End of life care in primary care

Omega,
the National Association
for End of Life Care

2009 national snapshot

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

| Identify | Assess | Plan | Deliver | Manage | Support |

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.[1]

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.[2] 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.
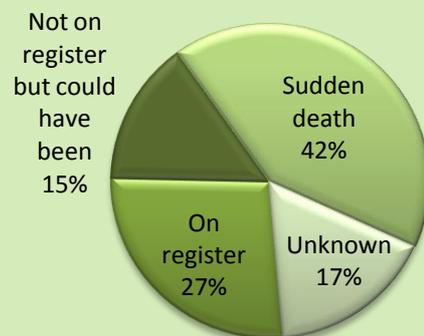
Action point: practice teams might need more help to identify and predict which people may be nearing the end of life.

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,[2] 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.[3]

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.[4]

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.[10]

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	🟧	**92%** of participating practices
% whose preferred place of care is recorded	🟧	**56%** of those on a care register
% who die in their preferred place of care	🟥	**42%** of those on a care register
Quality marker 2.3: mechanism to assess and document carer needs		
% carer's assessment / carers needs recorded	🟧	**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	🟩	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	🟥	**46%** of those on a care register
Quality marker 2.6: nominating a key worker		
% with a key worker identified	🟩	**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	🟧	**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	🟧	**60%** of practices invited
% who die at home	🟥	**31%** on a register; 20% overall
% who die in their preferred place of care	🟥	**42%** of those on a register
% of carers who receive bereavement support	🟥	**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.
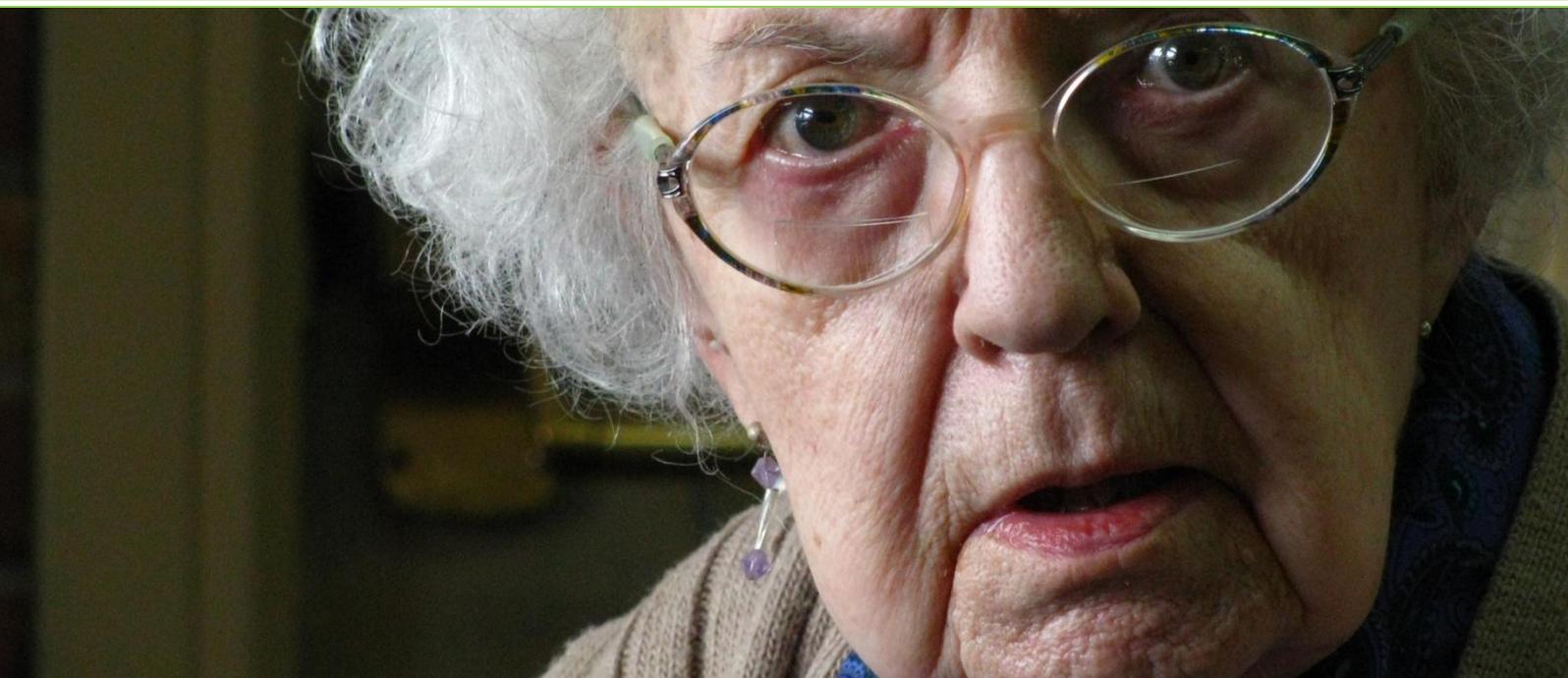
Recommendations for commissioners

a. Benefit from available tools

Best care can be cost effective care.[5] 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 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 suggesting 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.

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Acknowledgements

Context

Overview

Cultures all over the world believe that the way we care for people near the end of life demonstrates our humanity, integrity and compassion.[6]

Every year, about half a million people die in England, equating to 1% of the population.[1] The number of deaths is set to rise by about 17% over the next three years due to an aging population and greater rates of long term conditions.

'Getting it right' for people nearing the end of life is increasingly prioritised, yet as a society we tend not to discuss death and dying openly. This permeates to the care available to people in their final months and days, with professionals often feeling unsure about how to discuss and provide support to meet people's needs.[7]

"Study after study documents that medical care for the dying is poorly planned and frequently ignores the treatment preferences of the patient and family." [8]

Death and dying affects us all and improving end of life care is now a national priority. The NHS Next Stage Review[9] and national End of Life Care Strategy[1] both emphasise that supporting people nearing the end of life is just as important as promoting good health throughout life.

"The next few years are crucial for primary care if we are to ensure that we can deliver a gold standard of end of life care for all who need it – as the number of deaths increases there is a looming avalanche of need awaiting us."

Professor Keri Thomas, Clinical Lead for Gold Standards Framework Centre

The Department of Health's Quality Markers for end of life care,[10] the Gold Standards Framework[11] and similar have provided guidelines to help healthcare organisations and practitioners provide the best evidence-based care for people who are dying and their families. There is an increasing focus on the role of primary care in supporting people in the last weeks and months of life, yet current standards of care in general practice are not well known.

To understand more, Omega, the National Association for End of Life Care, conducted the first ever national snapshot of end of life care in primary care. The snapshot was co-funded by the NHS National End of Life Care Programme and selected primary care trusts throughout England.

The national snapshot had two key objectives:

1. **To provide a national overview of the quality of end of life care in primary care**

   This is the first ever 'snapshot' of end of life indicators in primary care, including place of death, support provided to carers, and use of registers and team meetings.

2. **To evaluate feasibility**

   An online version of the Gold Standards Framework's After Death Analysis (ADA) tool was used to collect information. The snapshot examined whether ADA is a useful tool for assessing and improving the quality of end of life care.

"The Department of Health estimates that the overall annual cost of end of life care to NHS and social care services is measured in billions of pounds."

National Audit Office

Approach

The methods for the national snapshot were designed to be manageable and feasible. Participation was completely voluntary and the snapshot was not designed to be representative of all practices or all deaths in England. Instead the aim was to understand trends in the quality of care available by focusing on all deaths, for all practices within the selected areas during a two month time period.

