

# End of life care in primary care



2009 national snapshot – executive summary

# Key themes

*“How we care for the dying is an indicator of how we care for all sick and vulnerable people. It is a measure of society as a whole and it is a litmus test for health and social care services.”*

Department of Health, End of Life Care Strategy 2008



After an extensive consultation with families, NHS teams, social care, hospices, voluntary groups and other stakeholders, the Department of Health launched the national Strategy for End of Life Care in 2008.<sup>1</sup>

The strategy encourages all health and social care services to recognise and value high quality care in the final years of life and emphasises a co-ordinated pathway approach.

Core components of the pathway include:

1. **identifying** people approaching the end of life
2. **assessing** and agreeing how to meet people's needs and preferences, using advanced care planning
3. **planning** and coordinating care
4. **delivering** high quality services in all locations
5. **managing** the last days of life
6. **supporting** carers



The End of Life Care Strategy suggests that the focus of end of life care should be on people's experiences, quality and safety. Following the release of the Strategy, the first ever national snapshot of end of life care in primary care was undertaken in 2009. The snapshot was facilitated by Omega, the National Association of End of Life Care, with practical support from the Gold Standards Framework Centre and The Evidence Centre. The snapshot was funded by primary care trusts and the NHS National End of Life Care Programme.

The aim was to understand the types of primary care services and support available for people in the final year of life and the extent to which general practices throughout the country were able to offer care that met best practice and supported the national End of Life Care Strategy.

**502 general practices took part from nine of the ten strategic health authority regions.** Practices used an online After Death Analysis (ADA) tool to provide anonymised information about all deaths that took place between February and March 2009. Records were provided for 4487 people.

**Six out of ten eligible practices provided information (502 of the 874 invited) and data is available for about half of all deaths during February and March 2009 in the 15 participating PCT areas.**

This is the first time that such a large amount of information is available from primary care, although the snapshot did not aim to represent the care offered by all practices or make detailed comparisons between areas. It is important to acknowledge limitations such as construct validity, variation in interpretation and the potential for selective reporting by practices.

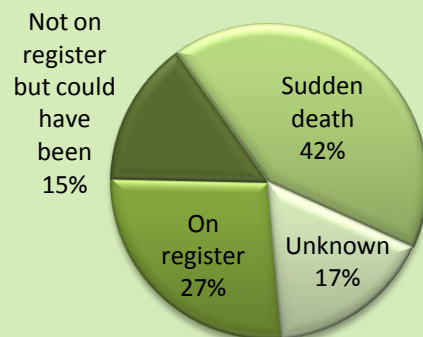
**The national snapshot includes information about 4487 deaths from 502 general practices in 15 areas. Nine out of ten SHA regions are represented.**

## 1. Identifying the right people

The End of Life Care Strategy suggests that everyone nearing the end of life should be identified and offered tailored discussions and support. The national snapshot found that this is underway, with room for further improvement.

Palliative care registers have been introduced in the last 10 years. In the national snapshot, practices 'predicted' or expected 27% of all deaths and these people were included on the palliative care register. A further **15% were thought by practices to have been predictable but were not put on the register**. Practices suggested that 42% of deaths were sudden or unpredictable. This is surprising given that the National Audit Office found that only about 8% of all deaths are completely sudden.<sup>2</sup> Further work may be needed to investigate why practices believe that so many of deaths are unpredictable.

Initially palliative care registers focused predominantly on people with cancer but this is changing. The Quality and Outcomes Framework (QOF) encourages practices to include people with non-cancer diagnoses, but the national snapshot found that **there continues to be inequity in the provision of end of life care for people with non-malignant diagnoses**. Among participating practices, 71% of people on the register had cancer yet just 28% of people dying had a primary diagnosis of cancer.



