Aim
To facilitate more research into palliative and end of life care focusing on areas where most people are not well informed.

Background
Research to improve palliative and of life care is poorly funded in the UK (1). To address this, the medical charity Marie Curie C2 initiated a project to raise the profile of this area of research and to gather evidence that would help to improve funding. A collaboration was established between research funders, patient organisations in the UK and Ireland, in partnership with the James Lind Alliance, known as the Palliative and End-of-Life Care Priority Setting Partnership (PeolcPSP) (2). The Motor Neurone Disease Association in the UK was one of the partners in the project.

The James Lind Alliance (JLA) is a UK non-profit making initiative which was established in 2004. It brings patients, carers and clinicians together in Priority Setting Partnerships (PSPs) to identify and prioritise the Top 10 unmet, or unanswered, questions about the effects of treatments that they agree are most important. The aim of the PJP is to help ensure that those who fund health research are aware of what matters to both patients and clinicians.

Methods
A national public survey was designed to reveal the questions identified by health and social care professionals who had experience of care, support and treatment for people who were in the last few years of their lives. The online survey was created using SurveyMonkey and widely promoted to the palliative care and MND community in the UK and Ireland. The wording is shown in Figure 1. Participants were asked to choose which category best described them, they could choose more than one (there was no limit). Data were subsequently uploaded into Nivo 10 question prioritisation analysis software.

The data were analysed using an inductively derived coding framework to draw out research questions. Patients, carers and professionals were then invited to prioritise these research questions.

Results 1: Identifying research questions
An overview and results of the methodology is given in Figure 2.

Results 2: Top ten priorities for research in palliative and end of life care in order of priority are:

1. What are the best ways of providing palliative care outside of hospital settings to avoid crises and help patients to stay in their place of choice?
   - This includes symptom management, comfort, and support for people at the end of life, in terms of the staff that they have contact with.

2. How can we best determine a person’s palliative care needs, particularly for patients with non-cancer diseases (such as COPD, heart failure, MND/ALS, multiple sclerosis, Crohn’s disease, Parkinson’s disease, dementia, and incontinence)?
   - What can the care palliative care services that should be provided, regardless of what the patient’s diagnosis is?

3. What are the benefits, and best ways, of providing care in the patient’s home or where a person can continue to be cared for as possible?
   - Does good co-ordination of services affect this?

4. 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 the imporant of palliative care? Is being a trained general care coordinator improve this process?

5. What are the best ways to assess and treat pain and discomfort in people at the end of life with communication and cognitive difficulties, perhaps due to Motor Neurone Disease (MND)?
   - Dementia, Parkinson’s disease, general anaesthesia (including General Anaesthesia) and head neck cancer, for example.

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 COPD, heart failure, MND?
   - The QR code links to a YouTube clip of the top ten priorities.

Results 3: Research priorities in palliative and end of life care in MND/ALS
Within the 83 questions, seven specifically raised palliative and end of life care for people with MND/ALS. Four of these were about managing the symptoms of the disease, care on the place and type of palliative care and one in the understanding dying theme. The results are given below for more details.

A secondary thematic analysis of the dataset based at all of the 65 responses submitted by people responding about MND/ALS. Using the same coding framework, these responses revealed concerns with access to, and coordination of services, the appropriate prescription of palliative care, and symptom management and care at end of life.

Results 4: Research priorities are applicable to palliative and end of life care for people living with MND/ALS

Discussions and conclusions
The Palliative and End of Life Care Priority Setting Partnership published its final report in January 2019. It includes details of the methodology and findings. Copies are available to download online (1). People identified as palliative and end of life care can be used in a variety of different settings. For research funders, it provides an evidence base on which to prioritise; for policy makers, it provides evidence of what topics matter to people in the last few years of life and their families; for researchers, it provides evidence of which topics matter to people in the last few years of life and their families; for patients, carers and health and social care professionals it provides evidence on which topics in palliative and end of life care may be important to the patient group, the treatment or intervention and outcomes were clearly defined in the intervention and outcomes were clearly defined in the population.

While the NIVO Association will promote research into these questions, more evidence on the broader, general questions will increase the care and support of everyone at the end of life, including people with MND/ALS.

As a direct result of this project, the NIVO Association, Marie Curie and the Chief Scientist Office in Scotland will prioritise evidence generation and funding calls for research projects based on the long list of 83 questions.

The deadline for any summary applications is 14 January 2016. The call is open to all applicants (international collaborations are permitted).

More information is available online.

www.mariecurieuk.org/research (1)

References
1. End of Life Care Strategy, Department of Health, UK, 16 July 2009
2. www.mariecurie.org.uk (last accessed 19 November 2015)

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- Marie Curie Cancer Care
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Figure 1: Questions used in the initial online survey to determine research priorities in palliative and end of life care.

Your question(s) about palliative and end of life care: What is the best way to ensure that people with MND receive essential care promptly on diagnosis, when is the best stage to transition to palliative care and when should it be in Care Kit(s) be considered?

What questions do you have about care, support and treatment for people who are in the last few years of life that could help them to live as well as possible?

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