Developing the tool

The After Death Analysis (ADA) tool was first developed in 2004 to assess care delivered against the key tasks of the Gold Standards Framework (GSF) and the levels of GSF adoption by practice teams. It was refined following evaluation, modified for different settings and developed into an online audit tool in partnership with the University of Birmingham.

Following extensive use and evaluation in different settings, ADA was declared fit for purpose as an audit tool for end of life care and was recommended in the Department of Health's Quality Markers and endorsed by the Royal College of General Practitioners.

In 2008 Omega, the National Association for End of Life Care redeveloped the ADA tool into a user friendly online interface, especially for use in the national snapshot. The redevelopment took place after consultation with clinicians and commissioners using the tool and researchers and evaluators who had assessed it. Questions were added to reflect key principles from the End of Life Care Strategy and the tool was pilot tested among a small number of clinicians. Further details about the development process are included in the 'Reflections' section of the report.

Figure 1: example of the ADA online tool format
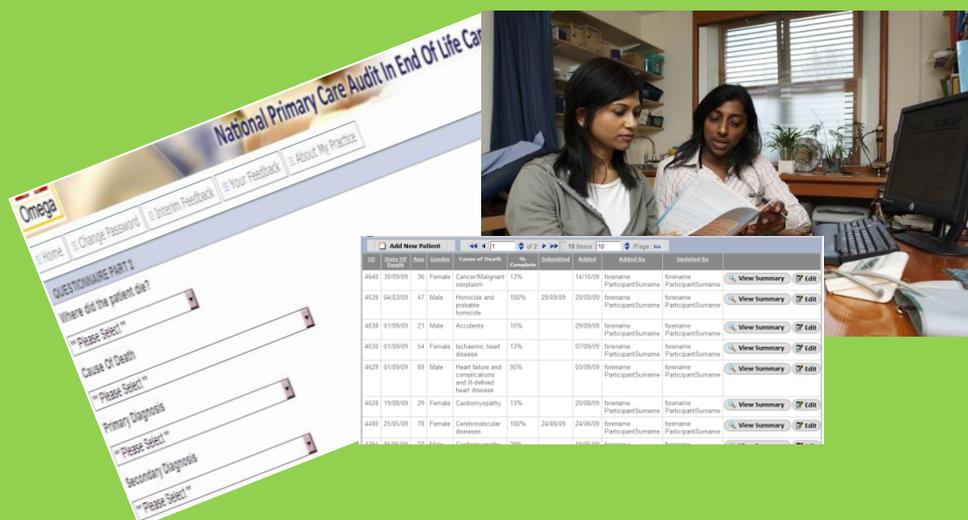
Inviting practices to participate

Primary care trusts (PCTs) were invited to volunteer all practices in their area to participate. When a PCT area was selected to take part, every practice from within that PCT area automatically became part of the national snapshot process and was registered on the online ADA system and invited to participate.

There was an excellent take up of the invitation to participate. Of the 874 practices invited to take part, 502 agreed (57%).

This is almost double the target of 30% set by the Omega team.

In selecting PCT areas to participate, it was hoped that there would be a good geographic spread. Fifteen PCTs spread across nine out of the ten SHA regions chose to take part (see Table 1). The North East is the only SHA area not represented.

About six out of ten practices in these areas chose to participate overall, but this varied widely between PCT areas. In some areas almost all practices participated (see Table 1). The snapshot did not aim to make comparisons between areas and the differing participation rates increase the need for cautious interpretation.

Figure 2: approximate areas included in the national snapshot
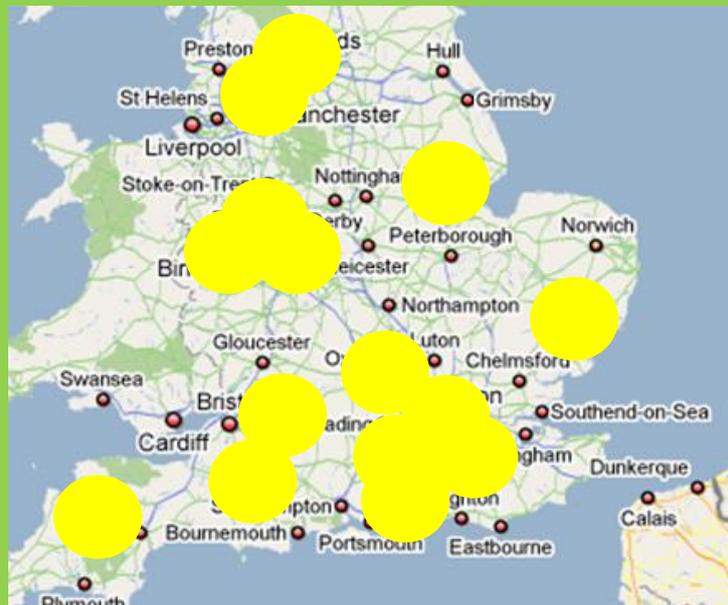
Collecting feedback

Using unique and secure log in details, practices from all 15 of the invited PCT areas were encouraged to submit data online for every death occurring in their practice population during February and March 2009. Data could be submitted retrospectively up until August 2009 and covered all deaths, including sudden deaths. No personal identifying data were requested.

Practices were not reimbursed by Omega but some individual PCTs chose to provide incentives. For example, one area made participation in the snapshot and an annual follow up part of a Local Enhanced Service agreement. Another reimbursed practices for each record submitted and another offered administrative support to input records.

A mix of people provided records, but GPs were heavily involved (see Figure 3).

Figure 3: proportion of records contributed to by various personnel
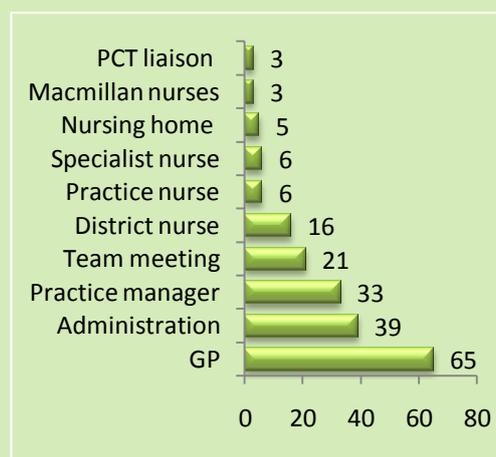
Note: more than one role could contribute to each record

It is important to bear in mind potential caveats with the data. Practices could have been selective about which records were provided and could have reported on their care in a positive light. With all snapshots of this nature the validity of the data is not perfect, but provides a good starting point to examine trends.

Table 1: Number of practices and records included

SHA area	PCT	Invited practices	Participating practices	Proportion participating	Records submitted
East Midlands	Lincoln	102	71	70%	868
East of England	Suffolk	68	36	53%	370
London	Sutton and Merton	54	31	57%	168
	Wandsworth	54	35	65%	163
North West	Salford	54	28	52%	200
South Central	Milton Keynes Health	26	13	50%	117
South East Coast	Surrey	36	26	72%	204
	West Sussex	94	37	39%	403
South West	Bath and NE Somerset	26	21	81%	214
	Bournemouth and Poole	44	29	66%	346
	Devon	108	55	51%	543
West Midlands	Heart of Birmingham	74	13	18%	48
	Solihull	31	30	97%	237
	Walsall	63	44	70%	233
Yorkshire/Humber	Wakefield	40	33	83%	373
Total		874	502	57%	4487

'Proportion participating' shows the proportion of all invited practices that submitted records

Analysing data

Originally, the Omega team hoped to include information about care for 1000 people. The final numbers far exceeded this, four times over, with 4487 records available. 57% of practices that were invited chose to take part (502 out of 874). Information about the total number of deaths in participating areas is not available but based on information provided by PCTs and national averages it is estimated that about half of all deaths in participating areas were included in the snapshot.

