

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

Appendices

www.palliativecarepsp.org.uk

January 2015

Palliative and end of life care
Priority Setting Partnership



SUPPORTED AND GUIDED BY

IN PARTNERSHIP WITH



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Appendix 1

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

PROTOCOL

Purpose

The purpose of this protocol is to set out the aims, objectives and commitments of the Palliative and end of life care Priority Setting Partnership (PSP) and the basic roles and responsibilities of the partners therein.

Steering Group

The Palliative and end of life care PSP will be led and managed by the following:

Marie Curie

- Dr Teresa Tate, Palliative Medicine Consultant and past Medical Director of Marie Curie
- Dr Bill Noble, Medical Director, physician and past president of the Association for Palliative Medicine of Great Britain and Ireland
- Dr Sabine Best, Head of Research
- Dr Annmarie Nelson, Deputy Director, Marie Curie Palliative Care Research Centre at the Wales Cancer Trials Unit, Cardiff University
- Dr Bridget Candy, Cochrane Research Fellow, Marie Curie Palliative Care Research Department, University College London
- Rhiannon Smith, Senior Research Information Officer
- Jennifer Tuft, Project Coordinator

Patient and carer representatives:

National Cancer Research Institute (NCRI)

Consumer Hub

- Joanna Eley, Patient representative
- Angela McCullagh, Lay representative

National Council for Palliative Care (NCPC)

- Joanna Black, Involvement Manager

Marie Curie Expert Voices

- Nick Tracey, Carer representative

Clinical representatives:

Association for Palliative Medicine of Great Britain and Ireland (APM)

- Dr Mike Stockton, Consultant in Palliative Medicine

Royal College of Nursing (RCN)

- Amanda Cheesley, Long term conditions advisor
- Lauren Berry, Macmillan lead nurse

Macmillan Cancer Support

- Dr Catherine Burton, GP Adviser, LASER & CSW Regions

St Christopher's Hospice

- Andrea Dechamps, Director of Social Work, Bereavement and Welfare

Scottish Partnership for Palliative Care (SPPC)

- Elaine Stevens, Lecturer in Cancer and Palliative Care, School of Health, Nursing and Midwifery, University of the West of Scotland

National Bereavement Alliance

- Alison Penny, Principal Officer / Coordinator, Childhood Bereavement Network

Help the Hospices

- Linda McEnhill, Social Care Lead

**Representatives from co-funding partners:
Chief Scientist Office (CSO)**

- Dr Alan McNair, Research Manager

Motor Neurone Disease Association (MND Association)

- Dr Belinda Cupid, Head of Research

National Institute for Health Research (NIHR)

- Sarah Fryett, Senior Programme Manager / Beccy Maeso, Senior Programme Manager

National Institute for Social Care and Health Research (NISCHR)

- Angharad Kerr, Senior Project Manager / Dean Chapman, Research Infrastructure Lead

All Ireland Institute of Hospice and Palliative Care (AIHPC)

- Professor Sonja McIlpatrick, Head of Research

Economic and Social Research Council (ESRC)

- Naomi Beaumont, Senior Portfolio Manager

The Partnership and the priority setting process will be supported and guided by:

The James Lind Alliance (JLA)

- Katherine Cowan (JLA, chair)
- Mark Fenton (UK DUETs)

The steering group includes representation of patient/carer groups and clinicians.

The steering group will agree the resources, including time and expertise that they will be able to contribute to each stage of the process. The JLA will advise on this.

Background to the Palliative and end of life care PSP

The JLA is a project which is funded by the National Institute of Health Research. Its aim is to provide an infrastructure and process to help patients and clinicians work together to agree which are the most important treatment uncertainties affecting their particular interest, in order to influence the prioritisation of future research in that area. The JLA defines an uncertainty as a known unknown in this case relating to the effects of treatment.

The PeolcPSP was initiated by Marie Curie with the intention to address the dearth of evidence in palliative and end of life care and direct scarce resources at the issues most important to the 'end users' of research, ie patients, current and bereaved carers and families, clinicians and health and social care practitioners in general. Marie Curie committed the initial funding and is joined by a number of other funding bodies in the area (NIHR, CSO, NISCHR and the MND Association) who also want to see improvements in evidence-based care and treatments at the end of life and who committed to co-funding the partnership project. The results of the partnership will help direct future research funding by all the partners and beyond, for the benefit of patients, carers and families.

Aims and objectives of the Palliative and end of life care PSP

The aim of the Palliative and end of life care PSP is to identify the unanswered questions about palliative and end of life care from patient, carer and clinical perspectives and then prioritise those that patients, current and bereaved carers and clinicians agree are the most important. This means unanswered questions about care towards the end of life including the treatment of symptoms. The scope of the PSP is limited to care and treatment of adults.

