Appendix 1: Pan-London End of Life Alliance – Lay Representatives Board Launch Statements

Facing the transition to life's end is an emotionally vulnerable time for us as patients and for those of us who love them. We want professionals to recognise this is often a traumatic period in our lives and a memory of a "good'' death can support us as carers[1] to feel consoled after they have died, whereas the memory of a death involving unnecessary suffering can often be a long-term painful memory.[2]

What does "good'' look like for End of Life for us (patients and their carers)?

- To be supported by professionals, surrounded by people who love us and supported to be at peace with our circumstances and to maximise our life quality.
- To be cared for by professionals with compassion, care, commitment, competence, courage, communication and good listening skills.
- To have our (patient and carer's) voices, needs and preferences heard, respected and acted on sensitively. Taking into account our individuality including culture, ethnicity, gender, spiritual and religious beliefs to ensure care is tailored to the needs of us as individuals in London. For example, efforts are made to actively reach out to our community members who come from minority groups or who have been marginalised or socially excluded by society such as homeless people, or people with dementia who may be challenged in communicating their needs, or the BME community where language barriers may exist[3].
- To receive a high quality experience of care based on our individual needs and preferences; rather than care delivered based on assumptions about what we prefer e.g. to die at home.
- To be actively engaged in 1:1 discussions about our *holistic* emotional, physical, cultural and spiritual needs and preferences through a mechanism of advanced care planning. For example, our preferences about the issue of DNRs should be handled with sensitivity at all times and our choices documented and respected. In addition, where we have complex needs and multiple health conditions we are treated by taking into account these various conditions, not just our primary diagnosis.
- To have seamless continuity of care at all times in which all organisations work together in a holistic manner and we only need to communicate information *once* rather than needing to repeat ourselves i.e. ensuring that everyone has access to the most up to date and accurate information about us.

---

[1] The pan London End of Life alliance lay representatives board emphasised where a reference to carers has been made in these statements it refers to "individuals of significance to the patient'' not only those identified as next of kin, family or partner.

[2] Statements highlighted in blue were emphasised for their importance by the pan London End of Life alliance lay representatives board.

[3] Other examples include the traveller community, the hard of hearing, blind, mentally ill and people with learning disabilities.

What are the biggest challenges to achieving this?

- A proportion of health and social care professionals have a *disrespectful attitude* to us at times which is *unacceptable* during an often traumatic period in our lives – largely we consider this is a consequence of either recruitment mismatches, gaps in their training needs, or their institutional management and leadership culture which does not inspire better behaviour. For example, carers who often are most senitive to the patient's needs are occasionally told by the medical team, against the patient's wishes, to leave the area away from view of the patient to enable the medical team to focus on carrying out the caring/nursing procedures.
- Many of our community members are socially isolated and lack support from their family or a community network.
- Our care currently is often reactively managed and fragmented rather than care we have actively been involved in planning and which is joined up.
    - Currently, there are innumerable 'missed opportunities' to discuss wishes for the future for those of us who are 'at a higher risk' of dying.
    - The links between health and social care are often criticised as less effective than they need to be, and should be strengthened, especially in discharge from hospital into the community. Transitions between urgent and emergency care, longer term and intermediate care and end of life care all suffer from a lack of overall coordination between agencies. Capacity or logistical issues in one service can often adversely impinge on another, without any corresponding means of adjustment.
- We need a culture change in terms of people more openly talking about dying to support shifting the 'taboo' that often surrounds it.
- We are aware there is often inequity of access to high quality care across London, especially for minoriity groups or sectors of society who have been marginalised or socially excluded such as BME communities, vulnerable adults, people who are homeless, the Lesbian, Gay, Bisexual, and Transgender (LGBT) community and others. For example in London considering 22%, or 1.7 million residents, use a main language other than English we need to ensure language is not a barrier for "good'' care.
- Inequity of care is also a key issue for those with a non-cancer terminal diagnosis.

What could have the most positive impact on improving our experience of care?

- ***We are actively engaged in preparing our own holistic care plans** in which our individual voices, needs and preferences are heard, respected and acted on sensitively. These care plans should reflect our individuality including culture, ethnicity, spiritual beliefs, religion and gender.*
- ***We are given equity of access to care across London i.e. good end of life care is equally accessible to everyone across borough boundaries and for cancer and non-cancer patients alike. In particular we do this by actively reaching out to minority groups and sectors of society who have been marginalalised or socially excluded such as BME communities, vulnerable adults, people who are homeless or have issues with substance misuse, the LGBT community, and others.***
    - In order to achieve this most effectively more innovative techniques to reach out to people need to be considered – for example where language barriers exists (and an appropriate interpreter is not available) patients could be assisted to reflect their needs with pictures/signs.
- We are supported by professionals who provide advice, support and information both in terms of what is practicable but also to empower us to explore purpose and meaning in order to derive maximum life quality.
- We are empowered as carers to support our loved ones and professionals equally support us and our holistic needs as individual needs in our own right.
- When we are in crisis we have access to high quality out of hospital care 24 hours, seven days a week capable of guaranteeing good responsive services which uses NHS resources most effectively.
- We receive continuity of care in which we communicate information once which is supported by electronic systems which play a role in ensuring that everyone has access to the most up to date and accurate information about us. For example, when discharging a patient from hospital into the community, discharge reports need to be issued promptly in which content has taken account of consultation with relevant agencies, carers and (our) holistic needs.
- We are supported as a community to talk more openly about death and end of life for example through soap operas covering such story lines or by having celebrity spokespeople.
- We minimise social isolation of those dying by actively engaging communities to provide a network of support.
- We optimise the use of pharmacists and pharmacies to support our clinical and palliative care needs.
- We are cared for by professionals from all disciplines who are appropriately recruited based on their natural aptitude for caring, who are well trained and are inspired by role models and a supportive management/leadership culture to ensure patients and their carers' needs are met in particular
    - GPs are highly skilled in identifying end of life patients at an early stage and are confident in sensitively managing 'difficult conversations' but GPs are not seen as the sole solution for this.
    - Professionals from all disciplines including those in social care and care homes are skilled to confidently manage meeting the individual care preferences of End of Life patients and their carers. For example, cultural sensitivities are respected in terms of cooking techniques.

Appendix 1: Guidelines and standards to follow to support delivery of “good’’ End of Life care.

- NICE Quality Standard: End of life care for adults (QS13). http://publications.nice.org.uk/quality-standard-for-end-of-life-care-for-adults-qs13
- NICE Guide for commissioners on End of life care for adults, 2011. http://publications.nice.org.uk/guide-for-commissioners-on-end-of-life-care-for-adults-cmg42/1-commissioning-services-for-end-of-life-care-for-adults
- “Homelessness and End of Life Care” information pack jointly developed by Marie Curie and St Mungo’s. http://www.mariecurie.org.uk/Documents/Commissioners-and-referrers/HomelessReport.pdf
- End of life care strategy: promoting high quality care for all adults at the end of life (Department of Health 2008).
- End of life care strategy: quality markers and measures for end of life care (Department of Health 2009).