All data from the national snapshot was collated using *SPSS, the Statistical Package for the Social Sciences*. Each practice received an individual report and PCTs received a report of key trends for their local area.

Any differences between groups described in the report are statistically significant at the 95% level of confidence ($p < 0.05$ throughout).

Evaluating feasibility

Alongside collecting data for the national snapshot, an evaluation of the process took place. All feedback submitted to the Omega team was recorded and all PCTs and practices were invited to take part in surveys and telephone interviews.

Every PCT was telephoned to gain feedback about taking part and all participating practices were invited to complete an online survey. In addition, a random sample of 150 practices were telephoned to provide more detailed qualitative feedback. Practices that chose not to participate as well as those that did take part were contacted. The aim was to examine the extent to which practices felt empowered to make improvements as well as the ease of use of the ADA online tool. Overall, feedback was received from half of participating practices. The 'Reflections' section of this report describes key trends in this feedback.

"Measurement of end of life provision is a key lever for change and is essential if we are to monitor progress."

End of Life Care Strategy

Characteristics

52% of the 4487 records in the snapshot were for women who died between February and March 2009, 81% were White and the age at death ranged from 0 to 106 years (average 79 years). This is likely to broadly represent the demographics of people dying in February and March 2009 throughout England, though the snapshot did not aim to be representative.

51% of people died in hospital. Further information about the place of death and preferred place of care is provided overleaf.

The most commonly recorded causes of death were cancer, infection and unknown causes. Even so, only 23% were recorded as dying from cancer related complications. This is important because it demonstrates that the national snapshot includes a wide range of both cancer and non cancer related deaths.

Table 2 lists people's primary diagnosis, which was collected in addition to people's cause of death.

Table 2: primary diagnosis

Diagnoses	% overall	% on register	% sudden
Lung cancer	6	16	2
Upper GI cancer	4	11	2
Colorectal cancer	3	9	1
Breast cancer	2	6	1
Haematological	2	4	1
Prostate cancer	2	5	1
Gynaecological	1	3	<1
All other cancer	6	17	2
Total cancer	**26**	**71**	**10**
Heart failure	10	4	14
COPD / respiratory	7	4	10
Frailty or 'old age'	7	5	6
Stroke	6	2	8
Dementia	5	3	4
End stage renal	2	2	2
Multiple morbidity	2	1	3
Parkinson's	1	1	1
Other neurological	1	1	1
Other diagnosis	15	2	24
No diagnosis	3	<1	7
Not known	15	3	10
Total non cancer	**74**	**29**	**90**

Quality of end of life care

Identification

The Department of Health's End of Life Care Strategy encourages all health and social care services to provide high quality care in the final year of life using a pathway approach. Core components of the pathway include:[1]

Identify	• identifying and including the right people on the practice's palliative care register
Assess	• assessing and communicating so we know people's wishes and preferences
Plan	• planning and co-ordinating care
Deliver	• offering high quality services
Manage	• managing the final days sensitively and appropriately
Support	• supporting people at the end of life and their families and carers

The following sections examine how practices that participated in the national snapshot are addressing each element of the pathway.

The first step in providing high quality end of life care is to identify people who may be in the last 6-12 months of life. The Quality and Outcomes Framework (QOF) and the Gold Standards Framework both encourage practices to create a palliative care register and 99.8% of practices now claim QOF points for having a register. This is positive because people added to a register often receive more proactive care planning and support and have better outcomes. However it can be difficult for practice teams to identify everyone nearing the end of life at the best time to optimise their care.

The ADA tool helps practices examine the proportion of deaths on a palliative care register, the ratio of cancer to non-cancer deaths included on the register, the proportion of sudden deaths and anyone whose death could have been predicted and thus should have been on the register.

The snapshot found that 27% of people dying in February and March 2009 from participating practices were on the palliative care register, alerting the team that the time had come to consider end of life care needs (see Figure 4).

High quality end of life care is recommended for everyone, regardless of diagnosis. From 2008-9 this has been reflected in QOF, whereby people in the final year of life of all ages and with all end stage conditions are to be listed on the palliative care register.

Traditionally, people with cancer have been over-represented on palliative care registers, even though more and more people are dying of frailty and co-morbidity. People with non-cancer illnesses have needs that are equal to, if not greater than, those with cancer. People included on palliative care registers generally receive more coordinated and better quality end of life care. If people without cancer are not routinely included, this means some of those most in need may be receiving suboptimal levels of care.

The snapshot found that 71% of those on a register had a primary diagnosis of cancer, suggesting that there is further work to do to help primary care teams identify and support those nearing the end of life without cancer diagnoses. There were regional variations (see Figure 5).

Figure 4: proportion of sudden versus predicted deaths

Unknown 17%

On palliative care register 27%

Sudden death 42%

Not on register but predictable 15%
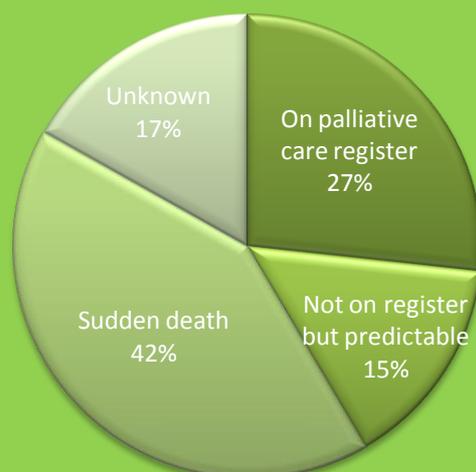
Figure 5: average proportion of people with and without cancer on register

