

# **Palliative and end of life care Priority Setting Partnership**

Putting patients, carers and clinicians at  
the heart of research

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

- The James Lind Alliance
- Establishing the PeolcPSP
- The priority setting process
- The results

# The James Lind Alliance

- **Tackling treatment uncertainties together**
- Finding out what research is important to:
  - Patients / service users
  - Carers / relatives
  - Clinicians / healthcare professionals



James  
Lind  
Alliance

Priority Setting Partnerships

# The James Lind Alliance

- Who normally decides what gets researched?
  - Researchers
  - Pharmaceutical industry

The priorities of people with conditions and the people who treat and care for them can be very different from researchers' priorities.

- The JLA offers an alternative framework.

# The James Lind Alliance

- Established in 2004
  - Royal Society of Medicine - Dr John Scadding
  - The Cochrane Collaboration - Sir Iain Chalmers
  - INVOLVE - Sir Nick Partridge
- Since April 2013: NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC)

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Working in partnership with

  
**National Institute for  
Health Research**

# Establishing the PeolcPSP

- Working with the James Lind Alliance to consult:
  - people likely to be in the last years of life,
  - current and bereaved carers and families, and
  - health and social care professionals
- To identify their priorities for palliative and end of life care research.

# Establishing the PeolcPSP

- Funding partners



[www.palliativecarepsp.org.uk](http://www.palliativecarepsp.org.uk)

# The priority setting process

## **Following the JLA method:**

- Set up steering group
- Invite partners
- Gather questions
- Prioritise questions
- Promote priorities to researchers and funders



# The priority setting process

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**Palliative and end of life care  
Priority Setting Partnership**

Do you have questions about palliative and end of life care?  
If you do please fill in this survey.

**Why we need your help:**  
We are asking for your help so that we can identify priority areas for research in the treatment, care, and support of those who are in the last years of their life.

**Who you are:**

- A person with a long-term illness who might be within the last years of life
- Caring for a loved one or someone you know in the last years of life
- A carer, nurse or family member
- Health or social care professionals or volunteers working with people who are in the last years of life
- A member of the public who has an interest in palliative and end of life care.

Your experience and knowledge, as someone who has been directly affected by end of life care, will be essential in helping us identify the most important questions that need to be researched.

**What we are asking you to do:**  
This is a unique opportunity to directly influence future research into palliative and end of life care.

Please think about your own experiences of palliative and end of life care and take part in our quick and simple survey over the page. It will take you approximately 10 minutes to complete. You can complete our survey on paper to be posted back to us at our freemart address, on-line or over the telephone.

**What we mean by palliative care:**  
Besides helping those with advanced, progressive, incurable illness to live as well as possible until they die, palliative care is about supporting everyone involved in a person's life, such as family, friends and carers.

For patients, it includes management of pain and other symptoms and provision of psychological, emotional, social, spiritual and practical support.

For family, friends and carers it includes the support that can be provided as and when required to help the family cope during the person's illness and in their own bereavement.

**What will happen to your question(s):**  
Your question(s) will be gathered together and examined with questions we receive from everyone else who takes part in this survey.

- The questions that haven't already been answered by research will be published (see below for more information)
- They will go through a process of prioritisation which you can be involved in if you like.
- This will result in a 'top ten' list of research topics which we will use to influence future research decisions.

**SUPPORTERS AND PARTNERS**

**MEMBERSHIP**

Logos for: Marie Curie Cancer Care, Chief Scientist Office, National Institute for Health Research, MRC, Cancer Research UK, E.L.A.C. Centre, NISGHR, and others.

# The priority setting process

- Gathering questions: survey respondents

Respondent type	No.	%
I am in the last few years of my life	43	4
I am a carer, family member, partner or friend	132	12
I am a bereaved carer	419	38
I am a professional	492	45
I am a volunteer	37	3
I am a member of the public with an interest	148	13
Other	104	9

# The priority setting process

Respondent type: professionals	No.	%
Palliative care doctor	45	14
Other specialist doctor	11	3
General practitioner	32	10
Specialist palliative care nurse	44	14
Other specialist nurse	28	9
Nurse	53	17
Professional allied to medicine	26	8
Social worker	14	4
Care home or home care staff	9	3
Chaplain	7	2
Clinical researcher	8	3
Other	38	12

# The priority setting process

- 1403 responses analysed
- 749 initial (interventional) questions
- Checked existing systematic reviews
- Combined to form 83 questions
- Second short-listing survey: 1331 participants
- 28 questions long-listed
- Final priority setting workshop
  - Top 10 priorities for research agreed

# The priority setting process

- The final workshop



# Thank you

Thank you to all of the patients, current and bereaved carers, and health and social care professionals who took part in...

- Both surveys
- Workshop
- And helped to disseminate the results.

# (Workshop 1)

Note to participants of workshop 1:

**Please choose one of the top 10** to think about further and discuss at the workshop

# The top 10

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 top 10

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?

# The top 10

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?

# The top 10

- 7 What are the **core palliative care services** that should be provided no matter what the patients' diagnoses are?

# The top 10

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)?

# The top 10

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?

# The top 10

- 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?

# The top 10

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?

# The top 10

2 How can access to palliative care services be improved for **everyone regardless of where they are in the UK?**



# The top 10

- 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.

# Today's workshop

- Brief discussion of the Top 10 questions
  - any surprises?
- How do we go about answering these?
  - who would fund?
  - what type of research?
  - what expertise needed?

# Thank you

- Sabine Best, Rhiannon Smith and Jennifer Tuft
- PeolcPSP Steering Group and Data Assessment Group

SUPPORTED AND GUIDED BY



SUPPORTING PARTNERS



[www.palliativecarepsp.org.uk](http://www.palliativecarepsp.org.uk)