Cohort Model for End of Life Care in Community settings

Report to accompany version 2 of the Cohort Model [April 2012]

www.endoflifecare-intelligence.org.uk/models
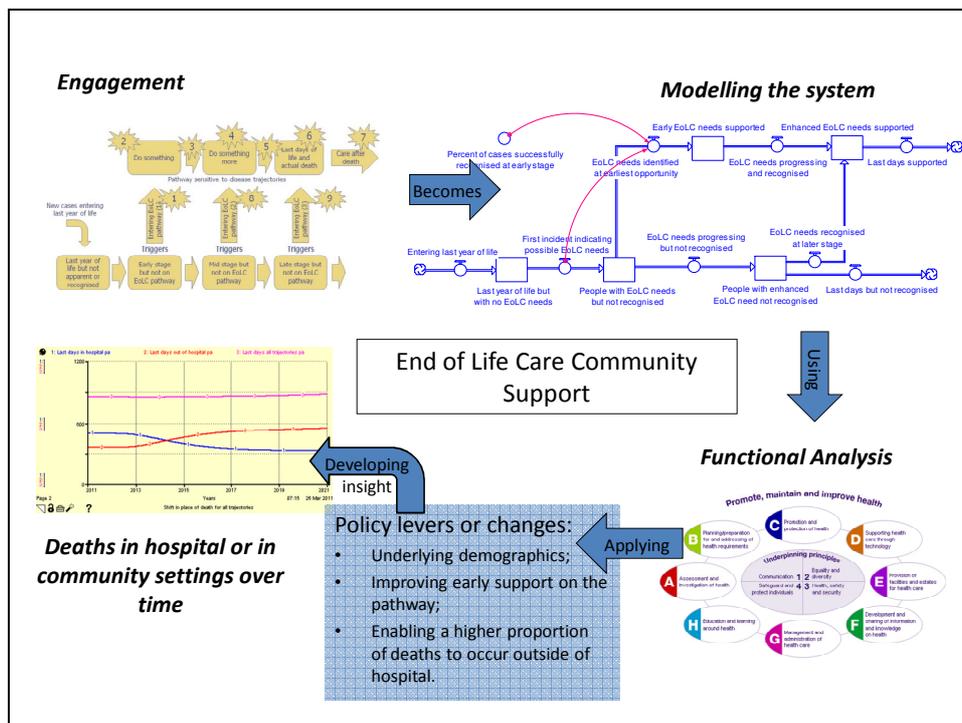
This work has been supported by the National End of Life Care Programme building on a previous partnership between East Midlands SHA workforce team, Skills for Health, Skills for Care and the Whole Systems Partnership. It reflects work with a number of early adopters during 2011/12 that have now made it possible to re-launch the tool and encourage wider uptake.

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1   Introduction

The Cohort Model for End of Life Care is the product of work supported by the National Programme for End of Life Care to inform the commissioning of End of Life Care services. The tool provides a simulation of population level needs for support over the last year of life in the context of early recognition of need and facilitating choice of place of death.

The tool does not tell you 'how to' deliver better End of Life Care services at an operational level, as this is the subject of a wide range of good practice case study material already available on the National Programme web site. Rather, it fills the gap in providing answers to questions that commissioners will have such as '*How many people*?' '*At what costs*?' '*With what implications for resources or capacity*?'

This report provides an overview of the Cohort Model for End of Life Care that has now benefited from the involvement of early adopter locations. During the winter of 2011/12 the tool has been calibrated for two CCGs in Nottinghamshire, for West Berkshire and Berkshire East and for Gloucestershire. This process has provided invaluable experience in the application of the tool and our thanks go to these localities for facilitating this process[1].

A companion workbook to this report is available that provides more detailed information about the way in which the tool can be used in its 'generic' version (i.e. to an average 200,000 population). This, and other related material, can be found by navigating from the link on the front page of this report. Whilst the use of the generic tool can bring useful insights there is benefit in completing a full calibration. This process requires support from WSP[2] and involves two important elements. One of these is the use of local demographic and death statistics data, the other is the engagement necessary to align and incorporate assumptions about progress in implementing the EoLC strategy locally.