The objectives of the Palliative and end of life care PSP are to:

- 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 of those uncertainties, for research
- publicise the results of the PSP and process and to raise awareness of the priorities for research amongst the research community
- take the results to research commissioning bodies to be considered for funding and inform research strategies

Partners

Organisations and individuals will be invited to take part in the PSP, which represent the following groups:

- people who are likely to be within the last years of their life. This will include people who:
 - are receiving palliative care, or those who are nearing the end of life but are not receiving palliative care
 - people who are living with a life-limiting illness and for example have just been diagnosed, experience significant deterioration or are approaching the end of life.
 - people who have been advised that no further treatment is possible or who have decided against undergoing further treatment.
- carers, family members, partners and friends of the above people
- bereaved carers, partners, family members and friends
- medical doctors, nurses, social workers and professionals allied to medicine with experience of treating and caring for people in the last years of their life
- care professionals including care home and home care staff and social care representatives with experience of working with people at the end of life
- members of the community, such as volunteers with experience of end of life care
- members of the public who have an interest in the subject

It is important that all organisations which can reach and advocate for these groups should be invited to become involved in the PSP. The JLA will take responsibility for ensuring the various stakeholder groups are able to contribute equally to the process.

Organisations wishing to participate in the PSP will be asked to affiliate to the JLA in order to demonstrate their commitment to the aims and values of the JLA. Details on the affiliation procedure can be found at www.jla.nihr.ac.uk.

Exclusion criteria

Some organisations may be judged by the JLA or the steering group to have conflicts of interest. These may be perceived to adversely affect those organisations' views, causing unacceptable bias. As this is likely to affect the ultimate findings of the PSP, those organisations will not be invited to participate. It is possible, however, that interested parties may participate in a purely observational capacity when the steering group considers it may be helpful.

Methods

This section describes a schedule of proposed stages through which the PSP aims to fulfil its objectives. The process is iterative and dependent on the active participation and contribution of different groups. The methods adopted in any stage will be agreed through consultation between the partners, guided by the PSP's aims and objectives. More details and examples can be found at www.JLAGuidebook.org.

1. Identification and invitation of potential partners

Potential partner organisations will be identified through a process of peer knowledge and consultation, through the steering group members' networks and through the JLA's existing register of affiliates. Potential partners will be contacted and informed of the establishment and aims of the Palliative and end of life care PSP and advised when and how they can participate.

2. Initial steering group meeting

The initial steering group meeting will have several key objectives:

- to welcome and introduce potential members of the Palliative and end of life care PSP
- to present the proposed plan for the PSP
- to initiate discussion, answer questions and address concerns
- to identify those potential partner organisations which will commit to the PSP and identify individuals who will be those organisations' representatives and the PSP's principal contacts
- to establish principles upon which an open, inclusive and transparent mechanism can be based for contributing to, reporting and recording the work and progress of the PSP
- to discuss methods that partner organisations can use to collect uncertainties

The administrative process for convening this meeting will be managed by the steering group with input from the JLA.

3. Identifying care and treatment uncertainties

Each partner will identify a method for soliciting from its members questions and uncertainties of practical importance relating to care towards the end of life including the treatment of symptoms. A period of three to six months will be given to complete this exercise.

The methods may be designed according to the nature and membership of each organisation, but must be as transparent, inclusive and representative as practicable. Methods may include membership meetings, email consultation, postal or web-based questionnaires, internet message boards and focus group work.

Existing sources of information about treatment uncertainties for patients and clinicians will be searched. These can include question-answering services for patients and carers and for clinicians; research recommendations in systematic reviews and clinical guidelines; protocols for systematic

reviews being prepared and registers of ongoing research.

The starting point for identifying sources of uncertainties and research recommendations is NHS Evidence: www.evidence.nhs.uk.

4. Refining questions and uncertainties

The steering group will need to have agreed exactly who will be responsible for this stage – the JLA can advise on the amount of time likely to be required for its execution. The JLA will participate in this process as an observer, to ensure accountability and transparency.

The consultation process will produce raw unanswered questions about care towards the end of life including the treatment of symptoms. These raw questions will be assembled and categorised and refined by an information scientist / systematic reviewer based at the Marie Curie Palliative Care Research Centre, Cardiff into "collated indicative questions" which are clear, addressable by research and understandable to all. Similar or duplicate questions will be combined where appropriate. The information scientist / systematic reviewer will be supervised by Dr Annmarie Nelson and Dr Bridget Candy.

The existing literature will be researched by the systematic reviewer to see to what extent these refined questions have, or have not, been answered by previous research.