Region	primary diagnosis cancer	all other primary diagnoses
Yorkshire	82	18
West Midlands	70	30
South West	69	31
South East Coast	61	39
South Central	75	25
North West	75	25
East Midlands	76	24
London	69	31
East of England	73	27
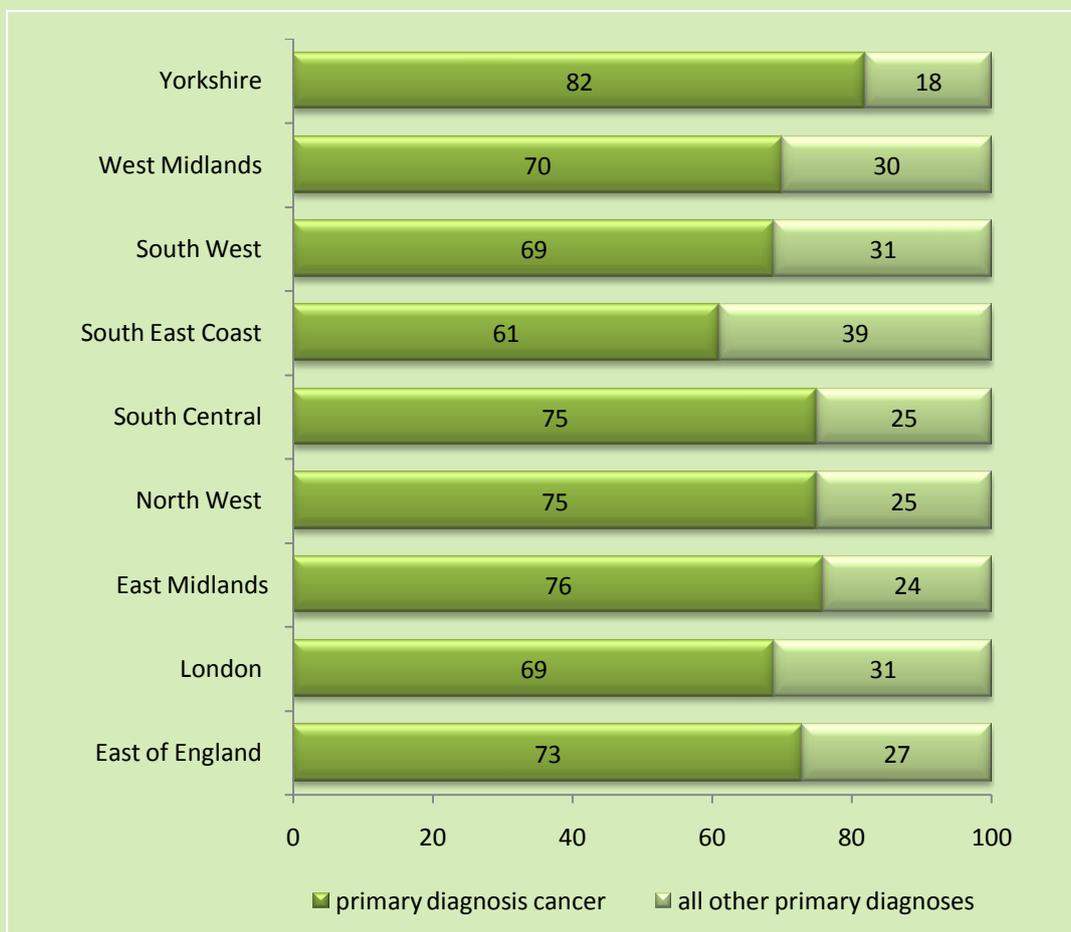
Note: areas that have a greater proportion of non cancer diagnoses on the register may be attempting to provide more inclusive end of life care

There was wide variation in exactly when people had been added to the register. Practices most commonly reported that people were added one to six months prior to death (see Figure 6). It is positive that 27% were placed on the register more than six months before death.

Figure 6: timeframe when people on the register were added
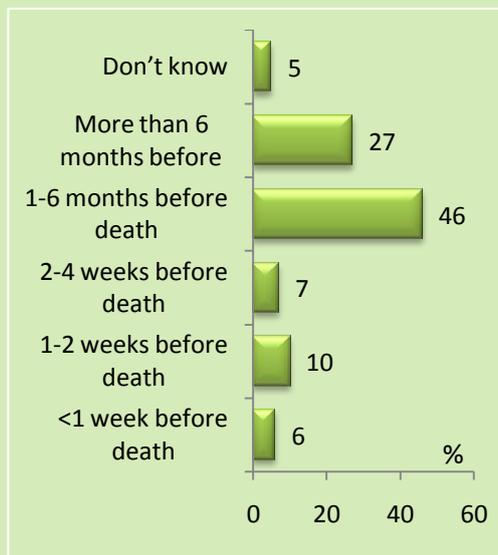
There is most potential for improving care when a person could have been recognised as being in the last year of life but wasn't. Practices thought that about four out of ten deaths in the national snapshot were sudden or unpredictable, but research from the National Audit Office suggests only around 8% of deaths are totally sudden or unpredictable.[2]

It appears that many more people could be on the palliative care register than currently and practices might need more information and support to identify these people.

The ADA tool helps practice teams reflect on whether they might have been able to predict the deaths of people who were not on a register weeks or months in advance.

On reflection, practices thought that 661 people had deaths that could have been predicted weeks, months or even a year in advance of their death, but these people were not placed on a palliative care register to receive supportive end of life care. This means that **15% of all of the people in the national snapshot may have missed out on components of end of life care even though their deaths were predictable.**

Practices said that 1% of all deaths could have been predicted a year before death, 3% months before death, 5% weeks before death and 5% within a week of death. Whilst these proportions are small in the context of all deaths, they add up to 15% of all of the people who died in the participating areas potentially missing out on supportive end of life care because they were not identified.

There were some differences between geographic regions. The proportion of 'predictable but not on a register' deaths ranged from 9% in the South Central region through to 18% in practices in Yorkshire and the Humber (see Figure 7).

A key message is that practice teams may find it difficult to identify people early enough to be able to provide proactive end of life care. As well as the 'predictable but not on a register' deaths, 42% of all deaths were thought to be sudden or unpredictable. The top three causes of unpredictable deaths were influenza or infection (20% of all sudden deaths), heart disease (12%), and unlisted or unknown causes (32%).

It may be that some of these deaths were predictable but teams lacked a proactive approach in identifying patients early enough. There may have been other reasons for this though, such as it was quicker to complete the ADA tool for sudden deaths.

Figure 7: breakdown of deaths not on a register

Legend: Could have been predicted | Sudden death | Unknown

Region	Could have been predicted	Sudden death	Unknown
Yorkshire	24	64	12
West Midlands	16	70	14
South West	26	60	14
South East Coast	27	63	10
South Central	14	76	9
North West	24	68	8
East Midlands	21	64	15
London	22	70	7
East of England	21	56	23
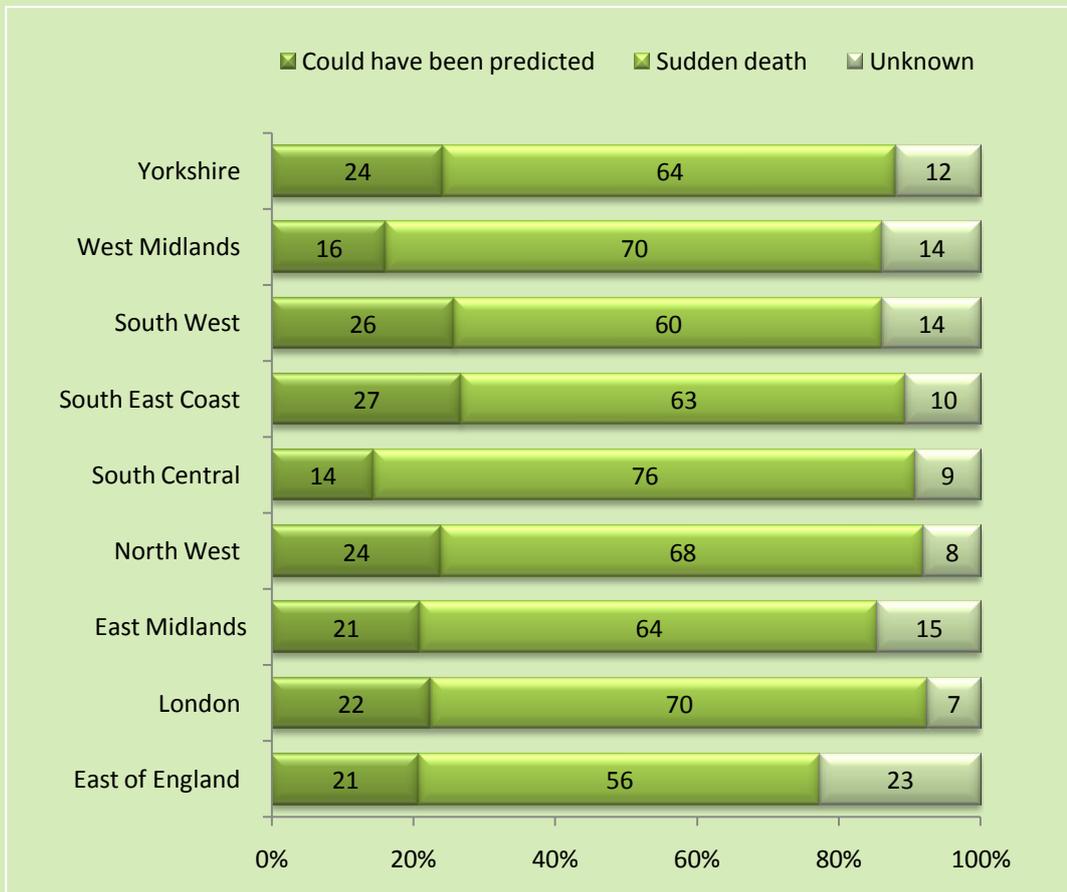
Note: differences referred to throughout the report are statistically significant (p<0.05)