The agreed purpose for the tool is to act as '***a framework tool for quantifying needs and associated workforce costs in the community during the last year of life for a given population, and the potential impact on reduced hospital admissions of improving early recognition and choice at the end of life***'.

2 An overview of the modelling framework

2.1   The systems modelling environment and approach

2.1.1   Introduction

The modelling approach adopted to undertake this work is particularly suited to complex or inter-disciplinary strategic challenges where the relationships between elements of a system are equally, if not more, important than the nature and quality of the individual components within that system[3].

2.1.2   Demography & needs

The modelling framework focuses on needs rather than disease trajectories. However, most data is based on cause of death attributed to specific diseases. This places a challenge on the process, which has been addressed by:

1. Using ONS cause and age of death data for England and Wales (with Welsh deaths and deaths under the age of 18 excluded);

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[1] For short case studies of this local calibration process refer to the web link on the front of this report.
[2] Details of support packages can be obtained by e-mailing peter.lacey@thewholesystem.co.uk
[3] See companion document, available on the Modelling Tools web page, "What is a systems model?"

2. Allocating these deaths to needs trajectories based on cause of death but making an allowance for age and frailty;

3. Identifying an age specific death rate for each trajectory that can then be applied to population projections, thus reflecting any shift in the demographic make-up of a given population[4];

4. Using these cohorts of people with similar needs trajectories as the basis for the subsequent modelling.

2.1.3 A pathway approach

The pathway approach has been developed to provide a 'bridge' into the modelling and the Functional Analysis and is therefore represented in such a way as to identify key transitions or stages along the pathway. Each 'star-point' represents a transition or stage of care, which provides the basis for work to identify workforce requirements.
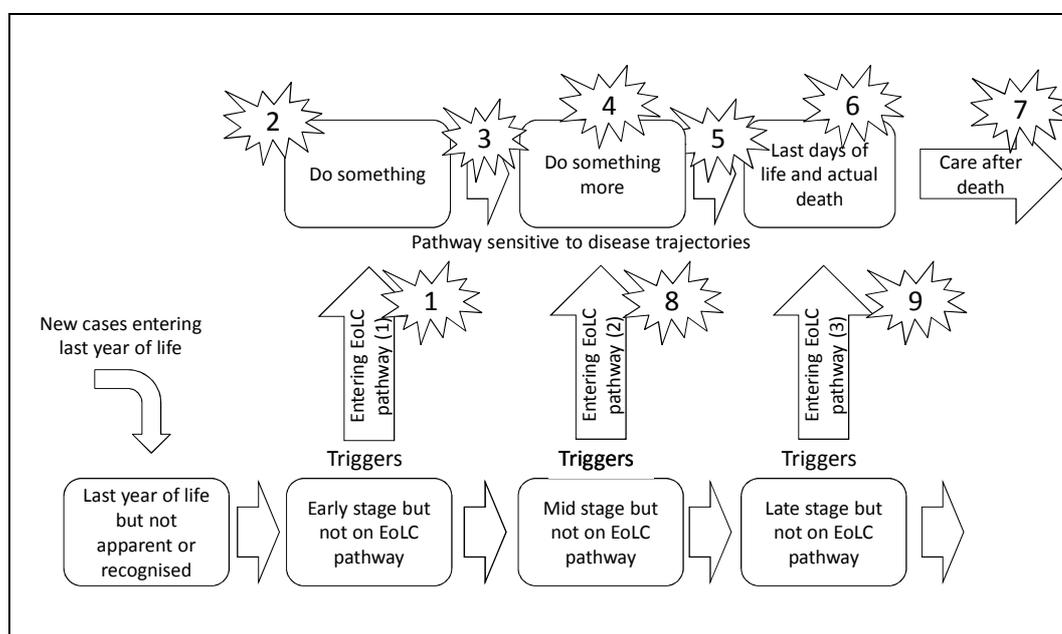

