The Palliative and end of life care Priority Setting Partnership with the James Lind Alliance (PeolcPSP)

An example for determining research priorities from the perspective of the ‘end user’ of research

9 September 2016
Dr Angela McCullagh, Service User Representative
Dr Sabine Best, Marie Curie

www.palliativecarepsp.org.uk
Outline of talk

1. Angela
   - Introduction to PeolcPSP and top 10 research priorities / evidence uncertainties
   - Service user perspective

2. Sabine
   - Next steps for PeolcPSP – past, current, future
Angela McCullagh – who am I?

- Patient, cancer survivor
- Former carer for family members: last illness
- Former Director R&D Thomas Pocklington Trust
- Lay/service user rep
- Member of the PeolcPSP Steering Group
What is palliative and end of life care?

**Palliative care**
- aims to improve quality of life
- provides relief from pain and other distressing symptoms
- combines psychological, social and spiritual support ('holistic' care)
- also applies to the earlier stages of an illness

**End of life care**
- is an important part of palliative care for people who are nearing the end of life
- is often defined as for people who are considered to be in the last year of life, but this timeframe can be difficult to predict
And why is palliative and end of life care research important?

Big gaps in evidence

• Palliative care is a relatively new specialty (1980s)
• Little evidence available to inform clinical guidelines and service development / improvement

In cancer research

Cancer-related palliative and end of life care research: less than 0.7% of cancer research spend in UK (2002-2013)

Health research in general

End of life care: 0.16% of health research in the UK in 2014
PeolcPSP – Scope and objectives

Scope
• palliative and end of life care
• care and treatment of adults

Objectives
• work with patients, carers, volunteers, clinicians and other health and social care practitioners to identify uncertainties about treatment and care at the end of life
• agree by consensus a prioritised list
• publicise the results of the PSP amongst the research community
• take the results to research funding bodies
Funding partners

- Marie Curie
- All Ireland Institute of Hospice and Palliative Care
- Cancer Research UK
- Chief Scientist Office (Scotland)
- Economic and Social Research Council
- Macmillan Cancer Support
- Medical Research Council
- Motor Neurone Disease Association
- National Institute for Health Research (NIHR, England)
- Health and Care Research Wales

- Plus: 29 organisations as stakeholders
Survey – two big questions

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?

Survey to help improve palliative and end of life care

Do you have questions about palliative and end of life care, support and treatment? If you do please fill out this survey.

Why we need your help:
We are asking for your help because we want to improve care, support and treatment for people in the last few years of their lives. We know that many people have important questions about care, support and treatment, and we want to find out what they are. We want to use these questions to set priorities for research that will improve care for people at the end of their lives and their families and carers in the future.

Who you are:
A person with a longer term illness who might be in the last few years of life.
A family member, carer or friend of someone you know in the last few years of life.
A health professional, or someone working in the palliative care field.

What will happen to your question(s):
All the question(s) we get from everyone who takes part in this survey will be gathered together.

What are some of the questions we might ask?
- What questions do you have about care, support and treatment for people in the last few years of their lives?

What we mean by palliative care:
We mean by palliative care: care for people who are nearing the end of their lives, including pain and other symptoms, and provision of psychological, emotional, social, spiritual and practical support. We also provide care for people who are not nearing the end of their lives, but for whom the disease has reached a terminal phase, and for whom the disease or treatment is causing significant suffering.

What we mean by end of life care:
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What we mean by priority setting:
We mean by priority setting: the process of deciding which aspects of care and support are most important for people in the last few years of their lives, and ensuring that these aspects are funded.

What we mean by research:
We mean by research: the process of investigating questions about care, support and treatment for people in the last few years of their lives, in order to improve care and support for these people.

How will the survey work?
The survey will be available online on our website. It will take about 10 minutes to complete. You will be able to save your progress and return to the survey later if you need to.

How can we use your feedback?
Your feedback will help us to identify the most important questions that need to be researched, and to set priorities for research that will improve care for people in the last few years of their lives.

