Marie Curie
Research Grants Scheme

Themes of call: 2018 call for applications
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Summary

In the 2018 call to the Marie Curie Research Grants Scheme, research study proposals are invited within the following themes:

- Any of the following five highlighted areas (see Section 2.1 for more details):
  - Out of hours palliative and end of life care
  - Support for carers and families
  - Continuity of care
  - Bereavement
  - Incontinence

- Follow on and implementation studies building on research previously supported by Marie Curie (see Section 2.1 for more details).

- Interventional research such as the development of interventions and/or feasibility studies relating to any of the 83 PeolcPSP questions. This includes research relevant to Marie Curie services and research relevant to common symptoms experienced at the end of life (see Section 2.1 for more details).

- Research related to motor neurone disease (MND), jointly funded with the MND Association (see Section 2.2 for more details).

- Research related to terminal primary brain cancer, jointly funded with The Brain Tumour Charity (see Section 2.3 for more details).
# Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>HRCS</td>
<td>Health Research Classification System</td>
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<tr>
<td>JLA</td>
<td>James Lind Alliance</td>
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<td>MND Association</td>
<td>Motor Neurone Disease Association</td>
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<td>PeolcPSP</td>
<td>Palliative and end of life care Priority Setting Partnership</td>
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<tr>
<td>PPI</td>
<td>Patient and Public Involvement</td>
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<td>UKCRC</td>
<td>United Kingdom Clinical Research Collaboration</td>
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1. Aim and introduction

Marie Curie, the MND Association and The Brain Tumour Charity 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 care and support for people living with a terminal illness and their families, friends, carers and communities through research.

Please see the Guidelines for applicants for more information regarding the application process, including but not limited to the:
- Timeline for the call
- Eligibility and funding criteria
- Outline application form and finance guidelines
- Advice from the Marie Curie Research Funding Committee

1.1. Background of the call

The results of the Palliative and end of life care Priority Setting Partnership (PeolcPSP) with the James Lind Alliance (JLA) were published in 2015 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.

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. **Scope of the call**

2.1. **Marie Curie-related themes**

Applications to the ‘Marie Curie only’ part of the scheme should address:

- Any of the following five highlighted areas (see Box 1 for more information):
  - Out of hours palliative and end of life care
  - Support for carers and families
  - Continuity of care
  - Bereavement
  - Incontinence

- **Follow on and implementation studies** building on research previously supported by Marie Curie.

- **Interventional research** such as the development of interventions and/or feasibility studies relating to any of the 83 PeolcPSP questions. This includes research relevant to Marie Curie services and research relevant to common symptoms experienced at the end of life.

2.1.1. **Background to the Marie Curie-related themes**

The 2017 Marie Curie Grant mapping report interrogating the 2014 UK Clinical Research Collaboration (UKCRC) Health Research Classification System (HRCS) database has shown that some questions from the PeolcPSP have received less attention than others. Marie Curie would like to particularly encourage research in five highlighted areas that have received little attention to date (see Box 1).

Additionally, Marie Curie has recently collaborated with a number of other charities/organisations to encourage research into improving the quality of life of people living with incontinence. As a result, another highlight of the call is the relevant PeolcPSP question addressing incontinence (see Box 1).
Box 1: Highlighted research areas for the current call

<table>
<thead>
<tr>
<th>What are the best ways of providing palliative care outside ‘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?</th>
</tr>
</thead>
<tbody>
<tr>
<td>What information and training do carers and families need to provide the best care for their loved one who is dying?</td>
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<tr>
<td>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?</td>
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<tr>
<td>Four PeolcPSP questions that address bereavement:</td>
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<tr>
<td>- Should bereavement support be made available to all bereaved people and, if so, how? Should GPs or other professionals provide bereavement visits?</td>
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<tr>
<td>- How can the risk of intense and long-lasting grief best be assessed and treated? Can this be prevented through early bereavement support?</td>
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<tr>
<td>- What are the benefits of bereavement support, including preventing depression and other illness?</td>
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<tr>
<td>- 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?</td>
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<tr>
<td>How is incontinence best managed in people who are approaching the end of life?</td>
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</table>

An application proposing a follow on or implementation study building on research previously funded by Marie Curie may be on any topic, not necessarily the five highlighted areas outlined above. In particular, Marie Curie is interested in implementation of interventions and service delivery strategies of proven cost-effectiveness. Relevant projects should have the aim of generating new knowledge about service improvement that is generalisable and widely applicable.