Key theme: identifying people towards the end of life is essential. It is positive that one quarter of people who died were identified in advance, but the snapshot raises questions about the care received by the other three quarters.

Assessing needs

In addition to creating clinical care plans which consider people's medical needs, it is vital to give people an opportunity to have open discussions about their care and preferences near the end of life. It is equally important to respect that not everyone wishes to discuss their preferences. These conversations must be handled with sensitivity. Sometimes practice teams fear a negative reaction, but such discussions can often help patients come to terms with things and enable them to live out their final stage of life felling better prepared.

Talking with people about their preferences at the end of life is known as 'advance care planning.' This is equally important to clinical care planning because it increases patient choice and may help families feel better prepared.[12] An advance care plan is a written statement which does not have formal legal power. It is not the same as an advance directive but it helps when considering a person's wishes.

The ADA tool did not focus on clinical care planning for assessing people's medical needs, but the national snapshot did ask practices to provide feedback about the extent to which they are offering advance care planning to people nearing the end of life.

20% of all people who died during February and March 2009 from participating practices were offered an advance care planning discussion. This figure is low but may be lower in reality as the term 'advance care planning' is often poorly understood.

People who died suddenly would not be expected to take part in care planning discussions. Focusing on people who primary care teams knew were nearing the end of life (ie those on a palliative care register), 58% were offered an advance care planning discussion and 43% had their wishes and preferences recorded in an advance care planning document (see Figure 8).

"All people approaching the end of life need to have their needs assessed, their wishes and preferences discussed and an agreed set of actions reflecting the choices they make about their care recorded."

End of Life Care Strategy 2008

If the term 'advance care planning' is being interpreted consistently by practices this suggests that practices generally recognise the importance of exploring people's needs and preferences and are making efforts to have such discussions among those they have identified as nearing the end of life.

However, there is room for improvement. According to the national snapshot, **42% of people known to be approaching the end of life were not offered a discussion to help plan how they wanted to die**.

There is also a discrepancy between the proportion of those offered discussions and those where a formal record of the advance care plan is kept and distributed to all members of the team, hospital, out of hours service and so on (58% had discussions versus 43% with documented advance care plans). Figure 9 illustrates regional variations.

Furthermore, a significant proportion of practices said they did not know whether people were offered advance care planning discussions. 18% said they did not know if these discussions were held or and 23% did not know if the discussions were documented.

It is also important to note that 15% of deaths were thought to be predictable but not on care registers. These people were not offered advance care planning discussions.

Overall, the national snapshot found that care planning is underway, but that more focus is needed to ensure that all those identified as nearing the end of life are offered discussions about their preferences and have their wishes documented.

Figure 8: proportion on register offered a care planning discussion and with their preferences documented

Offered discussion

Recorded advanced care plan
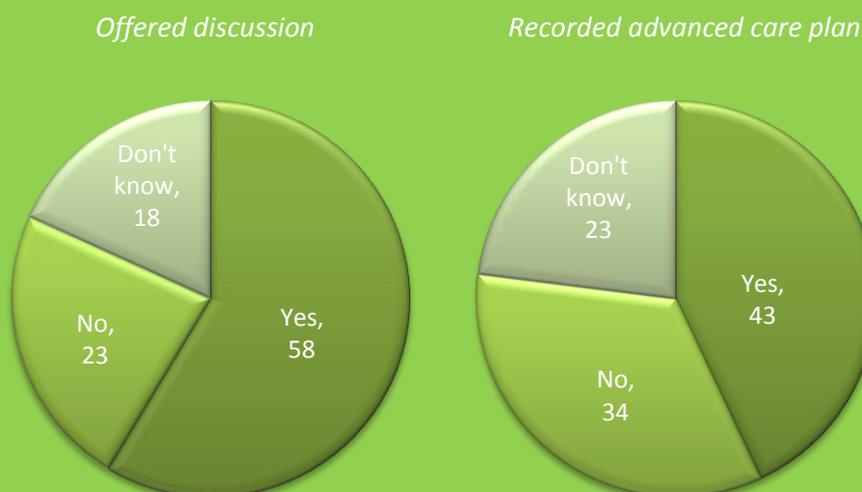
Figure 9: proportion on register offered a discussion and with a care plan

Region	% with documented care plan	% offered care planning discussion
Yorkshire	45	55
West Midlands	49	63
South West	39	56
South East Coast	53	67
South Central	27	49
North West	35	53
East Midlands	45	57
London	37	59
East of England	42	59
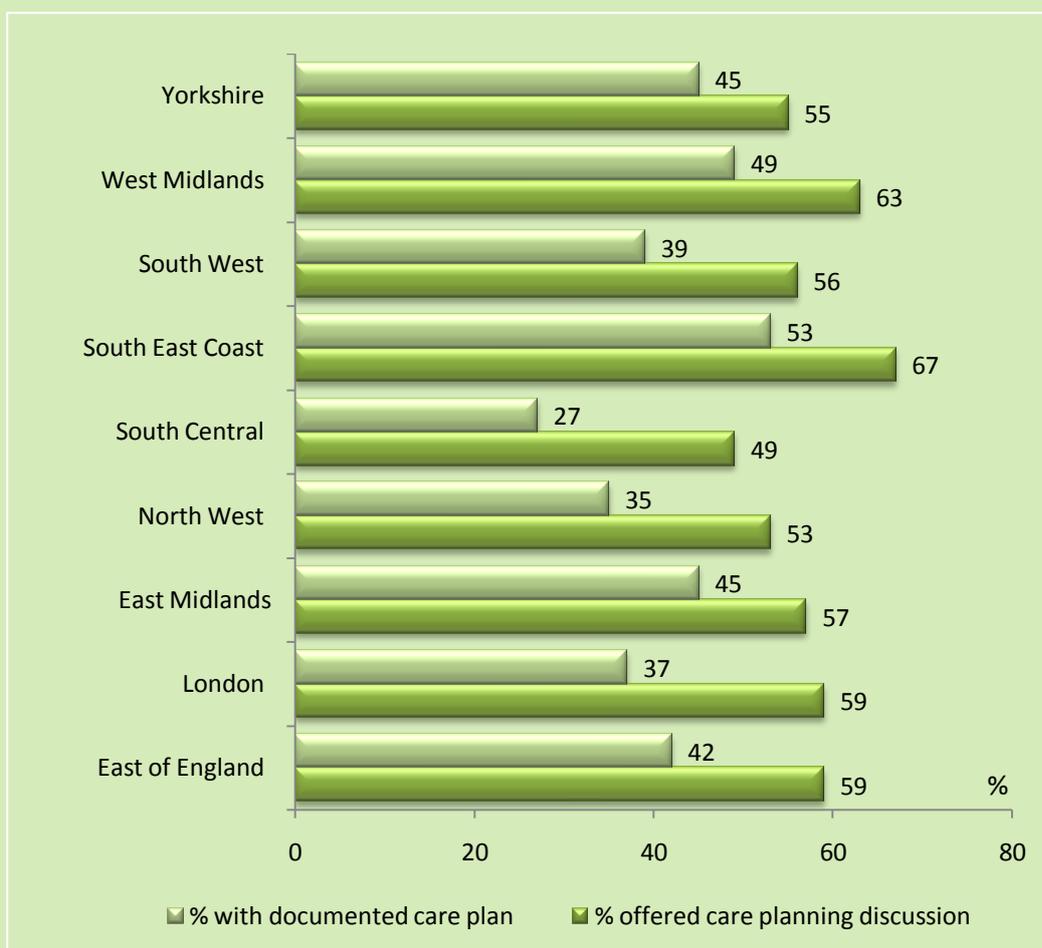
Note: there is no statistically significant difference between regions in whether a discussion took place ($p = 0.09$) but the difference in care plans is significant ($p < 0.05$)

