P131 Research priorities in palliative and end of life care: MND results from a broad analysis of patient views

*Cupid B[1], Van Godwin J[2], Tate T[3], Noble B[1], Smith R[3], Tuft J[3], Eley J[4], Black J[5], Stockton M[6], Cheesley A[7], Berry L[7], Loftus R[8], Dechamps A[9], Stevens E[10], Penny A[11], McEnhill L[12], McNair A[13], Fryett S[14], Kerr R[13], McIlfatrick S[16], Nelson A[2], Sivell S[2], Baillie J[2], Candy B[17], Best S[3], and Cowan K[18]

[1]Motor Neurone Disease Association, [2]Marie Curie Palliative Care Research Centre, Cardiff University, [3]Marie Curie, [4]NCRI Consumer Hub, [5]National Council for Palliative Care, [6]Association for Palliative Medicine of Great Britain and Ireland, [7]Royal College of Nursing, [8]Macmillan Cancer Support, [9]St Christopher's Hospice, [10]Scottish Partnership for Palliative Care, [11]National Bereavement Alliance and Childhood Bereavement Network, [12]Help the Hospices, [13]Chief Scientist Office, [14]National Institute for Health Research, [15]Health and Care Research Wales, [16]All Ireland Institute of Hospice and Palliative Care, [17]Marie Curie Palliative Care Research Unit, University College London, [18]James Lind Alliance

In partnership with

Aim

To facilitate more research into palliative and end of life care focussing on areas where people most affected by it feel it is needed.

Background

Research to improve palliative and of life care is poorly funded in the UK (1). To address this, the medical charity Marie Curie (2) initiated a project to raise the profile of this area of research and to gather evidence on which were the priority areas to fund. This was a collaboration of many research funders and 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) (3). The Motor Neurone Disease Association in the UK was one of the partners in the project.

The James Lind Alliance (JLA) (4) 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 uncertainties, or 'unanswered questions', about the effects of treatments that they agree are most important. The aim of the PSPs 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 question(s) patients, carers and health and social care professionals had about 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 NVivo 10 (qualitative analysis software) for coding.

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

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
Your question(s) can be about anything that you think is important that went unanswered for you. All you need to do is write a sentence or two about whatever it is. If a question relates to any particular condition or disease, please tell us which one. Send us as many questions as you like.

What question(s) do you have about care, support and treatment for people who are in the last few years of their lives that could help them to live as well as *possible*?

What question(s) do you have about care, support and treatment for those rapidly approaching the end of their lives?

Results 1:

Identifying research questions

An overview and results of the methodology is given in Figure 2

From the 1,403 responses received from the initial survey, 749 research questions were identified. The focus of the analysis was to identify 'intervention' research questions, where the patient group, the treatment or intervention and outcomes were clearly defined in the question – also known as 'PICO' analysis (Population Intervention Comparison and Outcome). Questions that did not fit this were considered out of scope.

Questions answered by systematic review, any duplicates and those out of scope were removed from further analysis.

The long list of 83 research questions were categorised into five themes: 'Communication', 'Managing symptoms and medications', 'Support', 'Service use' and 'Understanding dying' (Illustrated in Figure 3). The 83 questions were presented for prioritisation online via surveymonkey. A final priority setting workshop, involving patients, carers and professionals then took place to identify the top 10 research priorities. Figure 4 gives a breakdown of who completed the two surveys.

