

# Pan-London End of Life Alliance –Terms of Reference

## 1. Purpose of Pan-London End of Life Alliance

### *Rationale*

- Despite an overall picture of improvement nationally, it is recognised that there is significant scope for further improving end of life experiences of individuals, carers and their families.
- The quality of end of life care received in London currently under-performs against national averages. ONS Survey of Bereaved People VOICES, 2011-12 and Health and Social Care Information Centre, Carers survey, 2012-12 data demonstrate that:
  - 26% of bereaved relatives in London rated the care they received from GPs as excellent compared with the national average of 35%.
  - 34% of bereaved relatives in London rated the care they received from district and community nurses as excellent compared with the national average of 45%.
  - 66% of carers in London felt they were included or consulted in decisions compared to the national average of 73%.
- There is also considerable variation in the quality of care within London. ONS Survey of Bereaved People VOICES, 2011-12 data demonstrated that:
  - London scored that best (Islington) and worst (Newham and Waltham Forest) in the country in terms of overall quality of care in the last three months of life.

### *Aims of the Pan-London End of Life Alliance*

- The Pan-London End of Life Alliance is an initiative led by like minded people and organisations working to improve the care that people living with a terminal illness and their families receive in the capital.

## 2. Structure of the Pan-London End of Life Alliance

### Overarching approach

- The Pan-London End of Life Alliance itself is an inclusive membership for self-selected representatives who have a contribution to make to this agenda – consisting of wide representation from across health, social care, voluntary and education sectors, as well as individuals who can speak on behalf of families and others who have experience of terminal illness. The Alliance members will be supported by an Executive Steering Group.

### Executive Steering Group<sup>1</sup>

- The Pan-London End of Life Alliance Executive Steering Group which is led in partnership by senior representatives from across health, social care and voluntary sectors provides oversight from a system wide perspective to facilitate bringing together the efforts underway across London.

Executive Steering Group membership includes<sup>2</sup>:

- Co-chair - Dr Jane Collins, Chief Executive Marie Curie
  - Co-chair - John Powell, ADASS London Region – End of Life Care Network, Chair and Director of Adult Social Services Redbridge
  - Dr Caroline Sterling, London Clinical Network – End of Life Care, Clinical Director and Clinical Lead and Consultant in Palliative Medicine, End of Life Care Lead UCL Partners Camden, Islington ELIPSe, and UCLH & HCA Palliative Care Service CNWL
  - Dr Sarah Cox, LCA Palliative Care Group, Chair and Consultant in Palliative Care, Chelsea and Westminster Hospital
  - Dr Adrian Tookman, PallE8, Co-chair and Clinical Director, Marie Curie
  - Michael Kerin London Hospice CEOs group, Chair and Chief Executive St Joseph's Hospice
  - David Burland, Children's Hospices Across London, Representative, Chief Executive Shoot Star Chase Hospice
  - Eileen Sutton, Head of Service Redesign and Innovation (Urgent Care and 111), Healthy London Partnership, NHS England - London
  - Brian Andrews, chair of Pan London EoL lay representatives board, a bereaved carer from Beckenham and member of Marie Curie's Expert Voices group
  - Fran Woodard, Director for Policy and Influence, Macmillan Cancer Support
  - Trevor Arnold, Acting Director of Caring Services, Marie Curie
  - Tristan Brice, Programme Lead, ADASS London Region – End of Life Care Network
  - Paul Trevatt, Strategic Clinical Network Lead, NHS England – London
  - Dr Meeta Kathoria, Head of Programmes – Service Development, Marie Curie
- The Executive Steering Group meets four times a year.

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<sup>1</sup> The Pan-London End of Life Alliance is an independent body and does not have formal governance arrangements, whereas a number of the London-wide networks represented here have their own separate governance arrangements.

<sup>2</sup> It is noted not all London-wide networks involved in End of Life care are represented on the Executive Steering Group.

### **3. Working together to improve End of Life Alliance care across London**

- Several inter-dependent pan-London wide initiatives are in place with an aim of operationalizing improvements in End of Life care delivery across London including:
  - ADASS London Region – End of Life Care Network
  - London Clinical Network – End of Life Care
  - Hospice UK – London CEOs Network
  - Children's Hospices Across London
  - PallE8
  - London Cancer Alliance – Palliative Care Group
- The role of the Pan-London End of Life Alliance Executive Steering Group, which includes representation from each of these pan-London wide networks is to facilitate:
  - A system leadership approach;
  - The exchange of progress across partnership networks and to engender trust;
  - Work in conjunction with the pan-London networks to support aligning efforts and reduce complexity;
  - To act as an independent integrated collaboration to influence and lobby for positive change;
  - To identify what needs to be addressed from a London-wide perspective to improve End of Life care across the capital and establish which parties are best leading these efforts;
  - Blue sky thinking aimed at striving for excellence and equality in End of Life care across London.

### **4. Review of Terms of Reference**

- The Terms of Reference will be reviewed on an annual basis as a Standing Agenda Item at the Executive Steering Group meeting.

**Date of last update: November 2015 TBC**

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