Key theme: it is positive that practices are discussing preferences with six out of ten people on the register, but people's wishes are not always documented after discussions. About four out of ten people aren't having an opportunity to discuss their wishes.

Plan and co-ordinate

PLAN

The End of Life Care Strategy recommends that health communities should develop coordinated end of life care across sectors and at all times of the day and night. The national snapshot examined care from a primary care perspective rather than strategies across the entire care continuum. However practices did provide information about how they sought to enhance co-ordination amongst the practice team and with other close partners.

Team meetings

Planning and co-ordinating care is key to supporting people at the end of life. One approach is the Gold Standards Framework, whose basic principles are now recommended in QOF. 92% of practices that participated said they were applying some of the principles of the Gold Standards Framework generally.

Both GSF and QOF emphasise the importance of multidisciplinary team meetings. Most practices have a regular multidisciplinary team meeting to discuss people nearing the end of life. The aim is to discuss people's needs and ensure that all aspects of care are considered. At a minimum, multidisciplinary meetings should involve GPs, district nurses, palliative care community nurse specialists if available, and a member of the reception or administration staff.

> "The role of the GP is not as important as that of the team – working together towards the same goal: the district nurse puts the heart into professional caring, the receptionists often get to know the carers well, the administrator ensures all aspects of care are covered at the multidisciplinary team meeting. Everyone has a part to play."

Dr Helen Bowden, GP and Assistant Clinical Lead, National GSF Centre

29% of all patients and **78% of those on the register were discussed at a multidisciplinary team meeting at least once in their final three months of life**.

Almost all practices said they held multidisciplinary team meetings to discuss end of life care every 1-3 months. Holding multidisciplinary palliative care team meetings at least every three months is a Quality and Outcomes Framework target. Many practices find that three-monthly meetings are not frequent enough as patients' needs can change rapidly. For this reason monthly meetings are recommended.

Planning care

The End of Life Care Strategy recommends that practices take a systematic approach to end of life care. This includes putting a system in place to ensure that all aspects of care are considered for each person on the register. There is a national target date for everyone with a long term condition to have a formal care plan. This is linked to people's diagnoses and will develop into and end of life care plan when they are in their final months or years. Some people will bypass the long term condition phase and need an end of life care plan more promptly. The ADA tool did **not** ask about formal care plans.

However, one step towards the end of life care plan may involve ensuring there is a clear record of whether the patient has had an opportunity to discuss end of life issues, their preferences, and whether out of hours services have information about their condition.

It can be helpful to use a checklist or computer template to ensure that all aspects of care are considered, including all the things that the practice needs to consider when communicating with and supporting the person and their family.

Practices said that for 32% of all deaths a record was made to ensure that the practice team considered all aspects of care. 16% said no such record was made and in 52% of cases, it was unknown whether a care record was made.

It may be most appropriate to focus on those on the palliative care register when considering consistency of care, because these people were explicitly identified as nearing the end of life. **Thinking only about those on a palliative care register, practices said that 80% had documentation that all aspects of care were considered.**

Reflecting on quality of care

Reflecting on challenges and successes as a practice is an important part of improving care. It's also one of the recommendations from the Department of Health's Quality Markers and the Gold Standards Framework for Primary Care.

The primary care team discussed the patient's care following death in 29% of all cases, for example at a reflective practice session or during a significant event analysis. Among those on a palliative care register, this increased to 50% of all deaths (see Figure 10).

Taking part in the national ADA snapshot helped practices reflect on the care they provide. Other types of ongoing reflection are possible too. Significant event audit (SEA) can be used for any death, both to consider the good things that happened and any areas for improvement. A modified significant event audit is incorporated into the ADA tool.

*Figure 10: people on register where death was reflected on by team (%)*

Key workers

The Department of Health's End of Life Care Strategy suggests that that one approach to effective care coordination would be to establish a single point of contact through which services could be coordinated. The Quality Markers refer to a primary care key worker responsible for co-ordinating care, keeping patients and their families engaged and sharing information throughout the team.

The national snapshot found that 30% of all deaths had a key worker documented to help co-ordinate care. This proportion grew to 74% among those on a palliative care register. Key workers included (in order of frequency):

- GPs
- District / community nurses
- Specialist palliative care nurses
- Community matrons
- Care home nurses
- Social workers

Figure 11: proportion on register with a key worker

Region	%
Yorkshire	78
West Midlands	79
South West	74
South East Coast	82
South Central	76
North West	67
East Midlands	70
London	77
East of England	55
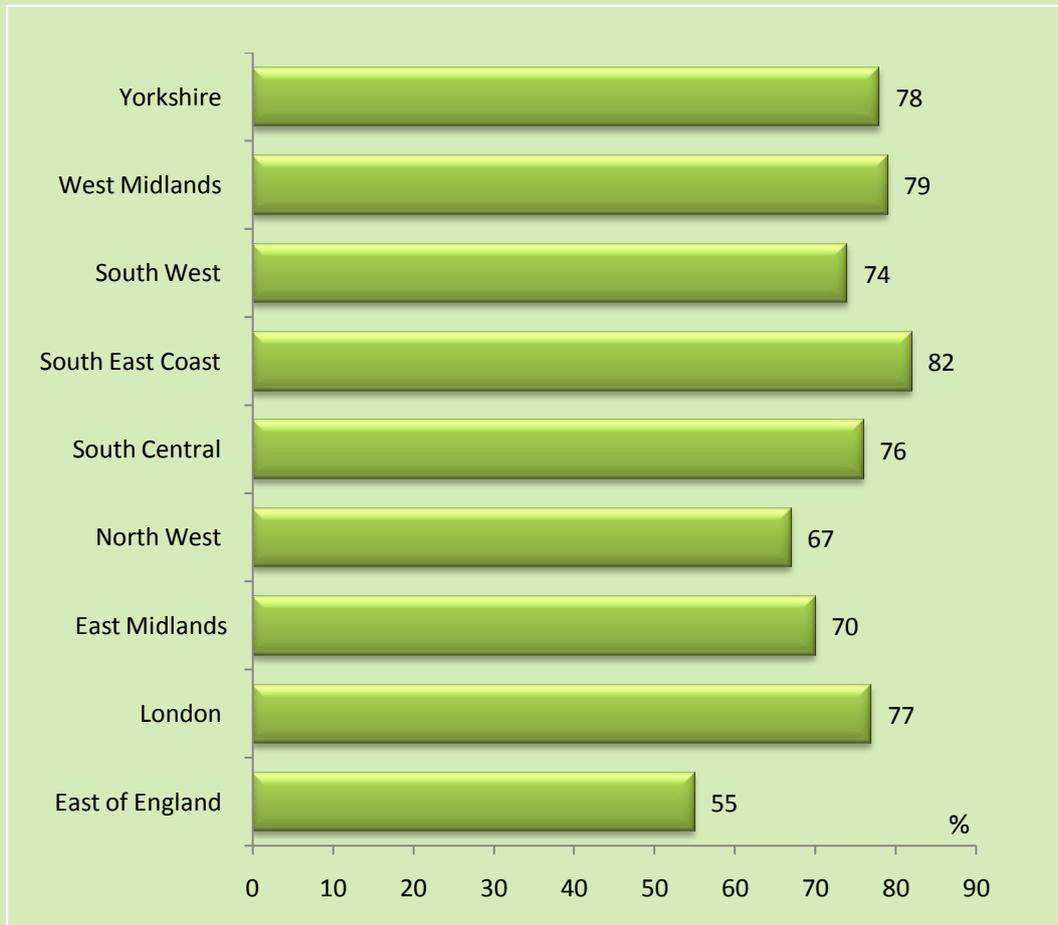
Note: differences between regions are statistically significant ($p < 0.05$)