What do you think about this survey?
We would really appreciate your feedback on this survey. Please feel free to contact us with any comments or suggestions you may have.

James Lind Alliance
Priority Setting Partnership

Palliative and end of life care Priority Setting Partnership

Care and support through terminal illness

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Care and support through terminal illness
Initial survey – identifying questions
1403 responses

Data analysis
Checked against syst. reviews and combined

Interim prioritisation
1331 responses

Workshop
24 participants

Top 10
749

Checked against syst. reviews and combined
83

Workshop
24 participants
28

Interim prioritisation
1331 responses

Initial survey – identifying questions
1403 responses

Top 10
10
Initial survey – 1403 respondents

<table>
<thead>
<tr>
<th>Respondent type</th>
<th>Number from PeolcPSP</th>
<th>Percentage from PeolcPSP</th>
<th>Percentages from Diabetes type 1 PSP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professionals</td>
<td>680</td>
<td>48%</td>
<td>5%</td>
</tr>
<tr>
<td>Carers / family</td>
<td>670</td>
<td>48%</td>
<td>23%</td>
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<tr>
<td>Patients</td>
<td>59</td>
<td>4%</td>
<td>71%</td>
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<tr>
<td>Other / public</td>
<td>366</td>
<td>26%</td>
<td>15%</td>
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</table>
Some quotes from respondents

“Who is responsible for me, the whole of me? Who is going to coordinate the care?”
Retired nurse in the last few years of life / carer/family member/partner/friend of someone in the last few years of life / member of the public who has an interest in the subject

“Why does most support stop on a Friday? Palliative care is about delivering services 24/7/365 surely?”
Professional working with people in the last few years of life

“How does one know when the time is near? What are the signs?”
Bereaved carer / family member / friend
My perspective

- Why I took part
- My views of the process
- How patients’ and carers’ views were reflected
- My views of significant results
The Top 10

1. Best ways of palliative care **outside of working hours** to avoid crises
2. Access to palliative care **regardless of where they are in the UK**
3. Listening and incorporating patients’ preferences via e.g. Advanced Care Planning
4. **Information and training** for carers and families
5. **Training** for healthcare professionals to deliver palliative care (healthcare assistants are specifically mentioned)
6. Best ways to deliver palliative care for those with **non-cancer diseases** (e.g. COPD, heart failure, MND, AIDS, MS, Parkinson’s, dementia, stroke)
7. **Core palliative care services** available to everyone
8. Benefits of **providing care in the patient’s home**
9. Ensuring **continuity of care** for patients at the end of life
10. **Assessing/treating pain and discomfort** for those with **communication or cognitive difficulties**
Sabine Best - Who am I?

- Patient, Service User Rep, Living (with and) beyond Cancer
- Occasional carer, heart failure, daughter
- Head of Research, Marie Curie (not a medical doctor)
- Leading PeolcPSP project
About Marie Curie

Marie Curie Nurses
- work night and day, in people’s homes across the UK, providing hands-on care and vital emotional support

Marie Curie Hospices
- throughout the UK providing round-the-clock care and support in a friendly and welcoming environment

Marie Curie Helper
- volunteers regularly visit people who need support to help them, be it for an appointment or a friendly chat over a cup of tea

Information and Support Service
- Provides practical information and support

Policy
- We campaign and influence decision-makers

Research
- We are the largest charitable funder of palliative and end of life care research in the UK – an area that is significantly under-researched and underfunded

Marie Curie’s vision: A better life for people and their families living with any terminal illness
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Publication and dissemination of PeolcPSP results

1) Researchers

- PeolcPSP report
  launched at joint event of NHS England and Public Health England (National End of Life Care Intelligence Network), 15th January 15

- Paper in *European Journal of Palliative Care* 22(3): 114-117 (2015), Identifying palliative and end-of-life care research priorities: a UK approach to consult end users

- Conferences
  - invited talks
  - abstracts submitted

- Blogs

- Twitter
Dissemination – posters at conferences
Publication and dissemination of PeolcPSP results