Sometimes, uncertainties are expressed that can in fact be resolved with reference to existing research evidence – ie they are unrecognised knowns and not uncertainties. If a question about treatment effects can be answered with existing information but this is not known, it suggests that information is not being communicated effectively to those who need it. Accordingly, the JLA recommends strongly that PSPs keep a record of these answerable questions and deal with them separately from the true uncertainties considered during the research priority setting process.

Uncertainties about treatments which are not adequately addressed by previous research will be collated and prepared for entry into a

Palliative and end of life care section within the UK Database of Uncertainties about the Effects of Treatments (UK DUETs - www.library.nhs.uk/duets) by the information scientist / systematic reviewer. Uncertainties not relating to treatment, eg about care, will be managed separately.

This will ensure that the uncertainties have been actually checked to be uncertainties. This is the responsibility of the steering group, which will need to have agreed personnel and resources to carry this accountability. The data should be entered into UK DUETs on completion of the priority setting exercise, in order to ensure any updates or changes to the data have been incorporated beforehand.

5. Prioritisation – interim and final stages

The aim of the final stage of the priority setting process is to prioritise through consensus the identified uncertainties relating to care towards the end of life including the treatment of symptoms. This will be carried out by members of the steering group and the wider partnership that represents patients, carers, clinicians and health and social care professionals.

The interim stage, to proceed from a long list of uncertainties to a shorter list (eg up to 20), may be carried out over email, whereby organisations consult their membership and choose and rank their top 10 most important uncertainties.

The final stage to reach – for example – 10 prioritised uncertainties, is likely to be conducted in a face-to-face meeting, using group discussions and plenary sessions.

The methods used for this prioritisation process will be determined by consultation with the partner organisations and with the advice of

the JLA. Methods which have been identified as potentially useful in this process include: adapted Delphi techniques; expert panels or nominal group techniques; consensus development conference; electronic nominal group and online voting; interactive research agenda setting and focus groups.

The JLA will facilitate this process and ensure transparency, accountability and fairness. Participants will be expected to declare their interests in advance of this meeting.

Findings and research

It is anticipated that the findings of the Palliative and end of life care PSP will feed directly into the research strategies or agendas of the funding and supporting partners. They will also be reported to funding and research agenda setting organisations such as the National Institute for Health Research (NIHR, who is also a funding partner), which includes the HTA Programme, as well as the major research funding charities. Steering group members and partners are encouraged to develop the prioritised uncertainties into research questions, and to work to establish the research needs of those unanswered questions to use when approaching potential funders, or when allocating funding for research themselves, if applicable.

Timeline

August 2013

First steering group meeting

November 2013 – April 2014 (max.)

Gather treatment uncertainties

January 2014 – May 2014

Categorise and check uncertainties

May – July 2014

Interim prioritisation

August – November 2014

Final prioritisation workshops

December 2014 – January 2015

Publish on DUETs, write report

January 2015

Publish results

Publicity and dissemination

As well as alerting funders, partners and steering group members are encouraged to publish the findings of the Palliative and end of life care PSP using both internal and external communication mechanisms. The JLA may also capture and publicise the results, through descriptive reports of the process itself. This exercise will be distinct from the production of an academic paper, which the partners are also encouraged to do. However, production of an academic paper should not take precedence over publicising of the final results.

Signed by the steering group

Appendix 2

Steering group (SG) and Data Assessment Group membership (DAG)

Name	Organisation	Role	SG/DAG
Katherine Cowan	JLA	Senior Adviser to the JLA, and chair for the PeolcPSP steering and data assessment group	SG/DAG
Dr Alan McNair	Chief Scientist Office	Research manager, co-funder representative	SG
Alison Penny	National Bereavement Alliance and Child Bereavement Network	Principle officer/coordinator, Childhood Bereavement Network	SG/DAG
Amanda Cheesley	Royal College of Nursing (RCN)	RCN Long Term Conditions Advisor	SG
Andrea Dechamps	St Christopher's but representing social workers	Director of Social Work, Bereavement and Welfare	SG
Angela McCullagh		Lay representative	SG/DAG
Angharad Kerr	National Institute for Social Care and Health Research (NISCHR)	Senior Project Manager, co-funder representative	SG
Anna Hobson	Cochrane PaPas	Managing Editor	DAG
Dr Annemarie Nelson	Cardiff University	Deputy Director, Marie Curie Palliative Care Research Centre	SG/DAG
Beccy Maeso	National Institute for Health Research (NIHR) Evaluation, Trials and Studies Coordinating Centre (NETSCC)	Senior Programme Manager, External Relations, JLA, Co-funder representative (taken over from Sarah Fryett)	SG
Belinda Cupid	MND Association	Head of Research, co-funder representative	SG/DAG
Dr Bill Noble	Marie Curie	Medical Director	SG
Dr Bridget Candy	UCL	Systematic Reviewer, Marie Curie Palliative Care Research Department	SG/DAG
Dr Cathy Burton	Macmillan Cancer Support	Macmillan GP Adviser, LASER & CSW Regions, co-funder representative	SG