Out of hours

Sharing information is important to ensure a smooth transition between services. Out of hours services are sometimes overlooked but there are three reasons for sharing information with out of hours services. Firstly, people are often concerned about using out of hours services as the doctors or nurses may not have any information about their condition. Secondly, out of hours services could prioritise those nearing the end of life if they had information about them. Thirdly, doctors working for out of hours services find it difficult to support patients without good information and may refer people to hospital inappropriately due to lack of information.

A simple paper or electronic handover sheet can help share information and is already part of QOF.

Practices reported that only 46% of people on a care register who died in February or March 2009 had handover information sent to out of hours teams. In 35% of cases handover communications were not sent and the rest were uncertain (19%). Figure 12 illustrates regional differences.

This is an area in need of further development. Having triggers that prompt practice teams to share information can work well. For example, information can be sent to out of hours services whenever someone is first put on the palliative care register, when they start declining week by week rather than month by month and when any part of their care plan alters, such as beginning syringe drivers. This way, the majority of people's information will have been shared by the last weeks of life, when unforeseen problems are most likely to occur.

Figure 12: proportion on register with information shared with out of hours
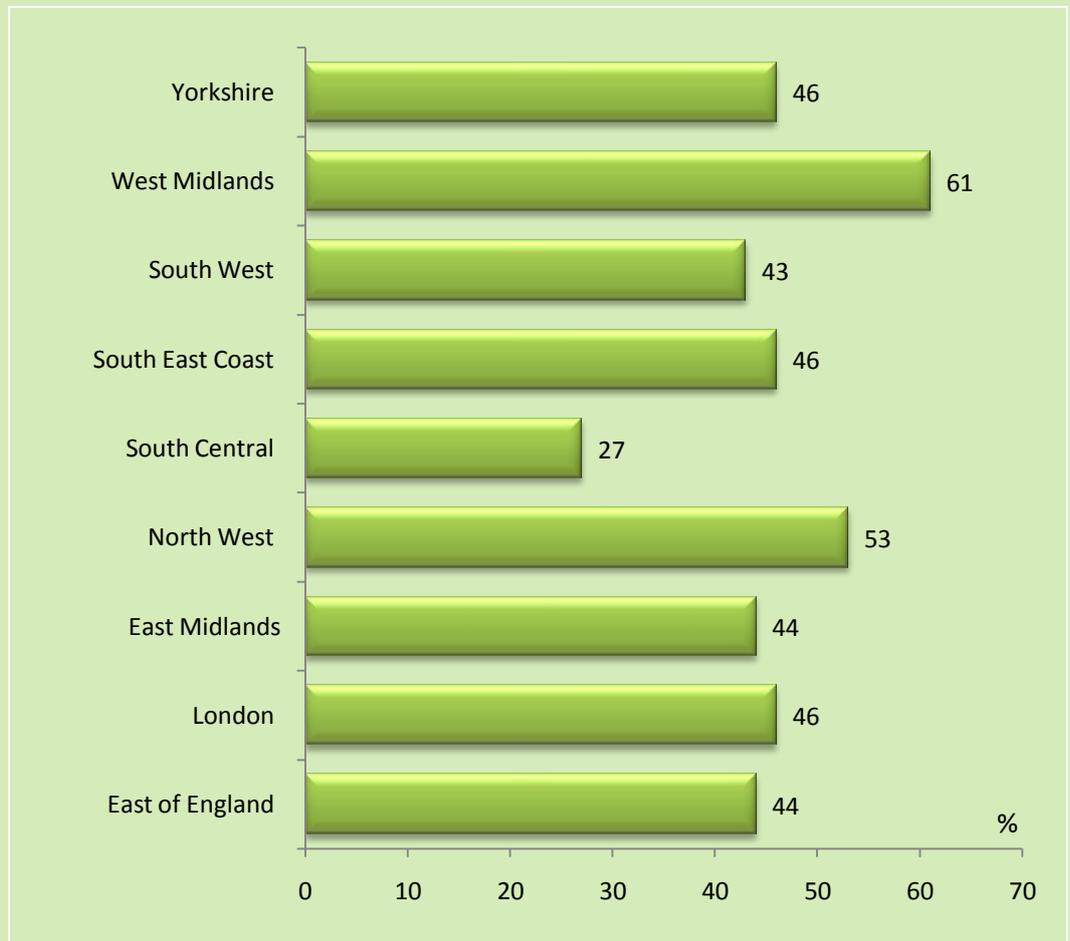
Note: differences between regions are statistically significant (p < 0.05)

'Passport information'

Patient held information can help cross boundary working, such as out of hours, when social or healthcare staff visit or when going to appointments. This 'passport information' can be given in different ways.

The snapshot found that a nursing plan, patient held record or home pack was used for 61% of people on a palliative care register. In 17% of cases, practices said that a nurse care plan or patient held record was not used and 23% did not know.

12% of those not on a register also had a nurse care plan, patient held record or home pack.

Resuscitation

The national snapshot also examined the extent to which people had signed DNAR (do not attempt resuscitation) forms in the community. Of the 1196 people on a palliative care register, 20% had a DNAR form in the community; 47% did not and practices were uncertain about the rest. 3% of those not on a register also had a DNAR form in the community.

A recurring theme throughout all of the topics about co-ordination was that practices were uncertain of what care and processes were used for individuals. This suggests scope for improved record keeping in line with the recommendations of the End of Life Care Strategy and Quality Markers.

Key theme: the national snapshot found that participating practices were using processes to support co-ordinated care amongst internal teams and partners, though there is room for ongoing development especially regarding out of hours care.

Deliver quality

DELIVER

Community services

The End of Life Care Strategy emphasises the importance of providing high quality services in all locations, including primary care, the community, care homes, sheltered and extra care housing, hospices, hospitals and ambulance services. The national snapshot looked at care from a primary care perspective, but also explored some of the hospital and community services that people used during their final six months of life.

Table 3 illustrates the proportion of people who used various community services. Those on a palliative care register were much more likely to use most services. Local variation in use was identified.

