	How are steroids best used in palliative care (dose, duration, etc) for patients with different conditions, including those with brain tumours?	NO
2.25	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?	
2.26	What are best ways of managing constipation, including when caused by medication, such as opioids?	
2.27	What are the benefits and limitations (physical, social, psychological) of blood transfusions at the end of life?	NO
2.28	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?	

2.29	What are the best ways to treat dry mouth in patients at the end of life, including medications and foods, such as pineapple	NO
2.30	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?	NO
2.31	What are the best models of palliative care for people who have learning difficulties?	NO
2.32	What are the best models of palliative care for people who have mental health issues?	NO
	Theme 3: Support - carers and families	
3.1.1	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?	YES (but out of date)
3.1.2	How can carers and families be encouraged to seek support for themselves at the right time?	NO
3.1.3	What information and training do carers and families need to provide the best care for their loved one who is dying?	
3.1.4	Do people who are dying and their carers and families fare better if domestic support with shopping, washing up, laundry, etc, is provided?	YES (but out of date)
3.1.5	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?	NO
3.1.6	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?	NO
3.1.7	Does practical advice for concerns about housing, finance and transport, etc, reduce anxiety for carers and families and increase their wellbeing?	YES (but out of date)
3.1.8	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?	NO
3.1.9	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.	YES (but out of date)
3.1.10	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?	
3.1.11	How can patients, carers and families be supported when the patient does not want their carers and families to know their prognosis?	
	Support - Bereavement	
3.2.1	Should bereavement support be made available to all bereaved people and, if so, how? Should GPs or other professionals provide bereavement visits?	NO
3.2.2	How can the risk of intense and long-lasting grief best be assessed and treated? Can this be prevented through early bereavement support?	NO
3.2.3	What are the benefits of bereavement support, including preventing depression and other illness?	NO

3.2.4	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?	NO
Support -Training and staff support		
3.3.1	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?	YES (but out of date)
3.3.2	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?	
3.3.3	What are the benefits of all health and social care staff having training in bereavement awareness and support? Is this possible?	NO
Theme 4: Service use - care coordination		
4.1.1	What are the best ways to facilitate communication across services and between healthcare professionals, including effective IT systems, team meetings and remote technology?	NO
4.1.2	Since patients are often seen by a variety of professionals and services, would care improve if patients carried their own medical notes?	NO
4.1.3	What are the benefits of increasing the numbers of palliative clinical nurses/nurse specialists in hospitals, GP surgeries, nursing homes and other settings?	
4.1.4	Who should be part of the care team (such as chaplains, occupational therapists, GPs, etc)?	NO
4.1.5	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?	NO
4.1.6	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?	NO
4.1.7	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?	
4.1.8	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?	NO
4.1.9	Is there evidence that some volunteer services that provide support for patients, carers and families reduce the need for paid trained staff?	
4.1.10	Do people at the end of life who receive support from volunteers, carers, family or friends, have better end of life experiences than those who do not?	
Service use - Accessing services		
4.2.1	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?	
4.2.2	How can palliative care information and services be made more accessible to people whose first language is not English?	NO
4.2.3	How can access to palliative care services be improved for everyone regardless of where they are in the UK?	NO

4.2.4	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?	NO
4.2.5	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?	YES (but only protocol)
4.2.6	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	NO (but SR exists that could be expanded on)
	Service use - Place and type of care	
4.3.1	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)	NO (but SR exists that could be expanded on)
4.3.2	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?	YES (but out of date)
4.3.3	What are the core palliative care services that should be provided no matter what the patients' diagnosis is?	NO
4.3.4	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?	NO
4.3.5	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?	
4.3.6	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?	
4.3.7	What are the best models of palliative care in an acute setting, such as a hospital?	NO
4.3.8	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?	NO
4.3.9	Are some palliative care approaches better than others (e.g. holistic support, co-ordinated care, nurse-led care, early intervention) and for whom?	YES (but only protocol)
4.3.10	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?	YES (but only protocol)
4.3.11	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?	YES (but only protocol)

	Theme 5: Understanding dying	
5.1	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?	
5.2	Do people with various types of terminal cancer have different palliative care needs? If so, what are the best ways of managing their symptoms?	YES (but of of date)
5.3	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?	NO

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Marie Curie

Care and support
through terminal illness