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

PROTOCOL August 2013

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 Cancer Care (MCCC)**
  - Dr Teresa Tate, Palliative Medicine Consultant and past Medical Director of MCCC
  - Dr Bill Noble, Executive 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
  - Bridget Candy, Cochrane Research Fellow, Marie Curie Palliative Care Research Unit, University College London

Patient representatives:

- **National Cancer Research Institute (NCRI) Consumer Hub**
  - Joanne Eley, Patient representative
- **National Council for Palliative Care (NCPC)**
  - Joanna Black, Involvement Manager

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, Palliative and Supportive Care
- **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

National Institute for Social Care and Health Research (NISCHR)
- Angharad Kerr, Senior Project Manager

All Ireland Institute of Hospice and Palliative Care (AllHPC)
- Dr Sonja McIlfatrick, Head of Research

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 Cancer Care 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, i.e. patients, current and bereaved carers and families, clinicians and health and social care practitioners in general. Marie Curie Cancer Care 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 e.g. 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, e.g. 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](http://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 3 - 6 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 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.¹

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, e.g. 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 (e.g. 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;

¹ Steering Group members should insert information on how they intend to do this.
James Lind Alliance: Priority Setting Partnership Protocol
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 of 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.²

Timeline

- First Steering Group meeting August 2013
- Gather treatment uncertainties November 2013 – April 2014 (max.)
- Categorise and check uncertainties January 2014 – May 2014
- Interim prioritisation May – July 2014
- Final prioritisation workshops August – November 2014
- Publish on DUETs, write report December 2014 – January 2015
- Publish results January 2015

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

² Add further detail here about how and where the priorities will be developed and researched.