Figure 1   Pathway map for EoLC

The 'two-dimensions' (time and level of need) reflected in Figure 1 is further refined by the third dimension of trajectory of need, which effectively replicates Figure 1 five times. The characteristics of these trajectories is summarised as:

Trajectory	Characteristics	Timescales
Cancers	Gradual decline and then rapid end stages but without previous exacerbations or sudden changes in need.	Changes in treatment regime come relatively late for this trajectory as EoL approaches, hence a shorter phase of enhanced need.

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[4] A full set of assumptions for this process, including the allocation of ICD10 codes to trajectories and adjustments made for frailty is contained in the companion document, "Assumptions and Workbook for the Cohort Model", which is available on the Cohort Model home page.

Trajectory	Characteristics	Timescales
Other terminal	Gradual decline with some exacerbations in initial phase of last year then rapid end stage.	The trigger for increased needs within the final year will vary significantly for this group. A mid-point has therefore been chosen for transition to enhanced needs.
Frailty	Multiple co morbidities accumulating with increasing age leading to a gradual decline and regular exacerbations before last days.	The range of timescales for this trajectory may be quite wide but the 'ideal' is to ensure EoLC support for a full year before death, by which time needs might already be quite significant due to co-morbidities.
Organ failure	One predominant chronic condition with regular or fairly frequent exacerbations and with end of life typically being the result of a crisis and therefore more rapid deterioration in functions.	Whilst organ failure can result in many years of poor health it is likely that the trigger for EoLC would follow a significant increase in needs, which may be followed by a shorter period of EoLC than a full year.
Sudden death	Any deaths where there was no obvious prognosis until last days.	Last days can be less than a day but this group includes people who will require last days support for up to a week, perhaps after a trauma. No previous EoLC needs are assumed for this group.

2.1.4 Frailty

The primary cause of death for many people will not necessarily reflect the needs they will experience in their last year of life. As a result this work has developed a frailty trajectory based on a small number of primary causes of death plus a proportion of other primary causes of death. The proportion of each Cohort re-allocated to the frailty trajectory increases with age[5]. One consequence of this is that as the general population ages so will the proportion of people whose needs, in their last year of life will, reflect the frailty trajectory.

2.1.5 Dementia

The Commissioning Guide for EoLC for people with Dementia highlights the potential number of people within this group. The Cohort Model has identified the age profile for each of the trajectories of need and then made the assumption, as in the Commissioning Guide, that the prevalence of dementia for these people is the same as that for the wider population. When undertaking the Functional Analysis, described below, additional consideration has been given to those with dementia, which has therefore enabled the model to take account of dementia needs at a population level.

2.2 Functional Analysis

In articulating any patient pathway, workforce will always be a resource that can significantly affect the quality of patient experience. It is therefore important when modelling a pathway to reflect best practice and that a robust and consistent methodology is used to articulate workforce needs. Competences are ideal for use in this scenario, and Skills for Health's Functional Analysis, which groups related competences into sets of "functions", provides an accessible vehicle for doing this.

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[5] Work is currently underway to refine the approach to estimating the number of people whose last year of life will be characterised by needs arising from frailty by matching data within predictive modelling and death statistic datasets. This will inform future versions of the model.

Functional Analysis is a tool that can easily be adopted by health and social care professionals, and with the right facilitation this enables them to take the lead in expressing what skills the delivery of a good quality service requires.

One of the key challenges and opportunities however, is that the focus must remain on skill requirement rather than existing roles. When undertaking Functional Analysis it is important to do so with the patient's need being paramount, rather than it being led by a particular professional focus. A range of factors, including the patient's location will have an effect on the actual person who delivers the care, but in essence the skill required remains the same.