Marie Curie also welcomes the development of interventions and proposals to test interventions in pilot and/or feasibility studies relating to any of the 83 PeolcPSP questions, which if successful should subsequently be scaled up and evaluated in a later definitive study. This includes research relevant to Marie Curie services and research relevant to common symptoms experienced at the end of life.
2.2. **Motor Neurone Disease-relevant themes**

Applications to the MND Association and Marie Curie part of the scheme should address:
- One or a combination of MND-related questions arising from the PeolcPSP (see Box 2), and/or
- The research recommendations highlighted in the recent NICE guidelines [NG42] on Motor neurone disease: assessment and management, as relevant to palliative and end of life care (see Box 2)

2.2.1. **MND-relevant themes highlighted in the PeolcPSP**

There are eight PeolcPSP research questions that directly refer to issues of relevance to people with MND (see Box 2).

Applications addressing PeolcPSP research questions that do not mention MND specifically, but where the suggested proposal addresses such a question in the context of people with MND, will also be considered.

**Box 2: MND-relevant themes highlighted in the PeolcPSP**

<table>
<thead>
<tr>
<th>‘Managing symptoms and medications’ theme</th>
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<tr>
<td>• 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?</td>
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<tr>
<td>• 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?</td>
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<tr>
<td>• 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?</td>
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<tr>
<td>• What are the best ways of managing cachexia (weight loss) in palliative care patients, including people with cancer or Motor Neurone Disease (MND)?</td>
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<tr>
<td>• 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?</td>
</tr>
<tr>
<td>• 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?</td>
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<table>
<thead>
<tr>
<th>‘Service use’ theme: place and type of care</th>
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<tbody>
<tr>
<td>• 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 neuron disease (MND), AIDS, multiple sclerosis, Crohn’s disease, Parkinson’s disease, dementia, and stroke)?</td>
</tr>
</tbody>
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<tr>
<th>‘Understanding dying’ theme</th>
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<tr>
<td>• 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?</td>
</tr>
</tbody>
</table>

2.2.2. **Research recommendations highlighted in recent NICE guidelines**

There are six research recommendations highlighted in the NICE guidelines on motor neurone disease: assessment and management from February 2016 (see Box 3).
Marie Curie and the MND Association will only fund research studies where applicants can show relevance to palliative and end of life care.

Box 3: Research recommendations from NICE guidelines on motor neurone disease: assessment and management, February 2016

1. Organisation of care
Is a network-based model as effective as a clinic-based model to deliver multidisciplinary care to people with motor neurone disease (MND)?

Why this is important
Multidisciplinary care improves survival in patients with MND. The evidence is drawn from models of multidisciplinary care that use a clinic based approach. However there are other models of care delivery in practice including care networks. Often these alternative models of care have arisen out of necessity in large geographical regions with low density populations. These alternative models may have similar survival advantages to patients with MND and this needs to be established.

2. Cognitive assessment
What is the impact of assessing for cognitive and behaviour change in people with MND on clinical practice, the person and their family and carers? Does repeated assessment provide more benefit than assessment at a single point at diagnosis?

Why this is important
Clinic-based and population-based studies demonstrate that up to 15% of people with MND have frontotemporal dementia. A further third of people with MND have changes in behaviour and cognition. These impairments are present at diagnosis. Their course during the disease has shown varying patterns between studies although several studies have shown that cognitive and behavioural impairments predict poorer survival and increased carer burden. A randomised controlled trial is needed to assess whether formal assessment at diagnosis and/or repeated assessment improves clinical practice, subsequent care of the person and quality of life for the person, their family and carers.

3. Prognostic tools
Is the ALS Prognostic Index an accurate predictor of survival in people with MND under NHS care in England and/or Wales?

Why this is important
Accurate predictions of survival in people with MND would be of great use to clinicians and to the person with MND, their family and carers. Accurate predictions would enable people with MND to be clearer about their prognosis, make plans for the rest of their life and have a well-prepared and dignified transition into the end of life phase. Family members would similarly benefit in being more aware of the likely progression and prepare themselves for the death of their loved one.

Accurate predictions of survival would enable professionals to create and deliver more effective management and care plans and access services when it is most appropriate, for example specialist palliative care.

The ALS Prognostic Index (ALS-PI) was developed in a cohort of people with ALS in the Republic of Ireland and externally validated in a cohort in Italy. However, it has not been validated in people with ALS, primary lateral sclerosis or progressive muscular atrophy in the NHS in England or Wales. The tool needs to be validated in a UK population using a simplified measure of executive function.

4. Saliva
How is excessive drooling of saliva (sialorrhoea) managed in people with MND?

Why this is important
Sialorrhoea affects up to 50% of people with MND and in 42% of these individuals the symptom is poorly controlled. There is no evidence base for clinicians to make decisions with regards to the treatment options available. Antimuscarinics are used first-line but there is no evidence to inform which antimuscarinic and at what dose. Botulinum toxin is used second- or third-line although there is little evidence to guide dosing,
which salivary glands to inject and which type of botulinum toxin to use. Currently there is no baseline information about how specialists are using these treatments and this information is required to inform comparative studies.

5. Nutrition  
Does a high calorific diet prolong survival of people with MND if initiated following diagnosis or following initiation of feeding using a gastrostomy?