**Action point: practice teams might need more help to identify and predict which people may be nearing the end of life.**

## 2. Assessing people's needs

Everyone nearing the end of life should be offered an opportunity to discuss their needs and preferences. Their wishes should be recorded in an advance care plan which informs both health and social care professionals. Part of this discussion may be about where a person wishes to be cared for in the final days of life.

**The national snapshot found that of those identified as nearing the end of life (ie on a palliative care register), 58% were offered a discussion about their preferences and 42% had an advance care plan documenting their wishes.**

It is positive that advance care planning is underway in practices, with 72% of those who had a discussion having their wishes formally documented. However, there is also room for continued development in this area. In participating practices, four out of ten of those known to be nearing the end of life were not offered a planning discussion so teams may have been unaware of their needs and wishes.

**Lack of documentation and uncertainty about what assessments and care had been provided was a common theme throughout the snapshot and a number of practices sought to improve this after taking part.**

**Action point: more work is needed to help practices increase the number of people offered Advance Care Planning discussions and documenting people's preferences.**



### 3. Planning and co-ordinating

Ensuring that there is a smooth transition between different services helps to support people nearing the end of life and their families. 74% of people on the palliative care register had a documented key worker to help co-ordinate care. This was most often the GP or district nurse.

Multidisciplinary team meetings to discuss people on the register can aid co-ordination and communication. 78% of people on the register were discussed at a team meeting in their final three months.

Whilst most practices are putting in place processes to help co-ordinate care internally and externally, there is room for development. For example, practices reported that only 46% of people on a register who died in February or March 2009 had handover information sent to out of hours teams.

### 4. Delivering quality services

The End of Life Care Strategy emphasises the importance of high quality care delivery in all settings including primary care, the community, hospitals, ambulance services, prisons, secure hospitals and hostels. The national snapshot examined service delivery from the point of view of primary care, but also collected some information about use of other hospital and community services.

Similar to the National Audit Office,<sup>2</sup> the snapshot found that people nearing the end of life had high use of community services. In addition to GP services, people on palliative care registers were likely to receive support from district nurses, GP and nurse out of hours services, and social care.

People had an average of one unplanned hospital admission and 13 days in hospital in the last six months of life.



**Action point: co-ordination within teams is improving since the introduction of the Gold Standards Framework and the Quality and Outcomes Framework, but more work is needed to develop cross boundary communication.**

## 5. Managing the final days

Supporting people in the final days is key and can have a lasting impact on bereaved families. Managing people well in the final days can also reduce the need for hospital visits and ensure resources are used most effectively.<sup>3</sup>

Prescribing medications in advance to help with common symptoms at the end of life can maximise symptom control and avoid crises, including relatives having to leave to visit a pharmacy at a crucial time. 65% of people on a palliative care register dying at home or in a care home received anticipatory prescribing.

60% of people on a care register who died at home were supported using a protocol or care pathway in their final days, such as the Liverpool Care Pathway.

**56% of those on the register had a preferred place of care recorded. Of those on the register who had a preferred place recorded, practices said 42% had died in their preferred place of care.** Preferred places of care included people's own homes, nursing homes and hospices. Almost no-one said they would prefer to die in hospital but about one third of those on a register died in hospital.

When people did not die in their preferred place of care, practices most commonly suggested this was due to:

- not being able to access palliative medicines
- the person having complex clinical problems that could not be managed in the community
- a breakdown in carer support
- the person dying in hospital before they could be discharged

**Action point: to help more people die at home, improvements are needed in 1) access to medications, including anticipatory prescribing, 2) proactive planning to improve clinical management of complex problems, 3) carer information and support, 4) hospital discharge planning and liaison**



## 6. Supporting carers

Evidence suggests that better support for carers leads to fewer admissions and more people dying in their preferred place of care.<sup>4</sup>

Many carers are well supported, but the national snapshot found that there is scope to improve the information and support given to carers whilst they are supporting their loved ones and during bereavement.

Practices reported that the carers of 69% of people on a care register were provided with tailored information. This is a high proportion and further insight into the quality and quantity of information provided may be valuable.