For example, a District Nurse going to see a patient in a rural location may well undertake a greater range of enhanced and generic tasks than in a more urban environment where the generic aspects may be carried out by a support worker in addition to the District Nurse. Additionally some tasks can appropriately be undertaken by either the patient themselves or a friend or relative acting as a carer.

The opportunity that using Functional Analysis brings is that it encompasses functions (and therefore competences) from across health and social care. This is critical in pursuing the patient focus that is required. As part of the Functional Analysis work, highly experienced clinicians have articulated the skills that meet the needs of patients for each trajectory using 'functions', this is known as functional mapping. This has been further enhanced by Functional Analysis specific to the EoLC context which defines the skills level(s), and general timings of need throughout the pathway.

In quality assuring this work, which drew on the perspectives of a range of highly experienced professionals, we have been able to cross-check against the national Common Core Competences for End of Life Care. In addition a review of stated need across trajectories has taken place which allowed reflection on the more specific needs of a given trajectory, in the context of the others. For example, a cancer patient in the early stage of their last year of life would have a relatively low level need in terms of health or social care input, given that their level of function would remain quite high.

Having undertaken this work, it becomes possible to use it as a vehicle for service and workforce development in terms of articulating new roles where appropriate, or informing education and training needs. The competences that sit within each function provide the link for this to happen.

2.3 Integrating needs, trajectories and Functional Analysis

Integrating the pathway approach with the Functional Analysis using a systems model has enabled the quantification of support needs at three different levels[6], at nine generic points on the pathway and for each of the five trajectories of need (also taking account of additional support needs of those with dementia in each trajectory). In order to 'organise' this information into a manageable framework for community support during the last year of life the points on the pathway identified in Figure 1 have been grouped according to needs at:

1. Early recognition (points 1,3 & 8), which would require higher levels of specialist input to ensure effective planning and advice;

2. Early support (points 2 & 4), which would require a balance of support from mainstream (health and social care) staff, the carer and the 'expert patient' with a small amount of specialist input;

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[6] Three skill levels of specialist, enhanced and generic are described in the accompanying workbook and as part of Appendix 3 in this report.

3. Last days (points 5,6,7 & 9), which would require a mix of specialist support plus mainstream health and social care staff trained in providing EoLC and support from a carer.

Throughout this work the contribution of the carer (be they a family member, close relative or neighbour) has been considered alongside those of paid professionals. Where they acquire the necessary skill level in a given task this contribution has the potential to be fully recognised within the framework of the model.
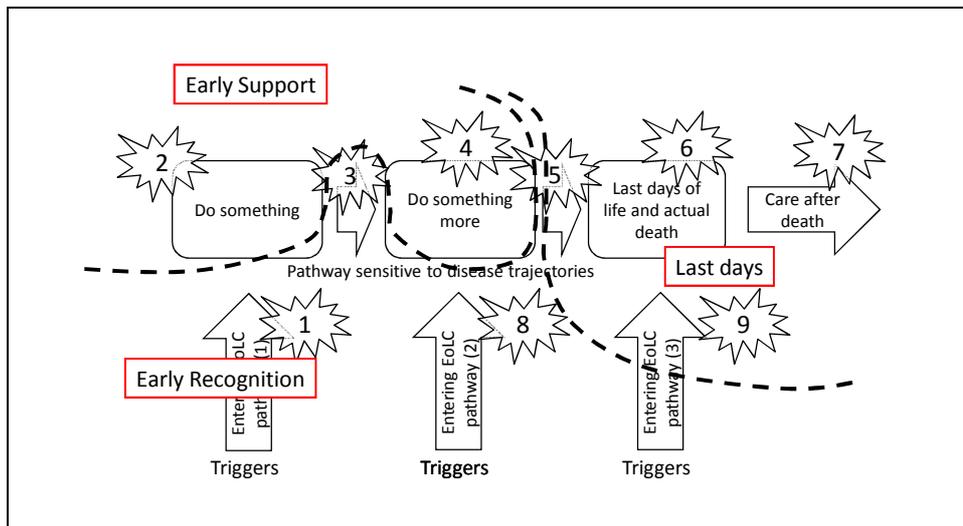

