**Pan-London End of Life Alliance – Launch Event Report**

1. **Background**

The first ever pan-London End of Life Alliance was launched on the afternoon of 22nd November 2013 at the King’s Fund in Central London aimed at tackling inequalities in end of life care across London.

Founded in partnership by NHS England (London), London Branch of ADASS (supported by London Social Care Partnership) and Marie Curie. The Alliance is an inclusive membership group and is supported by an Executive Steering Group who will provide oversight and prioritise activities, The Alliance provides an exciting opportunity to help secure significant improvements in the provision of high quality end of life care consistently across London. The Alliance hopes this will translate into a better end of life care experience for individuals, carers and their families

Over 100 delegates came together at the launch to support and promote patient-centred, coordinated care commissioning and delivery across London. Delegates included representatives from:

* Clinical Commissioning Groups
* Local Authorities
* NHS providers
* [Academic Health Science Networks](http://www.networks.nhs.uk/nhs-networks/academic-health-science-networks/show_all_similar_networks) (AHSNs)
* [Local Training Educational Boards](http://hee.nhs.uk/about/our-letbs/) (LTEBs)
* The Voluntary Sector
* Individuals who can speak on behalf of families and others who have experience of how services impact

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1. **Why is this work so important?**

* **Dr Jane Collins, Marie Curie Chief Executive,** “Whilst there are pockets of good practice, many Londoners are still not receiving the care they need or want. The End of Life Care Pan-London Alliance has the potential to be a real game changer and transform end of life care across London. As a leading end of life care charity and founding member of the Alliance we are committed to ensuring that the right care and support is delivered to the right people, at the right time, in the right place.”
* **John Powell, End of Life London ADASS Lead and Director of Adult Social Services Redbridge**: “An important role of the Alliance is to influence commissioners and providers of care to improve the experience of Londoners as they approach end of life. Working together I believe the Alliance can facilitate changes that empower individuals to have choice and control over their end of life plans. For many this relates to where they wish to die and there is real strength within the Alliance that can influence service delivery to help make this happen and so I am delighted that London ADASS and leaders within Social Care are fully engaged in this exciting London region development.”
* **Dr Andy Mitchell, Medical Director for NHS England (London)**: “Londoners deserve quality healthcare that is right for them – from the start of life, through to the end. It’s simply not right that seven out of 10 people would prefer to die at home, but in reality only around three in 10 patients in London do – the lowest proportion nationally.
* “There are some fantastic examples of excellent end of life care across our capital, but we want to make these the norm. This pioneering new Alliance will enable the NHS and health partners to develop services that truly respond to what patients and their families want during the most difficult of times.”
* **Dr Catherine Millington-Sanders, Co-Clinical Director for the London End of Life Clinical Network and Richmond CCG Board member**: “When someone is ill and dying, they or their carer should not have to think about how to get the best care for them in the last few months and weeks of their lives. We want to ensure that at this most difficult time for patients and their families, we give them seamless, high-quality care so they can concentrate on the precious time they have left together. It is crucial that as health and social care leaders we listen to what patients and carers want.”
* **Dr Catherine (Katie) Urch, Co-Clinical Director for the London End of Life Clinical Network and Lead Consultant Palliative Medicine ICHT**: “Our aim is to support and enable London to deliver a high quality and seamless service during a patient's dying phase. It is vital that palliative care teams and primary care professionals work together to provide the best possible experience for patients and their carers. The Alliance also gives us the opportunity to work with other key partners to improve London’s end of life care for all.”
* **Brian Andrews, a bereaved carer from Beckenham and member of Marie Curie’s Expert Voices group**: “Nothing prepares you for caring for someone you love at the end of their life. Different agencies, keen to help, must understand that 'we don't know what we don't know' and that this can lead to unintentional miscommunication, and in our case, distress."

1. **Key themes from Alliance discussions**

To inform the priorities of the Alliance launch delegates were asked to provide feedback on a series of structured questions. A number of strong themes emerged from these discussions which have been outlined below.

**What does ‘’good’’ look like?**

* The elements of a ‘’good’’ end of life included:
* End of life care needs are well integrated into other pathways such as dementia, COPD, heart failure, organ failure etc.
* Care co-ordination/single point of access for carers: Carers are given one phone number, available 24/7 for them to contact to access, advice information and guidance.
* Coordinators are available to help carers navigate their options, these do not need to be clinicians but should be skilled individuals who are able to appropriately signpost patients to relevant services for example we could use volunteers.
* Electronic systems play a role in ensuring that everyone has access to the most up to date patient information.
* A library of information is available for carers, available in a variety of formats and through a number of channels.
* Good end of life care is equally accessible to everyone, including “harder to reach” groups such as BAME communities, people who are homeless, LGBT community and others.
* Appropriate community care is available 24 hours, seven days a week.
* Quality communication exists across CCGs about what services are available which is properly communicated to the patients and carers.
* Staff from all disciplines are well trained on identification and management of EoL patients’ in order to ensure their and their carers’ needs are met.
* GP practices and receptionists act as advocates for patients.
* To support consistency in terms local provision it was proposed that a generic regional best practice specification for the end of life pathway would be helpful to develop. In particular, clearer national standards of what “good” looks like at the end of life are needed and these standards need to inform care. Currently there are too many assumptions, particularly in social care. Commissioners need standards and an operating framework to use to guide their decision-making.At the heart of this, we need to listen to carers and learn from their experiences. Carers at the start of their journey do not know what is available nor what they might need so professionals across EoL care need to be able to provide accurate information.
* We need more forums for carers to share their experiences, both pre and post-bereavement and look for common patterns in the issues that are fed back. Healthcare professionals also need to be more proactive in asking carers for their feedback.

