

**The NHS End of Life Care Programme: An Evaluation of Processes,
Outcomes and Impact.**

Executive Summary

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Background

This document reports the findings and implications of a national evaluation study of the NHS End of Life Care Programme conducted by the Sue Ryder Care Centre for Palliative and End of Life Studies at the University of Nottingham between August 1st 2006 and July 31st 2007. The stated aim of the NHS End of Life Care Programme is to:

‘Improve the quality of care at the end of life for all patients and enable more patients to live and die in the place of their choice’.

Aim of the evaluation

To evaluate the NHS End of Life Care Programme in terms of its intended and achieved outcomes relating to quality of end of life care and to make recommendations for its further development.

Research questions

- What were the original perceived aims of the NHS End of Life Care Programme and to what extent have these altered over the life of the programme?
- How has the NHS End of Life Care Programme been implemented and what issues are perceived by key stakeholders to have been involved in this process?
- What key areas of change can be identified in end of life care policy and practice in the Strategic Health Authorities (SHAs) as a result of the NHS End of Life Care Programme?
- What impact has the NHS End of Life Care Programme had on measurable and subjective outcomes of care (place of care and death; style of care, emergency admissions and perceptions of quality of care) in the last four weeks of life?

Methods

A pragmatic evaluation approach was employed to account for how the programme has developed and changed over time. The evaluation comprised three elements: (a) a stakeholder enquiry; (b) a scoping exercise; (c) and a case study to shed light on care in the last four weeks of life in one locality.

Findings

1. Stakeholder enquiry

- Thirty seven participants took part in 27 individual interviews, one joint interview (n = 2) and one focus group (n = 8).
- Participants were drawn from three groups: 1. 'National Leads' (n=8); 2. Area Leads and Local Facilitators (n=11 and n=10 respectively); 3. Representatives from Associated National Organisations (n=8).
- The interviews and focus group discussions covered topics including: views of end of life care before the programme; aims and approach of the programme; barriers and facilitators to implementation; impact of the programme and monitoring of outcomes, and sustainability.
- Some of the issues highlighted or views given varied largely by the sample group, and a few were unrelated to sample group or the participant's role in the programme, and can be interpreted as individual or minority perspectives, views or experiences.
- Views about end of life care before the implementation of the Programme were similar across the three groups. Key challenges identified were:
 - *variability in service provision;*
 - *end of life care in care homes;*
 - *home care and GP services;*
 - *ambulance and out of hours services;*
 - *the related care of older people approaching the end of life.*
- Understandings of the Programme's main aims were similar across the three groups, but a number of subsidiary or incidental aims and priorities were identified. These included enabling:
 - *advance care planning;*
 - *improved communication and collaboration;*
 - *awareness of generalists' roles in end of life care;*
 - *improved development of staff support systems.*

- Participants from all three groups were largely positive about the Programme’s approach, with some exceptions. The following factors were perceived as key to the programme’s success:
 - *decisions delegated to area level about local initiatives which encouraged the sharing of good practice and the clear identification of areas for improvement;*
 - *the strength and leadership of the National Programme Team and supportive steering group;*
 - *the synergistic relationship between central direction and complementary local implementation, where the latter was driven by local facilitators;*
 - *the focus on implementation of the recommended end of life tools.*
- A few criticisms were expressed, mostly from participants involved at area and local levels. These related to their perceptions of:
 - *an over emphasis on ‘tool’ implementation;*
 - *a relative neglect of strategic and long term workforce planning;*
 - *a relative neglect of development and training;*
 - *a lack of emphasis on the development of end of life care policies, across clinical areas and networks.*
- The recommended tools (Gold Standards Framework, Liverpool Care Pathway and Preferred Priorities of Care, formerly Preferred Place of Care) were perceived in largely positive terms, but some at area and local levels argued that the development of a single, integrated care pathway may have been preferable.
- Several referred to how the different tools contribute to the increasingly prominent notion of Advance Care Planning.
- The National Leads considered it important for the programme to focus on a limited number of initiatives supporting good practice, and to endorse and encourage the spread and uptake of end of life tools nationally in the pursuit of better systems of care.
- The LCP and GSF were seen to have wide support networks of key individuals, while the PPC was seen as less well supported. This was perceived to involve a professional power issue: LCP and GSF have eminent medical staff leading them, plus the support of major national organisations, whereas the PPC was seen by

some as a 'poor relative' developed by nursing staff, without the backing of a major organisation.