2) Research funding bodies
- AMRC, NCRI blogs
- UK end of life care Research Interest Group (UKeolcRIG)
- Many funders already funders or stakeholders of project
- Individual catch ups with individual research funders
- James Lind Alliance Shared Learning Group

- Collaboration is key!
  - ‘It is amazing what you can accomplish if you do not care who gets the credit’ (Harry Truman)

- Marie Curie Research Grants Scheme Call 7 opened November 2016
Collaboration with CSO and MND Association
Further work

Analysis of whole data set, including ‘out of scope’ data

- Dr Annmarie Nelson, Cardiff University
- Thematic analysis: 1/6 themes was not reflected in ‘interventional questions’
Further work

Analysis of whole data set, including ‘out of scope’ data

- Dr Annmarie Nelson, Cardiff University
- Report includes quotes from survey respondents to illustrate each theme

“Don't give people false hope. Be realistic and honest.”
Bereaved carer / family member / friend

“My mother and father were terrified by the word hospice and would not consider receiving help from a 'death centre'. I would like more research on use of terminology in palliative and end of life care.”
Professional working with people in the last few years of life

“How to identify best practice to ensure cancer patients are correctly informed that future treatments are palliative and will not offer them a false sense of hope / cure?”
Bereaved carer / family member / friend / professional working with people in the last few years of life

“Terminology - how do patients feel about the use of terms 'end of life care' and 'palliative care'. Are there better alternatives?”
Professional working with people in the last few years of life
How the results of the PeolcPSP have been taken further

- Prioritisation by All Ireland Institute for Hospice and Palliative Care Longlist prioritised in All Ireland Workshop Report June 2015

- NIHR HTA commissioned call:

  16/102 - Understanding the impact of noisy breathing on carer distress and the use of antimuscarinic drugs at the end of life

  7 February 2017

  Access commissioning brief (pdf, 294.5 KB)
  Access guidance notes (pdf, 269.17 KB)

- Also research recommendation in NICE guidelines [NG31] Care of dying adults in the last days of life, December 2015
How the results of the PeolcPSP have been taken further

CLAHRC Manchester
Set of workshops/group meetings/interviews with carers and professionals to prioritise the PeolcPSP top 10 to address local need
Also: identification of more detailed, locally applicable research questions
Report June 2016

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<thead>
<tr>
<th>Table 4. Access to 24 hour care and support research questions</th>
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<tbody>
<tr>
<td>Question 1</td>
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<tr>
<td>- For carers?</td>
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<td>- For professionals?</td>
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<td>- Across all settings?</td>
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<td>Question 2</td>
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<tr>
<td>- What is the specialist/generalist mix required?</td>
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<td>Question 3</td>
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<td>- by disease diagnosis?</td>
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<td>- by demographic/socio-economic factors?</td>
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<td>- By locality?</td>
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<td>Question 4</td>
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<td>Question 5</td>
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<td>Question 6</td>
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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.

Conference
Round the clock: Making 24/7 palliative care a reality

• Marie Curie Annual Conference jointly with the Palliative Care Section of the Royal Society of Medicine, 19th October 2016

Invited speakers

• Understanding the role of nurses in decisions to use anticipatory prescriptions to manage symptoms and distress in the last days of life - Dr Eleanor Wilson, University of Nottingham

• The E-Shift project: An electronic solution to 24/7 palliative care - Dr Deborah Fitzsimmons, Faculty of Health Sciences, Western University, Ontario, Canada
Learnings from PeolcPSP

• Takes time (18 months good estimate)
• Many priorities are broad and in need of further work to define more specific research questions
• Different questions require different types of research as the next step
• Many questions will need a concerted effort from a number of research funders and/or other organisations - **collaboration is key!**
• ‘Out of scope’ data can provide useful insights in areas where there is very little evidence to inform possible interventions or where research in the social sciences is needed
• Getting research funders involved early helps with the later steps
Acknowledgements

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Dr Bridget Candy, Marie Curie Palliative Care Research Unit, UCL
All Steering Group members
All funding partners and stakeholders
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Many thanks

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