Practices said that for 50% of those on the palliative care register there had been some assessment of the carer's needs.

**In assessing all deaths, including sudden deaths, only 32% of families were offered bereavement support.**

Bereavement support was offered following 52% of the deaths of people on the register.



**Action point: there is much room for improvement in offering proactive support for carers whilst they are caring for their loved ones. All families should be offered bereavement support whether the death was predicted or not.**

## Quality implications

The Department of Health has outlined a series of Quality Markers for general practices and PCTs to strive towards in enhancing end of life care.<sup>10</sup>

These are not mandatory but findings from the snapshot provide a benchmark and suggest areas that may need further focus in policy and in practice.

### *Progress towards Department of Health Quality Markers (primary care section)*

| Quality marker   | Status | Snapshot  |
|--|--------|---|
| Quality marker 2.1: developing strategy and plans (not measured)                   |        |   |
| Quality marker 2.2: mechanism to assess and document                               |        |   |
| 100% of practices adopt GSF or similar approach                                    | Yellow | 92% of participating practices                          |
| % whose preferred place of care is recorded  | Yellow | 56% of those on a care register                         |
| % who die in their preferred place of care   | Red    | 42% of those on a care register                         |
| Quality marker 2.3: mechanism to assess and document carer needs                   |        |   |
| % carer's assessment / carers needs recorded                                       | Yellow | 50% on a care register; 20% all                         |
| Quality marker 2.4: use of multidisciplinary team meetings quarterly               |        |   |
| % dying discussed at a multidisciplinary team meeting in final year                | Green  | within 3 months: 78% on a care register; 29% all deaths |
| Quality marker 2.5: communication with out of hours                                |        |   |
| % on register with info given to out of hours                                      | Red    | 46% of those on a care register                         |
| Quality marker 2.6: nominating a key worker  |        |   |
| % with a key worker identified   | Green  | 74% of those on a care register                         |
| Quality marker 2.7-9: awareness and action regarding training needs (not measured) |        |   |
| Quality marker 2.10: adopting care management pathway when dying                   |        |   |
| % of those dying at home where the Liverpool Care Pathway or equivalent was used   | Yellow | 60% of those on a register who died at home             |
| Quality marker 2.11: collate information on quality of care for audit purposes     |        |   |
| % who take part in audit   | Yellow | 60% of practices invited                                |
| % who die at home  | Red    | 31% on a register; 20% overall                          |
| % who die in their preferred place of care   | Red    | 42% of those on a register                              |
| % of carers who receive bereavement support  | Red    | 32% all deaths; 52% on register                         |

Current gaps include identifying appropriate patients, recording advance care planning discussions, sharing information across boundaries, providing community services to support people's preferences to die at home, increasing planning of care in the final days and proactively supporting carers



## Reflecting on the approach

Practices and primary care trusts reflected on the value of using a structured online After Death Analysis tool (ADA) for supporting improvements in end of life care. Representatives from all 15 participating PCTs were interviewed along with a sample of 150 participating and non participating practices. A further 125 practices completed an online survey, meaning that half of all participating practices shared their views.

The evaluation found that practices and PCTs generally valued participating in the snapshot. Two thirds said it was useful and would recommend it to others. Even before the results were available, **one third of practices said they had already made a concrete change such as improving record keeping, reflecting on their practice or offering support for carers.**

The main reason that practices gave for not participating was a lack of time, competing priorities or a lack of reimbursement. There was a perception that taking part would be time consuming. However, most participating practices estimated that each record took just 10-15 minutes to complete.

The evaluation found that overall, the first ever snapshot of end of life care in primary care was a success. The snapshot provided a benchmark of how participating practices throughout England are providing end of life care and signalled areas for both celebration and further development. The snapshot also demonstrated that, with revisions, **the ADA online tool is feasible and valuable for supporting improvements in end of life care and can be used as an improvement tool.**



**Action point: taking part in the audit helped some practices start thinking and doing things differently, so the process itself is valuable as an improvement aid. Further benefits may emerge over time.**

## Recommendations

The national snapshot suggests issues for policy makers, commissioners, practitioners and researchers to consider further.