Figure 2   Organising the response to needs

3   Model findings and discussion

3.1   Introduction

In the light of the original objectives, road testing and the changing context within which the Cohort Model has been developed five key questions have been identified that can be addressed using the tool:

1. ***What is the extent of end of life care needs in a given population and how does it change over time?***

2. ***What is the impact of early recognition of end of life care needs on resources and workforce for this population?***

3. ***What are the financial and workforce consequences of providing alternatives to dying in hospital?***

4. ***How does the recognition of different trajectories of need inform end of life care needs in a given population?***

5. ***What are the combined effects on the community workforce of these changes?***

The final section of this report describes high level' default' outputs from the model whilst the workbook that accompanies the model provides step by step guides as to how to interpret these and develop alternative scenarios that more closely reflect local circumstance.

3.2 Population needs

The **Cohort Model** suggests that for an average 200,000 population in England:

- That the profile of deaths is falling slightly up to 2014 but that after this it starts to rise, rising by approximately 3% from the 2014 minimum up to 2021;
- Approximately 1,700 adults will die each year from all causes in a typical 200,000 population;
- Of these 900 would currently die in hospital at a tariff cost of c.£1.2M;
- That the number of deaths by trajectory is either level or continues to fall through to 2021 for all trajectories except for frailty, which rises through the ten year period by 9.5%.

3.3 Impact of early recognition

The **Cohort Model** suggests that for an average 200,000 population in England optimising early recognition of EoLC needs so that at any one time 40% of people in their last year have these needs recognised (informed in part by "*End-of-life care in hospital: a descriptive study of all inpatient deaths in 1 year*[7] and subsequently by clinical opinion):

- Without the drive to early recognition only 470 out of the 1,700 adults who die each year will have these needs recognised before their last days – and just over half of these will currently be people with cancer;
- With optimised early recognition the number of people each year whose needs are recognised before their last days would rise to c.800 after 2 years and would then continue to rise to about 1,000;
- That the number on an End of Life care register per 200,000 population would rise from c.300 to about 450 over 2 years and then to over 700.

3.4 The impact on community workforce

The **Cohort Model** suggests that for an average 200,000 population in England, using default model assumptions including reduced hospital deaths and optimised early recognition, that:

- There would be a need for an increase in the number of people (in wte) supporting those with EoLC needs from about 53wte to just over 89wte between 2012 and 2017;
- That the largest increase is for those with specialist skills, although those with enhanced skills also increases significantly (the default assumptions are for generic roles to be undertaken primarily by mainstream services);
- That the largest increase along the pathway is for ongoing support once early recognition has been achieved – the increase in wte support during last days only rises from 24 to 27wte;
- That the balance of enhanced to specialist skills at early recognition to last days shifts from higher specialist skills at early recognition to enhanced skills during last days;
- That the ratio of support from an EoLC service to that provided by mainstream services changes along the pathway with the greatest contribution of mainstream input being during ongoing support and during last days from people with specialist skills.

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[7] J Abel, A Rich Weston Area Health Trust, Weston-super-Mare, T Griffin and S Purdy University of Bristol, Bristol

Good practice in developing existing services so that they are sensitive to the needs of people during their last year of life (where this can be identified) is fundamental to achieving a sustainable, integrated and high quality service for people with EoLC needs. The extent of 'specialist' or 'dedicated' community services is still the subject of debate although case studies on the National Programme web site linked to this section of the Cohort Modelling work does provide potential insight on this.

4   Conclusion

The Cohort model has undergone a number of phases of development and road testing, with the most recent involvement being with three early adopter sites. This has enabled refinements to be made and ease of use to be tested. Whilst the approach is perhaps unfamiliar to some the case studies from the early adopter sites demonstrate that the benefit to local commissioners has been considerable.

Appendix: Principles and use of language for End of Life Care modelling

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

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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.