

# Principles and use of language for End of Life Care modelling

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Consistency in the use of language for modelling EoLC needs is essential if there is to be clarity in application and ease of translation between different modelling tools. Whilst it is recognised that some of the terms noted below are in use with slightly different interpretations across the development of End of Life Care or Palliative Care services, as may be appropriate to their context, this short statement records the current meaning of such terms as they relate to the known modelling projects underway. The language and principles underpinning this work are primarily:

1. That the '**End of Life Care Cohort**' is defined as all those people whose needs can be realistically identified within the last year of life and who are supported by the full range of general and specialist health and social care professionals, in partnership with the person's carer, family and community wherever possible.
2. That whilst **early recognition** of EoLC needs across a population can be shown to bring benefit to the individual by facilitating improved choices about care it is neither possible nor necessarily desirable that each individual can be placed on a register.
3. That in supporting people in the early stages of EoLC the use of a '**register**' is understood as short-hand for GP registers and locality registers that are now being developed for EoLC as well as any means by which people are recognised and included in some formal way that expressly enables delivery of care to be 'EoLC sensitive'. Early recognition, including the identification of that person on a register of any sort, in no way implies a lessening of care, on the contrary it is to ensure the highest quality appropriate care.
4. That the primary driver for support is the **identification of need** at an individual level, meaning that which is required, in the context of the last year of life, to enable them to achieve an acceptable level of quality of life.
5. That to support an approach based on clinical need, the work uses a methodology for identifying and describing '**trajectories of illness**' underpinned by existing evidence on functional and symptom trajectories (which relate to clinical need). These trajectories relate to, but are not solely defined by, the corresponding 'cause of death' or 'condition/diagnosis'. These trajectories cluster people with different causes of death, whilst also being sensitive to age and co-morbidities, but may need to evolve as further evidence in this relatively new area of research continues to emerge.
6. That **frailty**, as a significant and growing cohort of people approaching the end of life, is characterised by multiple co-morbidities and a general

decline in functioning. The actual cause of death amongst those whose experience in their last year of life is typical of frailty is considered to be of less importance than the nature of their needs as they approach death, which may include multiple co-morbidities, including dementia.

7. That **enabling choice** at the end of life is as much about the preparation during the last year of life as it is about providing the necessary services and response in the last days to enable this choice to be realised. Without early recognition and support it is less likely that the preferred choice regarding place of death will be realised.
8. That whilst some members of staff will work exclusively with people at the end of life many more will have responsibilities that require designated or **protected time** to be allocated to people recognised as having EoLC needs. Protected time therefore forms a part of any persons care and support provided to people with End of Life Care needs, whether exclusively or as part of a wider role.
9. That in understanding **support roles**, whether employed or voluntary, the professional group or employing agency is less important than the skills required to provide the identified support. The following terminology has therefore been applied throughout:
  - a. Generic skills: meaning care or support not requiring training at a qualified or specialist level, and being taught in relation to a specified individual.
  - b. Enhanced skills: meaning tasks requiring competence that might be typical of a qualified member of staff, and where skills are transferable across a number of individuals with similar needs.
  - c. Specialist skills: meaning tasks that require knowledge of direct relevance to the condition(s). These may relate to the primary condition, the secondary condition or palliative care.