Steering group (SG) and Data Assessment Group membership (DAG) continued

Name	Organisation	Role	SG/DAG
Dean Chapman	NISCHR	Research Infrastructure Lead and co-funder representative	SG
Elaine Stevens	Scottish Partnership for Palliative Care (SPPC)	Lecturer in Cancer and Palliative Care, University of the West of Scotland	SG/DAG
Jennifer Tuft	Marie Curie	Project Coordinator – Research	SG/DAG
Joanna Black	National Council for Palliative Care (NCPC)	Involvement Manager	SG
Joanna Eley	NCRI	Patient representative, NCRI Consumer Hub	SG/DAG
Jordan Van Godwin	Cardiff University	PeolcPSP Information Scientist	DAG
Lauren Berry	RCN	Macmillan Lead Nurse	DAG/SG
Linda McEnhill	Hospice UK	Social Care Lead for Hospice UK	SG/DAG
Dr Mike Stockton	Association of Palliative Medicine (APM)	Consultant in Palliative Medicine, APM representative	SG
Naomi Beaumont	Economic and Social Research Council	Senior Portfolio Manager	SG
Nick Tracey	Marie Curie Expert Voices Group	Carer representative	SG/DAG
Rhiannon Smith	Marie Curie	Senior Research Information Officer	SG/DAG
Dr Sabine Best	Marie Curie	Head of Research	SG/DAG
Sarah Fryett	National Institute for Health Research (NIHR) Evaluation, Trials and Studies Coordinating Centre (NETSCC)	Senior Programme Manager, External Relations, JLA, co-funder representative	SG
Dr Sofia Araujo-Betancor	NIHR	Researcher Fellow, Identification	DAG
Professor Sonja McIlpatrick	All Ireland Institute of Hospice and Palliative Care (AIHPC)	Head of Research, co-funder representative	SG
Dr Teresa Tate	Marie Curie	Former Medical Adviser	SG/DAG

Appendix 3

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 long-term illness who might be in the last few years of life
- Caring for a loved one or someone you know in the last few years of life
- A bereaved carer or family member
- A health or social care professional or volunteer working with people who are in the last few years of life
- A member of the public who has an interest in care for people at the end of their lives

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

What we are asking you to do:

Please think about your own experiences of care, support and treatment and fill in our quick and simple survey over the page. It should take you about 10 minutes to complete. You can do the survey on paper and post it back to us free of charge. Or you can complete it online or over the phone.

This is a unique opportunity to directly influence future research into care, support and treatment for people in the last few years of their lives.

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.

- The questions that we haven't yet got the answers to will be published (see overleaf for more information).
- We will bring together groups of patients, carers, family members, doctors, nurses and other healthcare professionals to look at these questions and identify the most important ones. You can be involved in this, if you like.
- This will result in a 'top 10' list of research topics which we will use to influence future decisions about research. For example it could help decide which research projects should get funding.

The online survey is accessible via our website palliativecarepsp.org.uk

What we mean by palliative care:

What we mean by palliative care:

For patients, palliative care 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 to help the family cope during the person's illness and in their own bereavement.

Besides helping those approaching the end of life 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.

Survey - section 1:

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. If you run out of room you can add an additional sheet of paper with your survey or fill the survey in online.

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? This could also include question(s) about care and support for current carers or families.

What question(s) do you have about **care, support and treatment** for those rapidly approaching the end of their lives? This could also include question(s) about care and support for current or bereaved carers or families looking after someone at the end of their life.

Which of the following categories best describes you? (Please tick all that apply.)

We need your answer so we can fully process your questions. Your name or organisation will NOT be published in association with the question.

- 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 their 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, please specify _____

Consent

By participating in this survey you are agreeing to allow us to anonymously publish your unanswered question(s) in an online tool for researchers called UK DUETs (UK Database of Uncertainties about the Effects of Treatments, library.nhs.uk/duets). UK DUETs also publishes research recommendations. This enables researchers to enhance existing research. Your name or organisation will not be published in association with your question(s).

By providing us with your unanswered question(s) you are consenting for us to enter them anonymously into SurveyMonkey for analysis. Data will be subject to SurveyMonkey's privacy policy which can be found online at surveymonkey.com/mp/policy/privacy-policy

If you do provide your personal contact details, we will keep them confidentially and securely, in accordance with the Data Protection Act.

Please note that there are rare circumstances under which the Palliative and end of life care Priority Setting Partnership will have a duty to share information provided in this survey with the relevant body, such as where abuse and/or criminal activity is disclosed, or where an individual is a risk to themselves or others (including children or vulnerable adults).

