# Meeting Agenda

**DATE:** Tuesday 5th May 2015  
**TIME:** 11:00-16:00  
**LOCATION:** Marie Curie Hospice, West Midlands [See Below for directions]  
https://www.mariecurie.org.uk/help/hospice-care/hospices/west-midlands/contact

## Project Team Members

- Dr. Martin Dempster, Queen’s University Belfast (Joint lead applicant)  
- Dr Noleen McCorry, Marie Curie Hospice, Belfast (Joint lead applicant)  
- Dr Kathy Armour, Marie Curie Hospice, West Midlands  
- Professor Joanna Coast, University of Birmingham  
- Professor Joachim Cohen, Vrije Universiteit, Brussels  
- Dr Michael Donnelly, Queen’s University Belfast  
- Dr Anne Finucane, Marie Curie Hospice, Edinburgh  
- Dr Joan Fyvie, Marie Curie Hospice, Belfast  
- Dr Louise Jones, Royal Free & University College Medical School  
- Professor George Kernohan, University of Ulster  
- Dr Kathleen Leemans, Vrije Universiteit, Brussels  
- Dr Sean O’Connor, Queen’s University Belfast  
- Professor David Oxenham  
- Dr Paul Perkins, Sue Ryder

## Agenda Item

<table>
<thead>
<tr>
<th>AGENDA ITEM</th>
<th>TIME</th>
<th>COMMENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Welcome &amp; introductions</td>
<td>11:00</td>
<td>Please bring details of travel costs. Reimbursement forms will be provided on the day</td>
</tr>
<tr>
<td>1 Project background, aims &amp; timelines</td>
<td>11:05</td>
<td>Briefing to review aims and identify key tasks and responsibilities during project</td>
</tr>
<tr>
<td>2 Project Methods</td>
<td>11:20</td>
<td>Brief overview of methods to be used in development of PCDS QI set including set up of panels / groups and the respective roles of each</td>
</tr>
<tr>
<td>3 Developing quality indicators in palliative care</td>
<td>11:30</td>
<td>This section will focus on previous work and experience of developing quality indicators in palliative care, including key barriers and facilitators encountered during development and implementation Dr Kathleen Leemans</td>
</tr>
<tr>
<td>4 Stakeholder identification</td>
<td>11:50</td>
<td>This section will provide an overview on key stakeholders identified to date and set the scene for <strong>group task 1</strong></td>
</tr>
<tr>
<td><strong>BREAK</strong></td>
<td>11:50</td>
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| 5 GROUP TASK 1 | 12:00 | **WHO is involved?**  
The aim of this task will be to review the list of stakeholders and:  
1) Identify important omissions  
2) Establish two groups  
   * An expert panel [with key role in development of initial QI set]  
   * A wider stakeholder group [with key role in maintaining visibility of the project and promoting active engagement during the later implementation phase] |
| LUNCH | 12:30 | |
| 6 GROUP TASK 2 | 13:00 | **HOW to best engage with people?**  
The aim of the task will be to identify key strategies for ensuring effective public engagement with the wider stakeholder group and other key individuals / organizations |
| **BREAK** | 14:00 | |
| 7 Candidate indicators [relevant to Palliative Care Day Services] | 14:10 | This section will provide a brief overview of the systematic review and narrative synthesis methods being used to identify candidate indicators based on current best evidence and will set the scene for **group task 3** |
| 8 GROUP TASK 3 | 14:30 | The aim of the task will be:  
1) Discuss identification of key resources including those outside PCDS [Relevant DS guidelines, strategy documents etc.]  
2) Discuss planning of / expected format for project team meetings / communications |
| 9 Other Business / Close | 15:30 | |
# MEETING NOTES

## ITEM 1: EXPENSES

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<th>ACTIONS</th>
<th>PERSON[S] RESPONSIBLE</th>
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<tbody>
<tr>
<td>Please provide scanned copies of any remaining receipts for travel expenses etc. to Sean O'Connor <a href="mailto:s.oconnor@qub.ac.uk">s.oconnor@qub.ac.uk</a> or by post to Dr Sean O'Connor, Room 01.015, School of Psychology, Queen's University Belfast, University Road, Belfast BT7 1NN</td>
<td>Project team</td>
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## ITEM 2: IDENTIFYING KEY INDIVIDUALS FOR THE EXPERT PANEL

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<tbody>
<tr>
<td>Please provide the name and contact details for any nominated individuals for the expert panel [a separate message will be e-mailed on this]</td>
<td>Project team</td>
<td>BY 5th June 2015</td>
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## ITEM 3: SETTING UP FUTURE TELECONFERENCE MEETINGS

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<th>ACTIONS</th>
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<tbody>
<tr>
<td>For project team members, who haven't done so, please forward suitable days/times for teleconferences. These will be set up shortly and dates circulated</td>
<td>Project team</td>
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## ITEM 4:

