**End of Life Clinical Leadership Group (Draft)**

**Minutes**  
Friday 25 March 2014  
2pm – 5pm  
NHS England (London Region) Offices

<table>
<thead>
<tr>
<th>Present:</th>
<th>Richmond CCG</th>
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<tbody>
<tr>
<td>Dr Catherine Millington-Sanders (CMS) (Co-Clinical Director End of Life Clinical Network – London Region) (Co-Chair)</td>
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<tr>
<td>Dr Catherine (Katie) Urch (KU) Co-Clinical Director End of Life Clinical Network – London Region) (Co-Chair)</td>
<td>Imperial College Healthcare NHS Trust</td>
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<tr>
<td>Dr Caroline Stirling (CS) Lead Clinician and Consultant in Palliative medicine</td>
<td>Central &amp; North West London NHS Foundation Trust</td>
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<tr>
<td>Dr Stephen Deas (SD) GP – EoLC Clinical Lead</td>
<td>Wandsworth CCG</td>
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<tr>
<td>Dr Kate Rees (KR) GP – EoLC Clinical Lead</td>
<td>Haringey CCG</td>
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<tr>
<td>Jane Eades (JE) CNS / Day Therapy Manager</td>
<td>Marie Curie Hospice Hampstead</td>
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<tr>
<td>Penny Jones (PJ) Director of Care Services</td>
<td>Greenwich &amp; Bexley Community Hospice</td>
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<tr>
<td>Hilary Shanahan (HS) Compassion in Care Co-ordinator / District Nurse</td>
<td>Central London Community Healthcare NHS Trust</td>
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<td>Sue Robinson (SR) Community Matron – Palliative/EoLC</td>
<td>Central London Community Healthcare NHS Trust</td>
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<tr>
<td>Dr Andreas Vercueil (AV) Intensivist</td>
<td>Kings College Hospital NHS Foundation</td>
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<tr>
<td>Dr Ameet Bakhai (AB) Cardiologist (Heart Failure)</td>
<td>Barnet &amp; Chase Farm NHS Trust</td>
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<td>Dr Luke Howard (LH) Consultant – Respiratory Medicine</td>
<td>Imperial College Healthcare NHS Trust</td>
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<td>Professor Allan Kellehear (AK) Public Health / Palliative Care</td>
<td>Middlesex University</td>
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<tr>
<td>Sharon Cavanagh (SC) Palliative Rehabilitation (Occupational Therapist)</td>
<td>London Cancer</td>
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<tr>
<td>Ben Rhodes (BR) Chaplaincy / Spiritual care</td>
<td>King’s College Hospital NHS Foundation</td>
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<td>Dr Susan Hennessey (SH) Clinical Health Psychologist – Palliative Care</td>
<td>Barts Health NHS Trust</td>
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<tr>
<td>Steve Wanklyn (SW) Lead Pharmacist – Palliative &amp; EoLC</td>
<td>Guy’s &amp; St. Thomas NHS Foundation Trust</td>
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<tr>
<td>John Powell (JP) Adult Social care</td>
<td>London Borough of Redbridge /ADASS</td>
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<td>JJ Nadicksbernd (JJN) EoLC &amp; Elderly / Frail Lead Facilitator</td>
<td>Richmond CCG/ ADASS</td>
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<td>Esme Young (EY) Nursing / Commissioning EoLC / Adult Safe Guarding</td>
<td>Hillingdon CCG</td>
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<tr>
<td>Brian Andrews (BA)</td>
<td>Lay Representative</td>
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<tr>
<td>Paul Trevatt (PT)</td>
<td>London Clinical Network EoLC lead</td>
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<tr>
<td>Caroline Moren (CM)</td>
<td>London Clinical Network Senior Project Manager EoLC</td>
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<td>Jenna Evans (JE)</td>
<td>London Clinical Network Senior Project Manager EoLC</td>
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<td>Ruth Evans (RE)</td>
<td>London Clinical Network Senior Project Manager EoLC</td>
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<tr>
<td>Dr Jane Fryer (JF)</td>
<td>Area Medical Director &amp; Support for CVD &amp; EoL</td>
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<tr>
<td>Dr Hugo De Waal (HDW)</td>
<td>Consultant Old Age Psychiatrist</td>
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<tr>
<td>David Whitmore (DW)</td>
<td>Paramedic</td>
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<tr>
<td>Dr Jane Collins (JC)</td>
<td>CEO Marie Curie</td>
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<tr>
<td>Helen O Kelly (HK)</td>
<td>London Clinical Network Deputy Lead EoLC</td>
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**Apologies:**