We are sorry, but we are unable to respond to specific personal questions that you may have about your own, or another person's care. If you need further support with any issues raised by filling out this survey this can be found at palliativecarepsp.org.uk

Need this in large print? Contact us at PeolcPSP@mariecurie.org.uk or call 020 7091 4153.
This survey is also available online at palliativecarepsp.org.uk

Survey - section 2:

Some questions about you

These questions will help us to understand the range of people who have responded to our survey.

1. Where do you live?

- England
- Scotland
- Wales
- Northern Ireland
- Republic of Ireland
- Other, please specify _____
- Prefer not to say

2. We would like to stay in touch with you so that we can keep you updated on the progress of the project and send you a report of the results in early 2015. Please tick below if you would like to be kept up to date:

- Yes please. I would like to be kept up to date on the progress of the project and the results.

Also, in autumn 2014 there may be an opportunity for you to get involved in workshops and focus groups to identify the most important questions we identify in the survey. Please tick below if you are interested in taking part in a focus group. We are happy to talk to you about your access needs if applicable.

- Yes please. I am interested in taking part in a focus group to prioritise the questions and would like to be invited.

If you answered '**Yes please**,' to the previous question(s), please enter your contact details below. Your details will be treated with complete confidentiality.

Name: _____

Organisation (if applicable): _____

Address: _____

City/town: _____

Post code: _____

Country: _____

Email address: _____

Phone number: _____

(We will detach this section so we can keep your contact details confidentially)

section 2 continued

Please tick how you would prefer us to contact you
(if you answered 'Yes please' to question 2):

- Email Phone Post

3. How did you complete this survey?

- On your own
 As part of a group (two or more people)
If you completed this as part of a group, how many were
in your group? _____

ONLY for health and social care professionals working in palliative care and/or with people at the end of life

4. Which is your primary profession (*please tick one box only*)

- Palliative care doctor
 Other specialist doctor, please specify

 General Practitioner
 Specialist palliative care nurse
 Other specialist nurse, please specify

 Nurse
 Professional allied to medicine
 Social worker
 Care home, or home care, staff
 Chaplain
 Clinical researcher, please specify area of research

Other, please specify _____

- Prefer not to say

Thank you for taking the time to complete this survey

Please return your completed survey by 30 April 2014 by email to
PeolcPSP@mariecurie.org.uk, or by freepost to:

FREEPOST RLUH-ATGY-BXSA

89 Albert Embankment
LONDON
SE1 7TP

If you need help with completing this form and/or if you would like to comment,
please either email us on the above email address or call on **020 7091 4153**.

You can help us by passing details of this survey on to anyone who might be interested.

You can tweet about us too **@PeolcPSP**.

Appendix 4

PeolcPSP Survey Status Update Report

Date of analysis: 13 June 2014

Purpose: Overview response to PeolcPSP survey

1.1 Overall Response

	Total number
Number of hard copies via post	78
Number of emailed responses (PDF)	5
Number from St Gemma survey	63
Number from N. Ireland survey	20
Number of completed online responses	1237
Total number of completed responses from all sources (this figure will be used for all data below)	1403
Number of partial (started but not complete) responses	1818
Number of non-consent responses	11

1.2 Which of the following categories best describes you?

The below is based on only completed responses

	Total number	Percentage of total completed
I am in the last few years of my life	59	4%
I am a carer or family member or partner or friend of someone in the last few years of their life	176	13%
I am a bereaved carer or family member or friend	494	35%
I am a professional working with people in the last few years of life (please refer to 1.2.1 for breakdown)	680	48%
I am a volunteer working with people in the last few years of life	43	3%
I am a member of the public who has an interest in the subject	181	13%
Other	142	10%

1.2.1 For health and social care professionals – which is your primary profession?

The below is based on only completed responses

NB – On 3 February 2014, it was discovered that all respondents were being asked the question above as a mandatory question. Therefore, many 'Other' and 'Prefer not to say' responses can be interpreted as 'N/A' responses and may account for the large number of responses in these fields. The question is now only asked to people who said that they were a health and social care professional in the preceding question.

	Total number	Percentage of total
Palliative care doctor	63	11%
Other specialist doctor	18	3%
General practitioner	36	6%
Specialist palliative care nurse	76	13%
Other specialist nurse	30	5%
Nurse	72	13%
Professional allied to medicine	37	6%
Social worker	18	3%
Care home, or home care, staff	12	2%
Chaplain	17	3%
Clinical researcher	11	2%
Other	141	25%
Prefer not to say	41	7%

1.3 Where do you live?

The below is based on only completed responses

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

The following information is based primarily on “Section 2” of the survey.

NB - Please note that this is an optional section in the online survey, so not all participants will complete it.