### *Recommendations for policy makers*

#### **a. Celebrate success**

The quality of end of life care may be continuing to improve. One quarter of deaths are now on a palliative care register and practices are using advance care planning, do not attempt resuscitation orders, and information for carers which may not have been the case a relatively short time ago. This is cause for celebration and promotion of the good work taking place in primary care. It is recommended that the positive findings are widely disseminated, along with tips to support commissioners and practitioners continue to put the End of Life Care Strategy into practice.

#### **b. Share widely**

The first ever national snapshot has collated a wealth of information and there is significant potential to undertake further analyses. For example, information can be broken down according to different conditions or ethnic groups. It is recommended that further analysis is undertaken and information and lessons learned are shared widely to inform the National End of Life Care Intelligence Network, to be launched in 2010. The data may also be future aligned with developments such as the end of life care locality registers and Transforming Community Services.

### **c. Build on strategic vision**

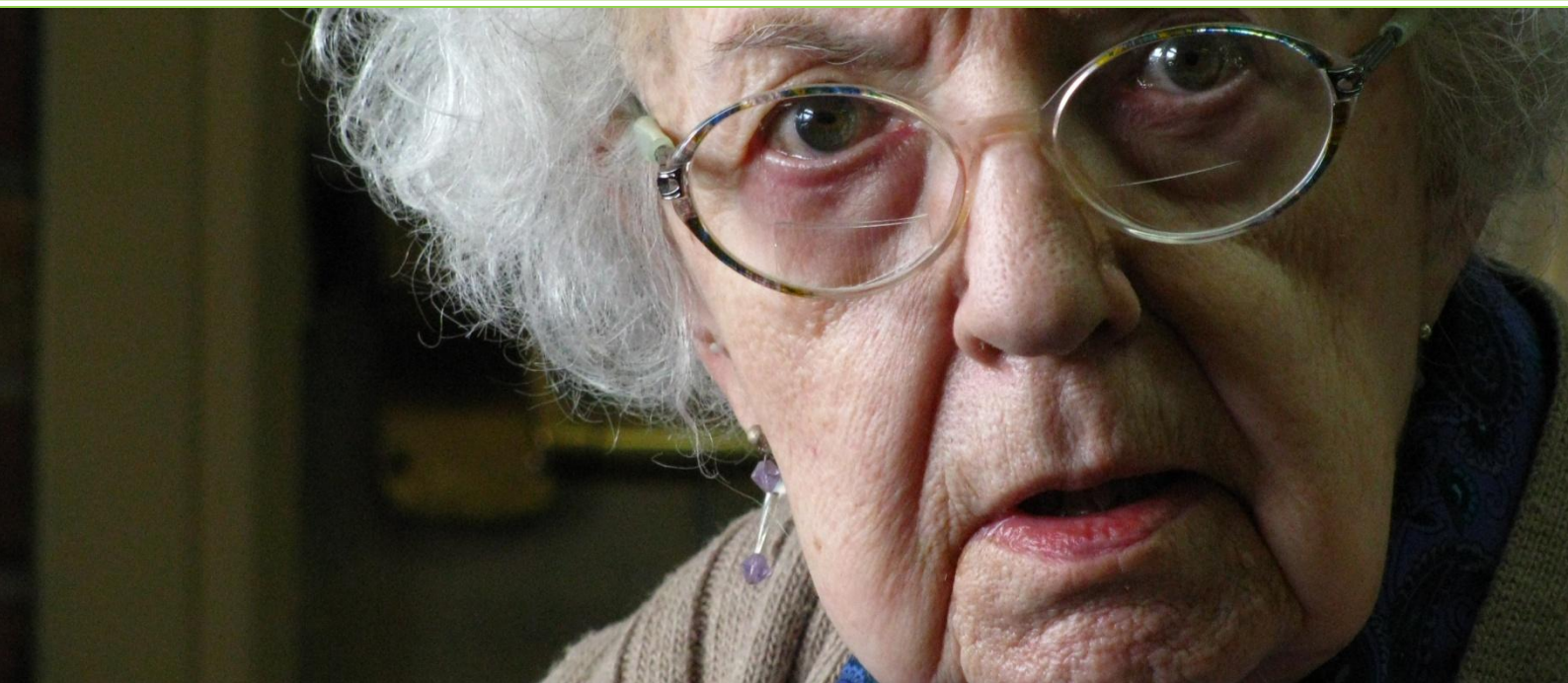
The End of Life Care Strategy provides a solid foundation on which to build practical improvements. The national snapshot illustrates some of the challenges that PCTs and practices face when seeking to implement the Strategy. It is recommended that policy makers consider how to further support implementation of the strategic vision, including:

- developing ways to help clinicians identify people near the end of life
- ensuring the availability of improved training to overcome key barriers
- developing infrastructure to support cross boundary communication and information sharing

### **d. Build on success**

The snapshot process has proven feasible and useful. It is recommended that a repeat of the snapshot is undertaken in 2011 in order to track any changes over time. The February-March timing and methodology of the snapshot could be kept consistent to allow comparisons. The snapshot could be used in a similar way to the Liverpool Care Pathway National Care of the Dying Audit, as a means to benchmark and improve primary care services over time.

The ADA tool has been named as an example of good practice in the Department of Health's quality markers, has proven its worth within the snapshot and is in demand from PCTs and practices. It is recommended that policy makers consider how the tool can be made more widely and freely available.



## *Recommendations for commissioners*

### **a. Benefit from available tools**

Best care can be cost effective care.<sup>5</sup> Supporting people to die in their preferred place of care, supporting carers and avoiding unnecessary hospital admissions can all help to reduce expensive crisis admissions. A first step is to measure and monitor changes in end of life care. The snapshot has shown that there is a feasible way to do this. It is recommended that commissioners continue measuring the quality of end of life care, including comparing before and after training, local enhanced services or other initiatives are put in place.

Taking part in the snapshot has already lead to improvements and a willingness to change in one third of practices, even before results specific to individual practices and PCTs were made available. Commissioners should consider how to use ADA further as an improvement tool.

### **b. Focus on key bottlenecks**

It is recommended that strategic health authorities and primary care trusts develop area-wide policies to reinforce best practices in end of life care. The snapshot illustrated that a low level of bereavement support is being offered by many practices, that more people could be offered advance care planning discussions, more people could have anticipatory prescribing in their last days and there is more room to apply co-ordinated pathways and protocols. Local enhanced service agreements could be used to support changes, with inbuilt audit to monitor effectiveness.

The snapshot has implications for commissioning services, such as expanding homecare support and night sitters, 24 hour district nursing teams, availability of medications out of hours, and collaboration with out of hours.

### **c. Invest in the workforce**

It is recommended that commissioners consider the training needs of practice teams to address some of the gaps identified, particularly regarding the identification of people nearing the end of life, training in advance care planning discussions and support for people and carers at all stages.

Workforce Deaneries and PCTs could consider making initiatives such as the Gold Standards Framework's 'Going for Gold' training programme or similar more widely available for practices.

### **d. Build infrastructure**

It is recommended that PCTs consider how to best incentivise practices to take part in ongoing audit and development initiatives. The snapshot found that some participating PCTs provided financial incentives to practices based on the number of records submitted, but the most effective incentives may be Local Enhanced Service agreements which reward practices for improved performance over time.

Other potential developments to infrastructure include strategies to enhance the effectiveness of localised collaboration between district nurses and practice teams, and systems and templates to support cross boundary care such as improving information sharing, 'passport information' and IT links between primary care, care homes and hospitals.