**What are key areas for commissioners, specialists, generalists, social care and the voluntary sector to work most effectively together to deliver the best rather than the worst end of life care, meeting the needs of London’s diverse population?**

**Education and training**

* Improved education and training is critical as professionals currently find it difficult to identify EoL patients and often feel unsure about when is the best time to start difficult end of life discussions. Therefore, **i**t is imperative to up skill all disciplines on both these issues. GPs and social workers should be a priority..
* In particular, we need to:
  + Seek revalidation of GP competencies to deal with EoLC.
  + Ensure that GPs and nurses are fully aware of all services available to patients in their area.
  + Strengthen the training and support of domiciliary and homecare workers who are often providing a lot of care at EoL without supervision and guidance from palliative care professionals.
  + Strengthen the training and support for care workers in residential/nursing homes possibly through developing a portable training programme given the fluid nature of this workforce.
  + Strengthen the training and education for community groups in order to sustain and support the care that is provided by community networks.
  + Set up joint training across statutory and voluntary sector agencies.
  + Have a long term and sustainable training plan not just quick fixes.
* We need more general public awareness and education on EoL issues.
* We need to have better ways of learning from others and sharing best practice.
* To enable the above it would be helpful to have EoLC education and training standards agreed on either a national or regional basis to support consistency. In addition, this needs to be supported by a bottom up approach to education including:
  + Link with universities.
  + Multi-professional.
  + Accreditation for staff.
  + Minimum standards we expect carers to have.
  + Availability of funds across CCGs and boroughs.

**Continuity & co-ordination**

* We need to ensure that care is available 24 hours a day seven days a week; in particular we know there are gaps for emergency care out of hours.
* We need to see EoL as part of a broader continuum for people with long-term conditions and ensure that conversations start early, we need more anticipatory care plans for people at much earlier stages in the journey. As such, end of life care needs need to be better integrated into other pathways such as dementia, COPD, heart failure, organ failure etc.
* We need more consistency across London in terms of what patients are getting as currently there are big differences.
* There is a need for a key person to coordinate services and end of life care champions.
* We need to standardise DNACPR forms across London.
* We need better integration across teams providing end of life care.

**Integration**

* We need to find a balance between specialist and generalist.
* We need more understanding of professional roles involved in EoLC.
* We need a shared clinical record that works.
* Paediatrics teams seem to have been very successful in developing integrated approaches to care, centre around the child and involving the family. We need to learn from these models and apply lessons to EoL.

**Continuing health-care (CHC)**

* There are concerns about how patients are receiving CHC applications and funding.
* There seem to be inequalities across London on how CHC funding is being accessed, who is eligible and how quickly funding is accessed.
* We need a better understanding of the pathway for continuing care - to prevent the current blockages.
* Funding applications should not get in the way of good care; the current processes for funding does not always enable this.

**Pace of change**

* There was a view that many of the problems/solutions have been expressed before but there is little action, the pace of change is very slow.
* There are many end of life care groups across CCGs in London, but many are not action-focused and fizzle out over time, however these groups do allow for collaborative working and information sharing across the CCG.

**What outcomes would we want to achieve to know that both locally and regionally we had improved end of life care for Londoners?**

**Multi-faceted measure**

* Measures monitored need to be multi-faceted, death in the usual place of residence is only a proxy measure and should not be the basis of measuring ‘’good’’ end of life care.
* Although process measures could be used as a starting point, we need to look at more qualitative measures such as asking patients whether their symptoms are better managed and their pain is lessened.
* Some outcome measures that we need to consider include:
  + Has the family felt supported?
  + Does the patient feel the information they have been given is right?
  + Does the patient feel symptoms were controlled?
  + Was the place of death recorded and then achieved?
* Some quality measures that the Alliance could also target include:
  + The number of key health and social care professionals involved feeling more confident and competent in EoLC.
  + That there is a multi-agency training plan in place for end of life care.
  + That there is a “VOICES” type survey in place for all deaths.
* We need a confidential reporting process where we can ask staff how they perceived the patient’s experience of death and enable them to feed back in a completely confidential, non-judgmental way and learn from their experiences.
* We need to measure admissions to hospital and admissions avoidance as this is key to getting commissioners to fund EoLC initiatives
* Work has recently been done some combining HES and ONS data to follow patients’ admissions, this has been done for only cancer but could be replicated for EoL.

**Consistency in monitoring**

* We need to have a simple pan-London framework that we can use to measure end of life care and act as a benchmarking and comparison tool.
* We need to better understand inequalities in care and focus on measures to tackle them. This could be inequality by region but also by group of person.
* Once outcome measures are agreed and monitored, a key issue will be determining what to do to redress and how to constructively support areas to make changes when outcome measures are not being met.

**Measures informed by learning and education**

* We need to get more feedback from patients and carers on their experiences. Current work is mainly focused on gathering feedback from families rather than patients. We need to get patients more involved.
* Examples from Camden on having GPs review their EoL patients and understand what could have been done differently.
* Patients at the end of life in Wales are given the opportunity to take part in surveys at any point in their patient journey, we could learn from the example that they have set.

1. **Next steps for the Alliance**

Based on the above rich themes that emerged from the participant discussion groups the Executive Steering Group of the Alliance is considering next steps and anticipates that initial priorities for the Alliance will be proposed to members in early 2014.