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<th>TIMELINE</th>
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### ADDITIONAL COMMENTS / NOTES

**KEY POINTS:**

- PROJECT TEAM members will be asked to nominate individuals to the EXPERT PANEL [see action point 1]
- The EXPERT PANEL will comprise both professional and lay members rather than using a separate lay panel
- The Marie Curie expert voices panel will be consulted to assist with development / gain feedback on lay summaries produced prior to the expert panel process starting
- An equal assignment matrix will be used to ensure balanced representation from all key groups in the expert panel
- The project team will be expanded to involve further representation from lay members. Service commissioners will be invited from the wider stakeholder group during work package 2 [exploring feasibility / acceptability of a toolkit for assessment of QIs in PCDS]
- A group size of approximately 15 members of the expert panel will be set
- Due to the duration and resource limitations of the project a separate advisory group will not be used during the project which will be guided by the core project team
- The best methods for data storage / sharing between project team members will be explored: ?Drop box / SharePoint
- It was decided to hold the second project meeting just prior to the start of phase II - Location: Marie Curie, West Midlands
- Times / dates when project team members are routinely available for teleconference held every 2 months will be sought
- The search strategy for the scoping review which forms part of the evidence gathering phase of the project will not include "intervention" terms. This is in order to not restrict the search to common types of PCDS in current use

### PROPOSED DATE / LOCATION FOR NEXT MEETING:

To maintain communication within the PROJECT TEAM teleconferences will be held every two months throughout the project [Dates will be arranged in advance with the first teleconference likely to be held in early July 2015]. The likely location of the next face to face meet meeting will be the West Midlands, Marie Curie Hospice [Date TBC].
KEY POINTS / ACTIONS FROM MEETING [MARIE CURIE HOSPICE, WEST MIDLANDS, 5TH MAY 2015]

FIG 1. PROJECT STRUCTURE

UK Consensus Project on Quality in Palliative Care Day Services

*Inclusion of an advisory panel to sit independently from the PROJECT TEAM was discussed but was decided against due to resource limitations

METHODS FOR IDENTIFYING KEY INDIVIDUALS FOR THE EXPERT PANEL AND ORGANIZATIONS FOR THE STAKEHOLDER GROUP

Focus groups; open questionnaires; targeted questions / interviews with individuals; scenario analysis; blogs /e-mail shot; project websites; etc.; can be used to help identify individual and / or stakeholders with combined approaches working best.

Other methods used include:

- Brainstorming with other organisations involved in related areas
- Consulting with colleagues to share knowledge about who may have an interest in the research
- Developing a ‘mind map’ that can be used to identify suitable stakeholders; assessing secondary data [e.g. historical records, media articles etc.]
- Utilising government statistics and data
- Initiating self-selection by promoting the engagement process and encouraging individuals with an interest to come forward
- Using ‘snowball sampling’ techniques, whereby one stakeholder identifies further stakeholders until no additional new stakeholders are identified
- Utilising existing lists of organisations in order to identify specific groups, networks and agencies who represent relevant elements of society e.g., CHAIN

Key umbrella organizations were discussed and an amended list was produced. These organizations are categorized as:

- Patient groups / charities
- Professional Bodies / clinical interest groups
- Research institutes
- Individual hospices [and linked charities]

SET UP OF EXPERT PANEL

A list of individuals to invite to sit on the EXPERT PANEL will be developed using some of the above methods:

- Individuals with experience of PCDS
- Individuals with experience of other DS[?]

We will aim to recruit a sufficient pool of expert panel members to ensure a minimum of 12-15 are available at the face to face consensus meeting. Recruiting approximately 20 individuals will allow for any loss of panel members over time or changes in personal circumstances

- Direct approach to key experts in area
- Social media / other online messages sent via key organizations asking for expressions of interest from interested individual s
- Request key organizations nominate 2-3 individuals with interest / expertise in the area of PCDS

Members of the expert panel should meet the following criteria:

Essential

- Experience of and interest in Palliative Care Day Services [PCDS]
- Willing to carry out an independent review / assessment of candidate quality indicators [QIs] and attend a single face to face consensus meeting on an agreed date to determine the draft QI set
- Knowledge of QIs and an understanding of their use in relevant Day Services

Desirable

- Knowledge of panel working / consensus development processes
- Experience of different care models relevant to delivery of PCDS
MEMBERSHIP OF THE EXPERT PANEL WILL BE COMPRISED OF INDIVIDUALS WITH EXPERTISE IN THE FOLLOWING ROLES [MANDATORY ROLES ARE HIGHLIGHTED IN BOLD]:

