A partnership approach to setting research priorities in health care

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

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Dr Sabine Best, Marie Curie

www.palliativecarepsp.org.uk
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)

• Lead for PeolcPSP project
About Marie Curie - 1

Marie Curie Nurses
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
Nine hospices throughout the UK providing round-the-clock care and support in a friendly and welcoming environment.

Marie Curie Helper
Our trained 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.

Total number of people helped = 40,712
Information and Support Services
Provides practical information and support through our:
• Marie Curie Support Line
• Online community
• Comprehensive information materials

Policy
We campaign and influence decision-makers on issues that affect people with all terminal illnesses and their families, to help them access high quality care and support when they need it most

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 a terminal illness
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 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 UK in 2014
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Aim of project
Research priorities identified and prioritised by the end users of research: patients, carers and clinicians / health & social care professionals

Recent research by RAND Europe (2016)
Researcher engagement with practitioners and patients in planning of research was associated with higher academic and wider impacts
Funding partners and stakeholders

- Age UK
- All Ireland Institute of Hospice and Palliative Care
- Alzheimer’s Society
- Association for Palliative Medicine of Great Britain and Ireland
- Barts Cancer Institute
- The Brain Tumour Charity
- Breast Cancer Campaign
- British Geriatrics Society
- British Lung Foundation
- Cancer Research UK
- Chest Heart and Stroke Scotland
- Chief Scientist Office
- Childhood Bereavement Network
- Cicely Saunders Institute (King’s College London)
- Cochrane Pain, Palliative and Supportive Care Group
- Dimbleby Cancer Care
- Economic and Social Research Council
- Health and Care Research Wales
- Help the Hospices
- Macmillan Cancer Support

- Marie Curie
- Medical Research Council
- Motor Neurone Disease Association
- Multiple Sclerosis Society
- National Bereavement Alliance
- National Cancer Research Institute
- National Council for Palliative Care
- National Institute for Health Research
- Parkinson’s UK
- Pilgrims Hospices
- Roy Castle Lung Cancer Foundation
- Royal College of General Practitioners
- Royal College of Nursing
- Scottish Partnership for Palliative Care
- Scottish Stroke AHP Forum
- St Christopher’s Hospice
- St Gemma’s Hospice
- Stroke Association
- Target Ovarian Cancer
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?
## The priority setting process

### Gathering questions: survey respondents

<table>
<thead>
<tr>
<th>Respondent type</th>
<th>No.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am in the last few years of my life</td>
<td>59</td>
<td>4</td>
</tr>
<tr>
<td>I am a carer, family member, partner or friend</td>
<td>176</td>
<td>13</td>
</tr>
<tr>
<td>I am a bereaved carer or family member or friend</td>
<td>494</td>
<td>35</td>
</tr>
<tr>
<td>I am a professional</td>
<td>680</td>
<td>48</td>
</tr>
<tr>
<td>I am a volunteer</td>
<td>43</td>
<td>3</td>
</tr>
<tr>
<td>I am a member of the public with an interest</td>
<td>181</td>
<td>13</td>
</tr>
<tr>
<td>Other</td>
<td>142</td>
<td>10</td>
</tr>
</tbody>
</table>
## Survey respondents – Country

### Where do you live?

<table>
<thead>
<tr>
<th>Country</th>
<th>Total number</th>
<th>Percentage of total completed</th>
<th>Population (UK – 63 million)</th>
</tr>
</thead>
<tbody>
<tr>
<td>England</td>
<td>672</td>
<td>65%</td>
<td>53 million [84%]</td>
</tr>
<tr>
<td>Scotland</td>
<td>105</td>
<td>10%</td>
<td>5.3 million [8.4%]</td>
</tr>
<tr>
<td>Wales</td>
<td>59</td>
<td>6%</td>
<td>3 million [4.8%]</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>90</td>
<td>9%</td>
<td>1.8 million [2.9%]</td>
</tr>
<tr>
<td>Republic of Ireland</td>
<td>78</td>
<td>8%</td>
<td>6.4 million [N/A]</td>
</tr>
<tr>
<td>Prefer not to say</td>
<td>6</td>
<td>1%</td>
<td>N/A</td>
</tr>
<tr>
<td>Other</td>
<td>24</td>
<td>2%</td>
<td>N/A</td>
</tr>
</tbody>
</table>
The priority setting process

The final workshop
The top 10 in no particular order

http://www.palliativecarepsp.org.uk/
The top 10

1. Best ways of out of hours palliative care to avoid crises
2. Access to palliative care across the UK
3. Listening and implementing patient 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 care in the patient’s home
9. Ensuring continuity of care for patients at the end of life
10. Assessing pain and discomfort for those with communication or cognitive difficulties
Most striking finding (personal choice)

Top priority

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?

Prioritisation survey result

- Current carers/family 1
- Former carers/family 1
- Professionals 1
- Patients 3

Prioritisation workshop result

- Group 1 1
- Group 2 1
- Group 3 1

All Ireland workshop

Overall result 1
What next?

- **Marie Curie Research Grants Scheme Call 7 (2016)**
  Largest call so far with £1,425,000 available
- **Additional funds:**
  - Chief Scientist Office (CSO, Scotland) - £225,000
  - Motor Neurone Disease Association - £200,000
- **Analysis of ‘out of scope’ data:** Dr Annmarie Nelson and team at Marie Curie Palliative Care Research Centre Cardiff
- **National Institute for Health Research (NIHR)**
  most recent highlight notice: *organisation and quality of end of life care services*
  Health Services & Delivery Research Programme (HS&DR)
  [http://www.nets.nihr.ac.uk/funding/hsdresearcher-led](http://www.nets.nihr.ac.uk/funding/hsdresearcher-led)
  highlights PeolcPSP research questions
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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