2.1 Follow-up questions

	Total number
I would like to be kept up to date on the progress of the project and the results	570
I am interested in taking part in a focus group to prioritise the questions and would like to be	414

Appendix 5

Data management protocol

This protocol sets out the process for managing the data generated for the Palliative and end of life care Priority Setting Partnership (PSP). It refers to:

- The Data Assessment Group (DAG)
- The Project Coordinator (PC)
- The Information Scientist Supervisors (ISS)
- The Information Scientist (IS)
- The steering group (SG)

It aims to create a process which is robust, transparent, fair and inclusive.

Action	Responsibility
All survey responses to be entered online, including hard copies.	PC
Survey Monkey account to be shared with IS and data to be downloaded directly into Nvivo 10. All data to be coded within Nvivo 10.	IS
Submissions to be split into those that fall within the scope of this exercise (ie relating to uncertainties about treatment and care at the end of life) and those that do not. [AN, BC, SB and KC due to discuss and finalise scope – protocol will be updated accordingly]	IS
DAG to approve the list of exclusions and take any problems to the SG for resolution.	DAG
DAG to recommend to SG if and how the out-of-scope submissions can be used outside of the PSP, at a later stage in the project or after the project is completed.	DAG
In-scope submissions to be sorted into main and sub categories (categories will have been previously discussed with the DAG).	IS
In-scope submissions to be formatted where possible using PICO construction (Patient/Population, Intervention, Comparison, Outcome). Duplicates and very similar submissions may be combined. Longer submissions may be split into two or more PICO questions.	IS
DAG to check and approve an agreed sample of the formatted questions for each main category, set out alongside the original submission(s) and the respondent type.	DAG

Action	Responsibility
<p>Each formatted in-scope question to be checked against existing systematic reviews and guidelines. Such documentation may include, but not be limited to, the Cochrane Database of Systematic Reviews, NICE guidelines, SIGN clinical guidelines, the UK Clinical Trials Gateway and the Database of Abstracts of Reviews of Effects.</p> <p>Two lists to be produced for each main category: true uncertainties; questions which do have an answer. The DAG should recommend to the SG how the latter group are managed.</p>	ISS DAG
Research recommendations identified through the reviews should be recorded and added to the list of uncertainties for each main category.	ISS
Long lists of verified uncertainties for each category to be approved by the DAG and presented to the SG for final discussion and approval prior to prioritisation.	DAG SG
Numbers of respondents, original submissions, in-scope submissions, formatted questions and research recommendations to be recorded and reported to the DAG and the SG.	IS
Verified uncertainties to be prepared in the correct format for entry into the UK Database of Uncertainties about the Effects of Treatments (UK DUETs) – nb the database should not be submitted	IS

Appendix 6

PeolcPSP interim prioritisation survey report and analysis

Interim Prioritisation Survey Report

Date of analysis: 4 November 2014

Purpose: Overview response to Interim Prioritisation survey

1. Overall Response

	Total number
Number of hard copies via post	5
Number of completed online responses	1326
Total number of completed responses from all sources (this figure will be used for all data below)	1331
Number of partial (started but not complete) responses	2073

2. Which of the following categories best describes you?

The below is based on only completed responses

	Total number	Percentage of total completed
I am in the last few years of my life	27	2%
I am a carer or family member or partner or friend of someone in the last few years of their life	115	9%
I am a bereaved carer or family member or friend	296	22%
I am a professional working with people in the last few years of life (please refer to 1.2.1 for breakdown)	848	64%
I am a volunteer working with people in the last few years of life	32	2%
I am a member of the public who has an interest in the subject	113	9%
Other	142	11%

3. For health and social care professionals – which is your primary profession?

This question was asked to every respondent in order to accommodate the routing issues from the previous question. Therefore the categories "Other", "Prefer not to say" and/or "Not Applicable" may be larger than otherwise expected.

	Total number	Percentage of total completed
Palliative care doctor	140	12%
Other specialist doctor	6	1%
General practitioner	19	2%
Specialist palliative care nurse	166	14%
Other specialist nurse	11	1%
Nurse	154	13%
Professional allied to medicine	103	9%
Social worker 2	9	3%
Care home, or home care, staff	29	3%
Chaplain	16	1%
Clinical researcher	14	1%
Other	249	21%
Prefer not to say	8	1%
Not applicable	233	20%

4. Where do you live?

The below is based on only completed responses

	Population (UK – 63 million)	Total number	Percentage of total completed
England	53 million [84%]	907	68%
Scotland	5.3 million [8.4%]	156	12%
Wales	3 million [4.8%]	125	9%
Northern Ireland	1.8 million [2.9%]	62	5%
Republic of Ireland	6.4 million [N/A]	50	4%
Other	N/A	28	2%
Prefer not to say	N/A	3	0.2%

5. Staying involved

	Total number
I would like to be kept up to date on the progress of the project and the results	965
I am interested in taking part in a focus group to prioritise the questions and would like to be invited	286

Interim survey analysis

Survey respondents were asked to rate each of the 83 long-listed questions on the following scale (each answer's weighting is given in brackets, this was used to analyse the results):

Very Low Priority – (1)

Low Priority – (2)

High Priority – (3)

Very High Priority – (4)

No Opinion – (no weight)

The survey was hosted by SurveyMonkey between 29 September and 26 October 2014. It was disseminated using the same channels as the first survey. The survey was disseminated online, but communications advertised the option to request a paper copy. Five paper copies were returned.