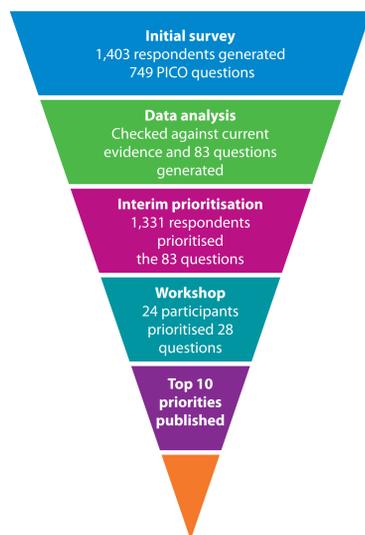**Figure 2:** Overview and results of the project methodology

Initial survey
1,403 respondents generated 749 PICO questions

Data analysis
Checked against current evidence and 83 questions generated

Interim prioritisation
1,331 respondents prioritised the 83 questions

Workshop
24 participants prioritised 28 questions

Top 10 priorities published

Figure 3: The 83 research questions illustrated by topic theme

Communication (3)

Understanding dying (3)

Support (18)
- Carers and families (11)
- Bereavement (4)
- Training and staff support (3)

Service Use (27)
- Care co-ordination (10)
- Accessing services (6)
- Place and type of care (11)

Managing Symptoms and medications (32)

Figure 4: Gives a breakdown of who completed the two surveys

Respondents to the first survey asking for experiences of palliative and end of life care in two free text questions

Respondents to the prioritisation survey – reducing the long list of 83 questions to 28 questions to be presented to the workshop participants

Respondents to survey All categories that apply could be chosen
- I am in the last few years of my life
- I am a carer or family member or partner or friend of someone in the last few years of life
- I am a bereaved carer or family member or friend
- I am a professional working with people in the last few years of life
- I am a volunteer working with people in the last few years of life
- I am a member of the public who has an interest in the subject
- Other

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 '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 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 COPD, heart failure, **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?

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. Five of these were about managing the symptoms of the disease, one on the place and type of palliative care and one in the 'understanding dying' theme, see Figure 6 below for more details.

A secondary thematic analysis of the dataset looked 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 introduction of palliative care; and symptom management and care at end of life.

Figure 6: Research questions applicable to palliative and end of life care for people living with MND/ALS

Managing Symptoms and medications
- What are the best approaches to providing pain relief for people with communication difficulties as a result of their disease – such as MND
- What are the best ways to manage the problems associated with difficulty swallowing including for people with MND who are at the end of life
- What are the best ways to manage drooling and excessive salivation in patients with MND who are approaching the end of their life
- What are the best ways of managing weight loss in palliative care patients including people with MND
- What are the best ways 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 a 'Just in Case kit' be considered?

Service Use: Place and type of care
- What are the best ways to begin and deliver palliative care for patients with a non-cancer diagnosis (including MND)

Understanding dying
- How can we best determine a person's palliative care needs, particularly for patients with non-cancer diseases such as MND

Discussions and conclusions

The Palliative and End of Life Care Priority Setting Partnership published its final report in January 2015. It includes details of the methodology and findings. Copies are available to download online (3).

Priorities identified for palliative and end of life care can be used in a variety of different settings. For research funders, it provides evidence on which topics in palliative and end of life care should be addressed first. For researchers, it provides evidence of which topics matter to people in the last few years of life and those around them, perhaps increasing researchers success rate in obtaining future funding of research into these topics. For those seeking to influence policy, the results and the project overall, raises awareness of this important area of research.

It is encouraging that non-cancer diseases, and MND/ALS specifically is mentioned in a number of the overall priorities.

While the MND 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.

As a direct result of this project, the MND Association, Marie Curie and the Chief Scientist Office in Scotland have recently announced a joint funding call for research projects based on the long list of 83 questions.

The deadline for summary applications is 14 January 2016. The call is open to UK applicants (international collaborators are permitted).

More information is available online:
www.mariecurie.org.uk/research2016

The QR code links to a YouTube clip giving an overview of the project.

References

1. End of Life Care Strategy, Department of Health, UK, 16 July 2008

2. www.mariecurie.org.uk (last accessed 19 November 2015)

3. www.palliativecarepsp.org.uk (last accessed 19 November 2015)

4. www.jla.nihr.ac.uk (last accessed 19 November 2015)