<table>
<thead>
<tr>
<th>ROLE</th>
<th>DESCRIPTION</th>
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<tbody>
<tr>
<td>LAY</td>
<td>Lay member / representative</td>
</tr>
<tr>
<td>MED</td>
<td>Medical staff</td>
</tr>
<tr>
<td>NUR</td>
<td>Nursing staff</td>
</tr>
<tr>
<td>MGMT</td>
<td>Day service manager / Service commissioner / Community service manager / Hospice manager / Divisional General Manager</td>
</tr>
<tr>
<td>OAHP</td>
<td>Physiotherapist/Occupational therapist/dieticians</td>
</tr>
<tr>
<td>CAM</td>
<td>Complementary therapist</td>
</tr>
<tr>
<td>SW</td>
<td>Social worker</td>
</tr>
<tr>
<td>PSY</td>
<td>Psychologist</td>
</tr>
<tr>
<td>PHARM</td>
<td>Pharmacist</td>
</tr>
<tr>
<td>RES</td>
<td>Researcher [methodologist with interest in quality improvement / measurement]</td>
</tr>
<tr>
<td>VOL</td>
<td>Hospice volunteer</td>
</tr>
<tr>
<td>SC</td>
<td>Chaplains or other spiritual care providers</td>
</tr>
</tbody>
</table>

SET UP OF STAKEHOLDER GROUP
For research to be considered valid and valuable, it has been recognised that it should be undertaken with credibility, relevance and legitimacy [sometimes referred to as ‘CRELE’]
The wider STAKEHOLDER GROUP [with key role in implementation phase] includes all key organizations with an interest in delivery of PCDS. Communication with the STAKEHOLDER GROUP will generally be one-way in order to ensure good visibility of the project.
1. It was recognized that it will be important to monitor engagement in order to identify stakeholders with an active interest in the project
2. Key strategies for ensuring effective public engagement with the wider STAKEHOLDER GROUP and other individuals / organizations were discussed: twitter, Facebook groups, project website etc. These have all been used with variable success as part of other projects.

PPI INVOLVEMENT WITH PROJECT TEAM AND EXPERT PANEL
1. We will recruit a minimum of two lay/PPI representatives to the EXPERT PANEL. An honorarium covering travel and time costs will be provided to lay/PPI members [see figure 1].
2. There will therefore be one EXPERT PANEL [versus one ‘professional’ and one ‘lay’ panel] which will limit the potential difficulty of reaching consensus between two separate panels.
3. Two PPI representatives will also be invited to sit on the PROJECT TEAM to assist with guiding the project throughout its development [these individuals will be different from PPI members sitting on the EXPERT PANEL. The role of the PPI members of the project team will be to give advice on plans for PPI engagement with the STAKEHOLDER GROUP; to mutually agree on developing the scope and protocol for the project [and work package II]; to influence search strategies and suggest further literature sources; to assist with interpreting review findings and logic model development; to give advice on dissemination to reach appropriate lay people and organizations; to give advice / support with writing lay summaries of key findings.
4. In addition to point 3, the Marie Curie ‘expert voices’ group will be asked to review all documents that will provided to lay/PPI members of the EXPERT PANEL [Documents explaining the RAND/UCLA consensus process and what their role will be in the process, plus examples of evidence summaries which will be used in during rounds 1 & 2 of the RAND/UCLA process]. This will done to ensure clarity, readability and suitability of the documents which are provided.
5. The logic model developed prior to the expert panel meeting [based on the systematic evidence reviews and evidence summaries] will be revised and further developed with input from key stakeholders [including those involved with the STAKEHOLDER GROUP]. This will also provide an opportunity to involve other stakeholders other than those involved in the PROJECT TEAM and the EXPERT PANEL.

METHODS OF ENGAGEMENT WITH STAKEHOLDER GROUP
The following methods of engagement were discussed:
1. Project website [www.qub.ac.uk/sites/QualPalUK]; Twitter [@QualPalUK]; seeking ‘branding’ from other organizations to feature on relevant websites, at forthcoming relevant conferences / meetings etc.; a project newsletter will be produced every 2 months [for publication on the project website with a printed version for hand out at relevant meetings etc.]; Occasional, regular e-mail to communications managers at key organizations; Use of CHAIN network.

METHODS OF ENGAGEMENT WITH PROJECT TEAM
1. In order to maintain communication with the PROJECT TEAM, a series of teleconferences held every two months throughout the project will be arranged in advance. Project team members at the meeting provided days / times during a typical week which would be most suitable.
2. Regular project updates for project panel will be produced [every 2 months to precede the teleconferences]
3. It was decided that the second [and final] PROJECT TEAM face to face meeting will be arranged for a date just prior to the start of work package II [i.e., following EXPERT PANEL meeting]. The likely location of the meeting will be the West Midlands, Marie Curie Hospice.
4. It is likely that we will recruit at least one service commissioner to the PROJECT TEAM prior to starting work package II [in order to maximize eventual implementation.