**Why this is important**
There is little specific guidance on the optimal calorie intake for people with MND. There is growing evidence that people with MND have a hypercatabolic state and have high energy requirements. A large cohort study in the UK has demonstrated that nearly half of people continue to lose weight following gastrostomy and most show no improvement in their weight. A small study has demonstrated that high fat and high carbohydrate feeding may prolong survival in gastrostomy-fed people. A larger randomised trial is needed to inform clinical practice.

6. Augmentative and alternative communication  
What is the current pattern of provision and use of augmentative and alternative communication (AAC) by people with MND in England?

**Why this is important**
Appropriate AAC equipment can have a significant effect on quality of life for people with MND. While the NHS has a responsibility to provide equipment and ongoing support in its use, there are no reliable data on the types of equipment found most useful at different stages of the disease process, or the number of people with MND who may benefit from AAC. A prospective census study of people with MND presenting with early onset of speech problems is needed to establish the current baseline provision and needs of this population and how best to utilise AAC equipment. The programme will begin with the collection and analysis of basic data. It will then progress to patient-related outcomes.

### 2.2.3. MND-related research studies funded in previous calls

In our previous two joint calls with the MND Association, we funded the following projects:

<table>
<thead>
<tr>
<th>Grantholders</th>
<th>Title</th>
</tr>
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<tbody>
<tr>
<td>Dr Kate Flemming</td>
<td>The palliative care needs of people with motor neurone disease (MND) and their informal care givers</td>
</tr>
<tr>
<td>Professor Christopher McDermott</td>
<td>A prospective observation of secretion problems in motor neurone disease (ProSec)</td>
</tr>
<tr>
<td>Professor Gunn Grande &amp; Dr Gail Ewing</td>
<td>Enabling tailored and coordinated support for family carers of people with MND through adaptation of a Carer Support Needs Assessment Tool (CSNAT) Intervention</td>
</tr>
<tr>
<td>Dr Sally Wheelwright</td>
<td>Development and pilot testing of a web-based decision aid for people with motor neurone disease considering a gastrostomy</td>
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</table>
2.3. **Brain Tumour-relevant themes**

The call is open to proposals that seek to address questions about the delivery and organisation of palliative and end of life care in relation to people with any terminal primary brain tumour and their families, friends, carers and communities. Applications to the Brain Tumour Charity and Marie Curie part of the scheme should address:

- One or a combination of questions arising from the PeolcPSP (see Box 4), and/or
- Issues highlighted in The Brain Tumour Charity’s patient and carer publications, as relevant to palliative and end of life care (see section 2.3.2. for details)

The Brain Tumour Charity has recently introduced a Research Involvement Network (RIN) and expects applicants to involve patients with brain tumours and/or past/present carers in all applications. This is in line with Marie Curie’s view on active Patient and Public Involvement (PPI) in all stages of research, which is part of the funding criteria for all calls.

2.3.1. **Brain tumour themes highlighted in the PeolcPSP**

There are a number of PeolcPSP questions with relevance to brain tumours, as shown in Box 4.

Applications addressing PeolcPSP research questions that do not mention brain tumours specifically, but where the suggested proposal addresses such a question in the context of people with brain tumours, will also be considered.

**Box 4: PeolcPSP questions with relevance to brain tumours and the strategic goals of The Brain Tumour Charity**

<table>
<thead>
<tr>
<th>‘Managing symptoms and medications’ theme</th>
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<tbody>
<tr>
<td>• 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?</td>
</tr>
<tr>
<td>• 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?</td>
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<tr>
<th>‘Service use - Accessing services’ theme</th>
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</thead>
<tbody>
<tr>
<td>• How can access to palliative care services be improved for everyone regardless of where they are in the UK?</td>
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</tbody>
</table>

2.3.2. **Issues highlighted in The Brain Tumour Charity’s patient and carer publications**

In 2015, the Brain Tumour Charity commissioned a survey and interview research study to investigate the reality of adults living with a brain tumour. 1,004 people completed a comprehensive survey, 15 people were selected to take part in face to face interviews and 25 were asked to keep on-line diaries over 7 days. The study resulted in a report ‘Losing Myself: The Reality of Life with a Brain Tumour’.

In 2015/16, the Brain Tumour Charity commissioned a further survey of almost 300 young people and their parents following a childhood brain tumour diagnosis. The resulting report ‘Losing My Place: The Reality of Childhood with a Brain Tumour’.
These reports highlight the issues that have the biggest impact on those affected, which includes, but is not limited to:

- Symptom management
- Treatment of side effects
- Cognitive impairments
- Emotional and mental health
- Survivorship issues
- Communication and social isolation
- Relationships

In this call, Marie Curie and The Brain Tumour Charity will only fund research studies where applicants can show relevance to palliative and end of life care.
For remit queries please contact:

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