- Dr Jane Fryer (JF)
- Dr Hugo De Waal (HDW)
- David Whitmore (DW)
- Dr Jane Collins (JC)
- Helen O Kelly (HK)

**In Attendance:**

Nil

1. **Welcome and Introduction (CMS & KU)**

Both CMS and KU welcomed members of the clinical leadership group. Individuals introduced themselves and outlined their roles and their end of life experience. It was felt that this was a very strong group in terms of its membership. The London EoLC Alliance was referenced. BA was thanked for attending as Lay member and representative of the Carer Group of the Alliance. His role was to ‘channel’ the carer voice from the Carer Group. It was noted that the EoL Alliance was developing a voluntary sector forum and that while this was being developed Jane Collins would represent the voluntary sector at this meeting. CMS and KU invited PT to update the group regarding the progress of the strategic and clinical networks.

2. **Overview of Strategic Clinical Networks and Clinical Networks in London (PT) (Appendix 1)**

PT gave an overview of the development of networks in London and their progress over the last year. He briefly outlined:

- Form and function
- Governance and accountability
- Leadership and membership
- Challenges

Governance was rooted through the London Oversight group chaired by Dr Andy Mitchell. The EoL CLG was represented through KU and CMS. Progress of the networks and work plans would be discussed here. PT outlined the various London networks all of whom were keen to work in...
partnership with the EoL clinical network. He felt that this was unique opportunity across London to focus on EoL issues for some of the clinical specialities such as stroke, diabetes and dementia that previously had received limited input.

3. National Context and View from Primary Care (CMS & KU) (Appendix 2)

CMS and KU updated the group on activity since taking up appointment in November. In December and January they chaired five roadshows across London extending invitations to the specialist palliative care community and EoL CCG leads. The roadshows offered colleagues an opportunity to list their priorities for EoL care in London. At the end of January they held a meeting at the Kings Fund and colleagues attended from a variety of clinical, non-clinical and locality settings. They were also invited to present and consult views at the LCA. From these meetings draft priorities were identified that then were grouped into themes. It was noted that these were draft and were part of an iterative process.

4. Form and Function (Terms of Reference) (Appendix 3)

PT discussed the terms of reference. These were generic ToRs that were used by the other networks and focused on key areas including:

- Quality and Performance
- Patient involvement and advocacy
- Clinical leadership
- Partnership and networking
- Commissioning

AB felt that research wasn’t referenced. He was happy to add one or two sentences. PT was supportive but attached the caveat that as far as he was aware that research would be driven through the Academic Health Science Networks that were both charged with this responsibility (and funded for it). KU mentioned that clinical networks had no specific research funding. PT said he would discuss it further with his director. AB would send an amended ToR with research included.

**ACTION (PT): Updated ToR to be circulated.**

5. Priorities for the Network (all) – Group Exercise

CMS and KU asked members to split into smaller groups and for them to focus on a number of key questions in relation to EoL priorities (Appendix 3). Groups were given thirty minutes to identify key concerns and EoLC priority areas.

Feedback – it was noted that there were some areas of overlap between groups.

**Group 1 (Feedback by SD)**

- Good quality care for all EoL patients and carers representing multi-faith membership.
- Core standards for EoL care (including pharmacy), guidance on medical equipment.
  Evidence based guidelines for equipment.
- Effective communication taking into account cultural issues.
- Bespoke individualised care (what are the experiences of patients / carers)
- Empowering communities to say what they want.
- Increasing volunteering and befriending to reduce isolation and strengthen carer support (Shropshire Befriend listed as a model).
- Engage Public Health
- Nothing as a carer prepares you for the ‘unknown unknowns’ of looking after someone who is dying. Multi-professional education required to recognise this and build in key components carers would find useful around the dying process.
- Empowerment of carers around use of medical equipment
- Out of hours calls to specialist palliative care. How may of these requires specialist advice and how many calls could be routed through other sources?

AV mentioned that we used to talk about ‘death & taxes’ now it seems only ‘taxes’ PJ ‘death affects everyone’ but the EoL system remains complex to those outside of healthcare knowing how to navigate it. Inequity in service provision noted.