- Perceived facilitators to Programme implementation included:
 - *the critical role of 'champions';*
 - *the importance of local implementation;*
 - *the strength of leadership from the National Team;*
 - *the varied nature of collaborative relationships between health and social care, and between professional groups within these sectors.*
- Perceived barriers to Programme implementation included:
 - *a need for a major cultural shift in attitudes to death and dying;*
 - *inadequate and short term resources;*
 - *the scale of the task in challenging entrenched traditions of biomedical approaches to disease management;*
 - *widespread resistance to change;*
- Views about monitoring the impact of the Programme included the expression of some concerns about the lack of, or poor quality of baseline data from which change could be measured. At area and local level, participants reported problems in filling out the feedback forms which were returned to the Programme office, and had related concerns about the reliability and validity of the data therein.
- Views about the impact of the Programme included:
 - *widespread anecdotal accounts of changes in ways of thinking about end of life care that were beginning to change practice;*
 - *a sense of changing trends relating to care at home and emergency admissions to hospital, which was related to tool uptake;*
 - *confidence in the potential of the Programme to improve patients' experiences across many dimensions;*
 - *exposure of areas of good practice as well as areas in need of improvement;*
 - *facilitation and development of policies addressing longstanding and intractable problems including DNAR policies and clarification of professional roles and responsibilities;*
 - *the generation of enthusiasm for end of life care among generalists;*
 - *the affording of a higher profile for end of life care in related organisations.*

- Widespread concerns were expressed about sustainability, in the context of broad agreement about the Programme's achievements. For many, announcement of the End of Life Strategy was perceived as a *'life line'*.

2. Scoping Exercise

- Existing data from three sources was used to undertake the scoping exercise: place of death data from ONS, end of life tool update data from the NHS EoLCP, and proxy measures of primary care quality from QOF data.
- We examined trends (both temporal and geographic) in the proportion of deaths that occur at home, and how this varied according to cause of death (cancer and non-cancer).
- At SHA level, change in uptake of end of life tool data was reported at three time points across the duration of the programme.
- Evidence of association between the proportion of deaths that occurred at home and (i) tool uptake and (ii) QOF measures of quality of primary care service were tested for.
- The recent decline in the proportion of deaths that occur at home appears to be slowing down but deaths at home account for less than a fifth of all deaths.
- Around a fifth of care home residents die in hospital although there is great variation between PCTs. Much of this disparity is likely to be accounted for by differences in both care home provision and proximity to hospital services.
- At SHA level, end of life care leads report a steady increase in the uptake of end of life tools.
- Some evidence was found to suggest that those SHAs that report higher uptake of end of life care tools also have higher home death rates. This association may be due to confounders for which data are not available.
- Although indicators relevant to the NHS EoLCP are limited in the first two years of QOF, at PCT level there was a positive association between practices achieving a higher level of QOF points for regular reviews of those with cancer and proportion of cancer deaths occurring at home.

3. Case study of care in one local area

- In order to provide insight into end of life care at the local level, we conducted a study of care provided by selected services within a defined case study area.
- The case study area is one of the thirty-two Cancer Networks in existence in 2006. It encompasses an area that includes a large urban conurbation as well as an extensive rural area with a geographically dispersed population. Demographically the area is similar to England and Wales in terms of age distribution and ethnicity.
- Four services were selected to be studied as ‘sub cases’. These included:
 - GP practice service using the Gold Standards Framework;
 - a heart failure community matron service;
 - a specialist palliative care hospital support service;
 - a care home nursing service (non-GSF – but using LCP).
- The case study consisted of (1) an audit of documented care during the last four weeks of life based on records maintained within the selected services, and (2) focus group interviews with case service providers.