The results of the survey were analysed by calculating the average score for each question using the weight of the scale and the number of responses to each question – it was possible for each question to receive a score between 1 and 4. This was done automatically through SurveyMonkey and the 83 questions were ranked from highest to lowest.

Appendix 7

Final prioritisation workshop scoring sheet

Palliative and end of life care Priority Setting Partnership (PeolcPSP) – pre-workshop exercise Individual ranking of questions for the workshop on 21st November 2014

This is a list of 28 research questions about palliative and end of life care. They have come from a survey of people in the last few years of life, current and bereaved carers, family and friends, and health professionals. Please spend some time before the workshop reviewing this list of research questions. Rank them from 1–28, 1 being the most important in your opinion and 28 being the least important, for research to address. Make a note of any comments in the right hand column

Please bring this with you to the workshop.

Ref	Question	Your ranking (1-28)	Notes
A	What are the best models of palliative care in an acute setting, such as a hospital?		
B	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 chronic obstructive pulmonary disease (COPD), heart failure, motor neurone disease (MND), AIDS, multiple sclerosis, Crohn's disease, Parkinson's disease, dementia, and stroke)?		
C	What are the best ways to facilitate communication across services and between healthcare professionals, including effective IT systems, team meetings and remote technology?		
D	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?		
E	How can distress that is not related to pain be best assessed and managed in palliative patients with dementia, Parkinson's disease and other diseases that affect communication?		
F	What are the best ways to diagnose and treat delirium, agitation, distress, and restlessness in people at the end of life? Which sedative drugs (such as midazolam, haloperidol and levomepromazine) are most beneficial and best in terms of side effects? Do these drugs have an effect on other symptoms?		

Ref	Question	Your ranking (1-28)	Notes
G	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?		
H	What are the best treatments for nausea and vomiting (including for people with bowel obstruction and those having palliative chemotherapy)?		
I	What are the best ways to make sure that palliative care patients receive adequate pain and symptom relief and which drugs for pain management are best in terms of side-effects, such as drowsiness? What are the best approaches to giving medicines such as morphine, for example using different cannulas, such as BD-saf-T-intima?		
J	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?		
K	What are the best ways to support children and young people when someone close to them is dying or has died? This includes communicating with them about the diagnosis and dying process, enabling them to talk about their experience and providing bereavement support.		
L	What are the signs that a person will die in the next few days and how can detection of these signs be improved? How can families be made aware?		
M	What are the best ways to recognise and treat depression, anxiety and low mood in people who are dying? What are the pros and cons of different psychotherapeutic interventions, including drug therapies, and when is the best time to provide them?		
N	How can access to palliative care services be improved for everyone regardless of where they are in the UK?		

Ref	Question	Your ranking (1-28)	Notes
O	How can people who live alone and do not have friends or family nearby receive adequate palliative care, particularly if they wish to stay in their homes?		
P	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?		
Q	Are outcomes (for example, symptom control and incidental prolonging of life) better for terminally ill patients the sooner palliative care is introduced and services are accessed?		
R	What are the core palliative care services that should be provided no matter what the patients' diagnoses are?		
S	What is the best way to give palliative care to patients with dementia and their carers and families? This includes communicating about their diagnosis when they are being cared for at home or elsewhere?		
T	What are the best ways to manage the problems associated with difficulty in swallowing, including drooling and excessive salivation, for patients with Parkinson's disease, motor neurone disease (MND) and dementia who are at the end of their life?		
U	What are the benefits of Advance Care Planning and other approaches to listening to and incorporating patients' preferences? Who should implement this and when?		
V	What are the benefits of, and best approaches to, providing palliative care in care homes, including symptom relief, emotional and spiritual support for patients, carers and families?		
W	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?		

Ref	Question	Your ranking (1-28)	Notes
X	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 coordination of services affect this?		
Y	What are the best ways for healthcare professionals to tell patients, carers and families that a patient's illness is terminal and also explain the dying process compassionately and honestly? Can literature, including leaflets, be helpful? Who is the best person to provide this information and communication?		
Z	What are the best care packages for patients, carers, family and staff which combine health care and social care and take individual prognosis into consideration?		
AA	Is there an appropriate time to withdraw artificial hydration and nutrition (for example, a drip) and how can this be done sensitively and consensually? What is the best way to communicate with the carers and family about this process?		
BB	What are the best ways to manage acute and/or chronic breathlessness in patients with cancer and non-cancer terminal illnesses?		