**Group 2 (Feedback from JP)**

- Inequity of provision (borough & locality)
- Core standards
- Following the removal of the Liverpool Care Pathway a void exists. How can this group influence what follows LCP?
- How to implement proactive palliative care across systems?
- Identification of EoL project champions / within MDTs up-skill one person around EoLC so that EoLC is included in clinical discussions / assessments.
- Mandatory education of EoLC (similar to health & safety / CPR)
- How to implement proactive palliative care across systems?
- Try not to re-invent the wheel

KU & CMS updated from the national EoLC meeting that Dr Bee-Wee (National EoLC Clinical Director) saw the LCP being replaced with core minimum standards / core quality outcomes driven locally rather than nationally. Programmes would no longer be mandated centrally. JP thought that the timing of commissioning plans gave the group some opportunity (Better Care Fund / 5 year commissioning plans) to influence the local EoLC agenda.

**Group 3 (Feedback by RE)**

- The importance of education in primary care
- Improvement in home deaths
- Development of bespoke EoLC
- Filling the void left by the removal of LCP
- How do we maintain communication across different systems
- Not enough emphasis on spiritual / psychosocial support
- How to influence change and provide value for money

**Group 4 (Feedback by Sharon Cavanagh)**

- Be realistic with the development of outcome measures
- Look at what can be achieved in 18 months
- Strong communication process so that stakeholders feel informed.
- A interactive web site with real time updates
- The use of social media in informing stakeholders

**Group 5 (Feedback by PJ)**

- Inequities in how hospice care is commissioned (operational challenges when patient / GP are in different localities and hospice care has been commissioned by a different provider)
- High quality timely bereavement support
- The importance of spiritual support / faith and non faith groups / representing the different groups across London (is it possible?) – informing the different groups across London.
- Diversity
- How decisions are made (primary & secondary care) in the absence of LCP. A process that truly listens to the patient. ‘Individualised care’ rather then formulaic. Personalised pathways. It was discussed that GPS tend to wait for secondary care consultant to make decisions about a patient’s prognosis and that these decisions are often avoided. Could the patient be empowered to make a decision about their care?
- Concern that in the absence of LCP care would stagger and decisions be avoided.

Group 6 (Feedback by JE)

- Bereavement and carer support
- Communicating a EoLC message to the public (using ‘thought of the day’ as a process)
- The value of Schwartz rounds in EoLC

CS mentioned the value of integration and the need for strong leadership, for someone to stand above the parapet (GP or consultant) to challenge how prognosis is determined. SD identified that the identification of terminal care needs strengthening.

There was a conversation about EoLC and how it is communicated to the public / the need for a conversation across London around the value of EoLC. PT cited the feedback from the North Central London roadshow as to previous campaigns. The group discussed ‘dying matters’ and local initiatives such as SPARKS.

6. Work streams

KU consolidated the priority areas and suggestions into identified work streams. It was noted that outcomes would be a cross cutting theme. These included:

Community and Acute delivery of care

- Identification and future care planning
- Reductions in OOH inappropriate admissions to secondary care
- What are community local working practices
- What are acute local working practices
- Coordinating generalist and specialist EoLC
- The role of social care
- Common core standards
- Bereavement support
- Faith groups development

Workforce Planning, Education, Research

- Core minimum standards
- Developing co-training with education boards
- Statement around cultural diversity
- Developing a education package / blended learning

What is a Good Death?

- The relationship between health and social care
- Joint principles (not simply a tick box)
- Is this what we think good looks like?
- Developing resilience / self care of health care professional
Future Vision

- What are our circles of influence? What are we trying to work towards?
- The role of London as a Compassionate City
- How do we talk about deaths in a grown up transparent way / giving adults responsibility
- Economic Evaluation

It was noted that there were current London groups that we would like to map and understand how to work together and communicate with, for example Hospice Chief Executives, Palle8, LCA, London EoL CCG Leads etc.

KU and CMS suggested that colleagues identify the work plans that they would like to be involved in. It was felt that it would be useful to begin the work plans small and then build up as required. External membership could be sought if membership was not adequately represented.

It was suggested that in order to agree and sign off the work plan that the EoL CLG hold its next two meetings sooner rather then later.

Dates of the next meeting were discussed and agreed.

- Friday April 25th (14:00-17:00)
- Friday June 6th (14:00 -17:00)

AOB
None