Audit of documented care received in the last four weeks of life

- The audit was carried out retrospectively on a random sample of deaths (n=65) occurring between January 2005 and December 2006 across the four sub case study services. There were a total of 407 deaths across the services during this period.
- A service audit tool was developed (see Appendix 3) to assess care as recorded in the patient records held by each of the sub case services studied. The developed service audit tool was adapted to the aims of the End of Life Care Programme.
- We advise caution in relation to the evidence from the audit which had a number of limitations.
- Key findings from the audit indicate:
 - *a lack of systematic recording of advance care planning discussions;*
 - *substantial variability in terms of recording the content, depth and location within case notes of relevant discussions about end of life care;*

- *confusion and lack of patient awareness cited as a reason for not recording ACP discussions in the care home service;*
- *in contrast, medication administration and prescription was recorded consistently and clearly across the four sub case services;*
- *where a preference for place of care was recorded, the sampled services enabled the patient to die in their preferred place of care in the majority of cases;*
- *services also avoided emergency admissions for the majority of cases;*
- *patient case study examples draw attention to the possibility that overly literal interpretation of PPC may lead to potentially inappropriately late transfer from hospital to home.*

Focus groups with sub case service providers

- The focus groups took place with staff from two services, one delivering palliative care to cancer patients and one to heart failure patients. Many of the issues raised within these focus groups represented similar views about the EoLCP to those of the wider stakeholder enquiry.
- Participants were overall very positive about the EoLCP.
- Their concerns focused on resource constraints and on the need for greater communication between those working at the strategic level and those working at the level of 'front-line' implementation.
- A number of challenges were identified. Most of these were areas where it was felt there is still room for further improvement such as: the development of services for non-cancer patients, issues for people living alone, and support for carers and staff.
- Participants identified that an audit of records of patients' last four weeks of care did not fully reflect the realities of the delivery of services. It was acknowledged that record keeping habits encouraged a focus on task orientated issues.
- Participants suggested that their record-keeping did not reveal the depth of work undertaken, particularly around conversations held with patients about preferred place of care and other aspects of advance discussions. It was acknowledged that this was an area in need of practice and policy development.
- Professionals spoke about building up detailed knowledge about their patients that they held 'in their heads' and passed on verbally to colleagues.

- Reasons identified for the lack of recording these aspects of delivery of care included constraints of time and resources alongside the practicalities of maintaining fully comprehensive records of lengthy conversations.
- Participants were highly motivated, hard-working individuals deeply committed to develop and deliver the best possible end of life care for their patients.

4 Conclusions and recommendations for consultation:

1. This evaluation was an ambitious project for a one year study. We have not been able to achieve everything we set out to do, because of limitations of time, resources and data availability. However, we see this report as shedding light on important aspects of the EoLCP at national, area and local levels. We believe that it is of value for the development of further research and policy in this challenging area.
2. This national programme was implemented within a short time span and has generated a great deal of enthusiasm at national, area and local levels which needs to continue as part of *Our NHS-Our Future* and the *End of Life Care Strategy*.
3. The implementation of the Programme was perceived to be associated with a sense of clear national direction and a high degree of local innovation which gave rise to positive intended and unintended consequences.
4. The role of the facilitator was reported to be critical in providing support to the clinical teams and this role should be an essential element to any future work.
5. We observe that it is important to understand the processes leading to local variation and to support innovation and implementation of change at local levels as one way of minimizing variation and inequalities in access to end of life care.
6. Problems were reported relating to a lack of clarity about monitoring impact, especially in terms of data collection and recording. The End of Life Care Strategy will need to decide on a minimum dataset that reflects the aims of the strategy and is not burdensome to frontline staff.
7. Some concerns were voiced about the logic of concentrating on the three end of life tools. Further consultation and discussion needs to take place about the relationship between these tools and other innovations developed to address local priorities and challenges.

8. Concerns about sustainability focused on short term resource and staffing issues. A workforce strategy needs to be developed locally and supported by work on competences for health and social care staff.
9. While it was seen as too early to make summative judgements about outcomes for patients, a range of positive consequences were perceived. Some of these have been further illuminated by the scoping exercise.
10. Difficulties in using ONS data together with Hospital Episode Statistics data limit the possibilities of acquiring a more detailed understanding of this issue. This is a particular issue in identifying how and where people in care homes die, a population of increasing importance.
11. The scoping exercise demonstrates that great variation exists in populations and service provision in relatively small geographical areas. As PCTs and SHAs have recently reconfigured to cover larger populations, it is likely to be increasingly difficult to pick up inequalities in end of life care. At a national level, as long as place of death is treated as the crude 'outcome' measure that it is then it is useful for highlighting geographic variation.

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