

Pan-London End of Life Alliance Lay Representatives Board Statements: What could have the most positive impact on improving our experience of care?

This paper presents the pan-London End of Life Alliance Lay Representatives Board's recommendations for priorities to focus on which are considered to have the most positive impact on the experiences of terminally ill patients and their carers across London.

Strategic groups with a remit for improving end of life care for patients and carers across London such as the London Social Care Partnership End of Life Care Network and Clinical Network for End of Life Care **are requested to review and respond to the Lay Representatives Board with how priorities identified are being or will be addressed by their groups.**

To establish these priorities the pan-London End of Life Alliance Lay Representatives Board reviewed their launch statements (Appendix 1) using an activity priority matrix scoring tool (illustrated in Figure 1). The principle behind using the tool within this context being – to score each activity on the degree of impact the activity will have on improving patients and carers experiences vs the effort involved in implementing it successfully taking into account resources and finances.

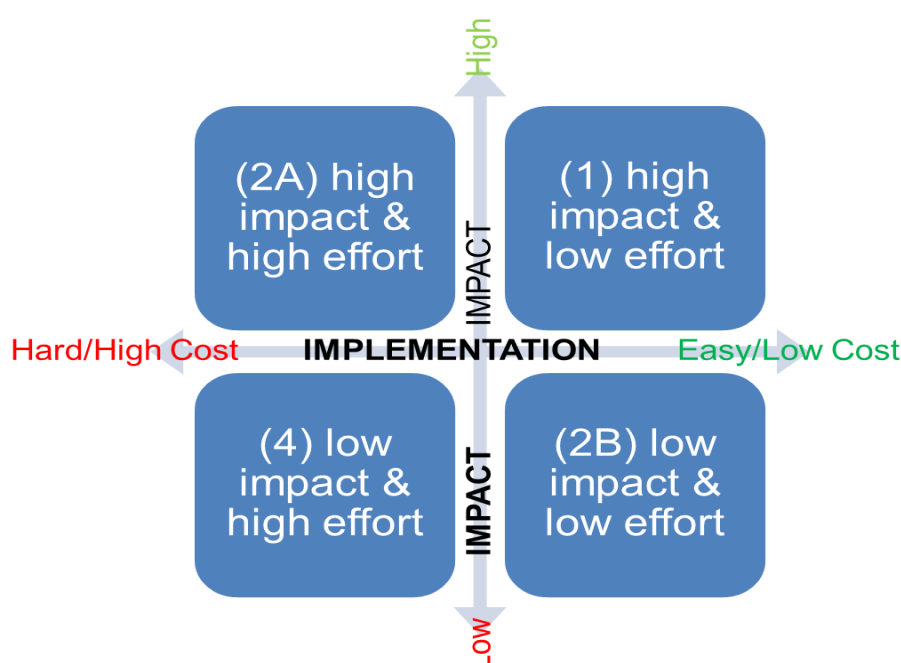


Figure 1: Activity priority matrix tool used to prioritise activities considered to have the most positive impact for terminally ill patients and their carers across London

The outcome of the action prioritising exercise is illustrated on the next page. In particular strategic groups are asked to focus on addressing activities detailed in categories 1 and 2A envisaged to have the most positive impact for terminally ill patients and their carers across London. Category 1 being 'quick wins' and category 2A being those with high impact worth prioritising but which require greater effort to implement and may be longer term projects.

1. High impact activities considered easier to implement

- We are actively engaged in preparing our own holistic care plans in which our individual voices, needs and preferences are heard. These care plans should reflect our individuality including culture, ethnicity, spiritual beliefs, religion and gender. In particular, those with high-need long-term conditions should be prioritised for advanced care planning to support ensuring the transition to a terminal phase is positively managed.
- We are supported by professionals who provide advice, support and information both in terms of what is practicable but also to empower us as both patients and carers to explore purpose and meaning in order to derive maximum life quality.
- We are supported through social media forums and through community representatives acting as facilitators to enable us to talk as a community more openly about death and end of life.
- Professionals from all disciplines are well trained to ensure terminally ill patients and their carers' needs are met in particular
 - GPs are effectively trained in identifying end of life patients at an early stage and sensitively managing 'difficult conversations' (GPs should not be seen as the sole solution for this).
 - Professionals from all disciplines including those in social care and care homes are trained 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.
- We receive continuity of care in which we communicate information once which is supported in time by 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.
- The use of pharmacists and pharmacies is optimised to support our clinical and palliative care needs.

2A. High impact activities considered harder to implement

- Our holistic care plans in which our individual voices, needs and preferences are recorded are respected, implemented effectively and acted on sensitively.
- 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 marginalised 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 exist (and an appropriate interpreter is not available) patients could be assisted to reflect their needs with pictures/signs.
- 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 minimise social isolation of those dying by actively engaging communities to provide a network of support.
- We are cared for by professionals from all disciplines who are appropriately recruited based on their natural aptitude for caring and are inspired by role models and a supportive management/leadership culture to ensure patients and their carers' needs are met.

2B. Low impact activities considered easier to implement

The lay representatives board did not identify any issues they considered of low impact that would be easy or of low cost to implement.

4. Low impact activities considered harder to implement

- We are inspired as Londoners to talk more openly about death and end of life to a sufficient degree to result in a positive change in how society responds to their own change in circumstance, or those of people around them.