Appendix 8

Final prioritisation workshop agenda

James Lind Alliance Palliative and end of life care Priority Setting Partnership

Final workshop

9:30am – 4.00pm 21 November 2014

Friends House, 173 Euston Road, London NW1 2BJ

Workshop objectives:

1. To give an overview of the priority setting process and work so far.
2. To reflect on and discuss participants' views of treatment and care in palliative and end of life care and the short list of questions.
3. In small and larger groups to order the shortlist by priority, noting areas of agreement and disagreement across groups. To agree together the 10 most important questions.
4. Consider next steps, so that the questions are taken forward for research funding.

09:30	Registration and refreshments.
10.00	Opening session * Welcome and overview of the JLA and the workshop. Katherine Cowan, James Lind Alliance, workshop Chair. * About the questions. Sabine Best, Marie Curie. * Questions from attendees.
10.30	Commence priority setting: Small group work – participants reflect on and discuss their pre-workshop priorities.
11.25	Refreshment break
11.40	First round of ranking: In the same small groups, participants rank the questions.
12.40	Lunch break.
13.30	Review of progress so far: Overview of the combination of all small groups' rankings.
13.45	Second round of ranking: Recommence small group discussions – with different group composition.
14.30	Refreshment break
14.45	Final priority setting session: Aggregate ranking presented – whole group discussion. Final ranking and top priorities agreed.
15.30	Summing up of the day and next steps
16.00	Workshop concludes

Appendix 9

Ranked 28 questions from final prioritisation workshop

- 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 chronic obstructive pulmonary disease (COPD), heart failure, motor neurone disease (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' diagnoses are?
- 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 coordination 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?
- 11** How can people who live alone and do not have friends or family nearby receive adequate palliative care, particularly if they wish to stay in their homes?
- 12** What are the best ways for healthcare professionals to tell patients, carers and families that a patient's illness is terminal and also explain the dying process compassionately and honestly? Can literature, including leaflets, be helpful? Who is the best person to provide this information and communication?
- 13** What are the best ways to facilitate communication across services and between healthcare professionals, including effective IT systems, team meetings and remote technology?

- 14** What is the best way to give palliative care to patients with dementia and their carers and families? This includes communicating about their diagnosis when they are being cared for at home or elsewhere?
- 15** How can distress that is not related to pain be best assessed and managed in palliative patients with dementia, Parkinson's disease and other diseases that affect communication?
- 16** What are the best models of palliative care in an acute setting, such as a hospital?
- 17** What are the best ways to diagnose and treat delirium, agitation, distress, and restlessness in people at the end of life? Which sedative drugs (such as midazolam, haloperidol and levomepromazine) are most beneficial and best in terms of side-effects? Do these drugs have an effect on other symptoms?
- 18** What are the benefits of, and best approaches to, providing palliative care in care homes, including symptom relief, emotional and spiritual support for patients, carers and families?
- 19** What are the best ways to make sure that palliative care patients receive adequate pain and symptom relief and which drugs for pain management are best in terms of side-effects, such as drowsiness? What are the best approaches to giving medicines such as morphine, for example using different cannulas, such as BD-saf-T-intima?
- 20** What are the best ways to manage acute and/or chronic breathlessness in patients with cancer and non-cancer terminal illnesses?
- 21** What are the signs that a person will die in the next few days and how can detection of these signs be improved? How can families be made aware?
- 22** Is there an appropriate time to withdraw artificial hydration and nutrition (for example, a drip) and how can this be done sensitively and consensually? What is the best way to communicate with the carers and family about this process?
- 23** What are the best ways to recognise and treat depression, anxiety and low mood in people who are dying? What are the pros and cons of different psychotherapeutic interventions, including drug therapies, and when is the best time to provide them?
- 24** What are the best care packages for patients, carers, family and staff which combine health care and social care and take individual prognosis into consideration?
- 25** Are outcomes (for example, symptom control and incidental prolonging of life) better for terminally ill patients the sooner palliative care is introduced and services are accessed?
- 26** What are the best ways to support children and young people when someone close to them is dying or has died? This includes communicating with them about the diagnosis and dying process, enabling them to talk about their experience and providing bereavement support.
- 27** What are the best treatments for nausea and vomiting (including for people with bowel obstruction and those having palliative chemotherapy)?
- 28** What are the best ways to manage the problems associated with difficulty in swallowing, including drooling and excessive salivation, for patients with Parkinson's disease, motor neurone disease (MND) and dementia who are at the end of their life?