## *Recommendations for practice teams*

### **a. Spread the word**

All participating practices received a detailed report with their data, comparisons to national and regional averages and tips for development.

The large numbers of records submitted mean that practices can benefit from the findings whether or not they were directly involved. It is recommended that reports are circulated to all practices throughout the country and that those who didn't participate use the information to help understand what they could be doing at practice and commissioning level.

### **b. Address gaps**

It is recommended that all practices create an action plan to address common gaps:

- including more people on the palliative care register
- earlier identification of people who may be in the final year of life
- offering advance care planning discussions to all on the register
- improving cross boundary communication such as handover to out of hours services
- using a care pathway to support people dying at home
- actively supporting carers and signposting early to carers' courses and benefits advice
- developing an all-inclusive bereavement protocol



### **c. Consider further training**

It is recommended that practice teams consider ongoing professional development and the training needs of both individuals and the team to help support further improvements in end of life care.

Organisations such as the Gold Standards Framework Centre offer training programmes for practice teams, including dvd-based training (see [www.goldstandardsframework.nhs.uk](http://www.goldstandardsframework.nhs.uk) for further details).

Local hospices and specialist palliative care teams offer a variety of courses, often more focussed on symptom control and clinical care.

The RCGP website offers guides such as *'Supporting carers: an action guide for general practitioners and their teams.'*

### **d. Make use of information**

Practice teams have a significant role to play at the end of life, and taking small steps to identify all people who should be on the palliative care register, regardless of diagnosis, can have an important impact on patients, their families, the practice team and partner organisations.

It is recommended that participating practice teams use the individual reports provided by the national snapshot to help inform their practice development programme.

Individual members can also use the report as part of their appraisal process. The report provides good clinical governance evidence that the practice is taking part in audit.

Practice teams can use the report when discussing significant event audits of care prior to death.

## *Recommendations for development*

### **a. Consider further analysis**

The snapshot has generated a wealth of information. There is much scope for further analysis of the dataset, including delving more deeply into the care provided for people with specific conditions such as dementia or COPD, for example.

The snapshot also raises a number of questions that may need further research and exploration. It is recommended that the findings from the snapshot are used to help shape ongoing research programmes.

### **b. Refine the snapshot tool**

The initial evaluation of the snapshot tool and process has identified a number of suggestions for improvements that should be considered. It is recommended that the snapshot tool and process is refined to make it even more user friendly and quicker to implement, building on some of the suggestions from participating practices and PCTs. It may be possible to work with HQIP to strengthen the quality of future snapshots further and make the tool more widely available.

The Quality Markers were published after the snapshot data collection and aligning the ADA tool more closely with the Quality Markers will make it an even more useful tool for PCTs. Questions on the tool that have not added to the analysis could be removed.

### **c. Evaluate the snapshot's impact**

It is recommended that an evaluation of the impact of the 2009 national snapshot is undertaken, to assess the value of this process as an improvement mechanism.

Although some preliminary information was collected about any changes that practices were making as a result of participating in the snapshot, the timing of the work programme did not allow impacts to be assessed after practices and PCTs received their individual findings.

A more comprehensive assessment of the value of the snapshot would be possible if practices and PCTs were followed up in 2010, once they have had an opportunity to reflect and act on the findings.

### **d. Ensure personalised support**

Just as patients and families value personalised and tailored support, so too do PCTs and practices taking part in information sharing activities. A strength and key learning point from the national snapshot is the use of an interactive and partnership approach.

The snapshot did not have the planned administrative support and this was perhaps the weakest part of the process. Practices that received proactive calls from the helpdesk were more likely to take part in the snapshot and more likely to provide a greater number of records. This suggests that proactive support can work well to improve response rates.

It is recommended that future snapshots build on and improve upon this approach. It is recommended that a full time administrative post is available to support large national snapshots of this nature.