Table 3: service use in final six months

Service	% on register	% non register	% all deaths
GP	98	45	60
District nurse	76	21	36
Out of hours GP	63	21	33
Community specialist palliative care	60	2	18
Night / out of hours nurse	37	5	14
Social services	26	9	14
Allied health professional	25	10	14
Hospice inpatient	23	1	7
Hospice at home	18	1	6
Community matron	17	3	7
Marie Curie service	17	0	5
Intermediate care	11	3	5
Hospice day therapy	10	0	3
Rapid response	6	1	2

"A lack of prompt access to services in the community leads to people approaching the end of their life being unnecessarily admitted to hospital. The absence of 24 hour response services and timely access to advice and medication leads to unplanned admissions."

National Audit Office

Hospital services

A core principle of providing high quality end of life care is to support people to receive care where they choose and to avoid unnecessary hospital admissions. The national snapshot collected benchmarking information about the number of unplanned crisis admissions and the number of days spent in hospital in the final six months of life. The aim is to allow any trends or changes to be examined if the snapshot is repeated in future and to allow comparisons with other research, such as that from the National Audit Office.[2]

For the 4487 people in the national snapshot, the average number of emergency admissions in the final six months was 1 and the average number of days in hospital was 13. These averages were the same for people on a palliative care register and all deaths (see Table 4).

There was a trend towards fewer emergency bed days among practices using a system for improving end of life care, such as the Gold Standards Framework. Whilst 92% of practices said they applied GSF principles in their work, 78% had been formally registered – though the GSF Centre is now no longer using a registration system. These 'GSF practices' had an average of 13 emergency bed days over the final six months whereas non GSF practices had an average of 16 days. The number of responses was too small to be statistically significant.

Table 4: hospital use in final six months

Unplanned admissions	On register	Not on register	All deaths
Average admissions and range	1 0-23	1 0-81	1 0-81
Av and range bed days	13 0-130	13 0-184	13 0-184

Key theme: the national snapshot found an average of 1 unplanned admission to hospital within people's final six months, with an average stay of 13 days.

Manage final days

Supporting people in their final days is crucial and can significantly impact on the emotional and physical wellbeing of both the dying person and their family.

Patients and relatives often appreciate being told, sensitively, if the end is near. Diagnosis of the dying phase is therefore important. The Liverpool Care Pathway or a local integrated care pathway for the final days of life can provide a useful structure for managing care at this time.

The national snapshot examined the extent to which practices were implementing a care pathway or protocol within the final days and whether people were supported to die in their preferred place of care.

Using protocols

The End of Life Care Strategy supports adopting a tool such as the Liverpool Care Pathway for use in hospital or at home. The snapshot found that 49% of those on a palliative care register were supported using a structured protocol or pathway (see Figure 13).

**Of those on a palliative care register who died at home, 60% were cared for using a protocol or care pathway.**

Prescribing medications in advance to help with common symptoms can maximise symptom control and avoid crises, including relatives having to leave to visit a pharmacy at a crucial time. 47% of those on a register had anticipatory drugs prescribed.

Figure 13: proportion on register using protocol for final days

Figure 14: proportion where a pathway was used for those on register dying at home
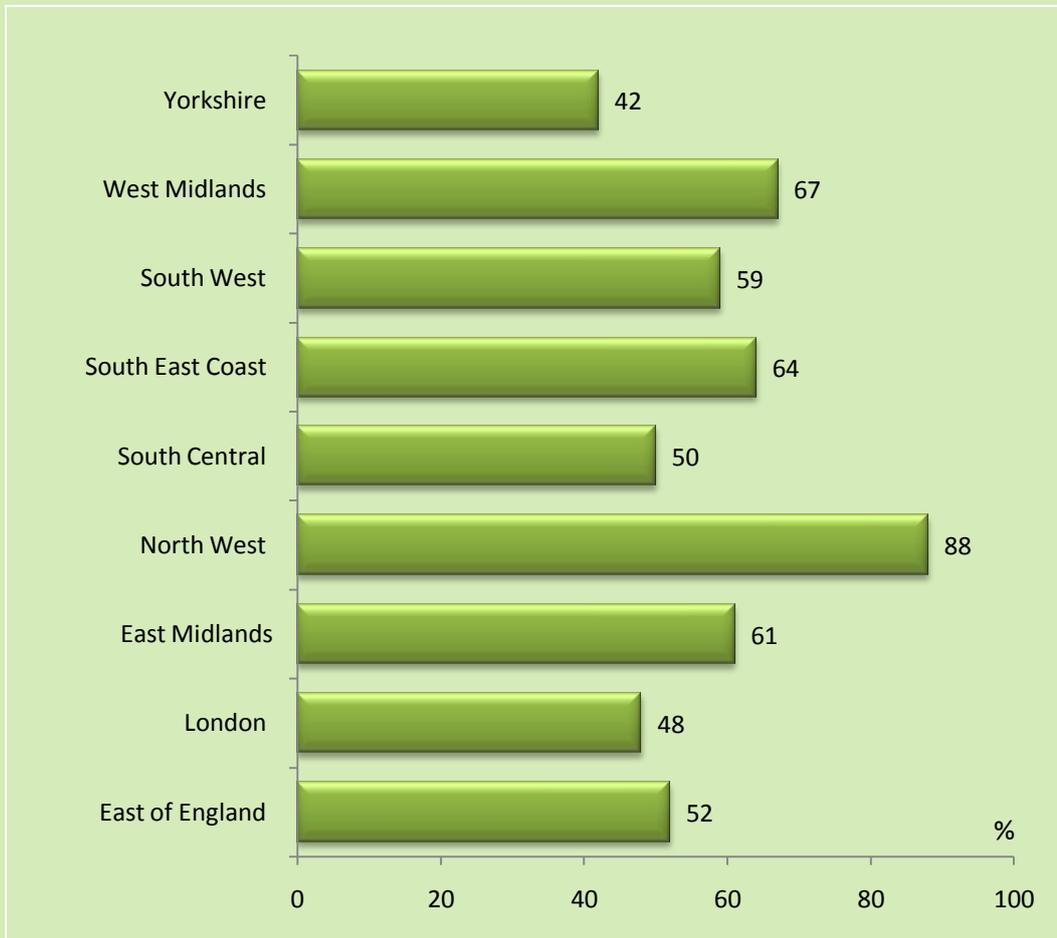
Note: There were no statistically significant differences between regions

Preferred place of care

Ensuring that people have an opportunity to live their final days in the place of their choosing is integral to providing high quality care.

Research suggests that many people would choose to die at home but the majority actually die in hospital.[2]

Practice teams have an essential role in helping people live their final days in their preferred place of care.[13] Evidence shows that if people are asked in advance about their preferred place of care at the very end of life, and this is documented, then professionals are more likely to be able to fulfil people's wishes.[14] Such documentation prompts care such as anticipatory prescribing and informing out of hours services.

The national snapshot found that while some people are being supported to die in their preferred place of care, there is room for significant improvement here.

56% of people on a palliative care register had a preferred place of care recorded (see Table 5).

Table 5: recorded preferred place of care

|	% on register	% non register	% all deaths
Recorded	56	7	21
Not recorded	25	26	26
Don't know / left blank	19	67	53

The preferred place of care was recorded on:

- nursing care plans (15%)
- practice clinical system (14%)
- palliative care register (12%)
- out of hours handover summaries (10%)
- patient held record or advance care plan (9%)
- hospital (<1%)
- other services (<1%)

It was possible, and preferable, for practices to record this information in more than one place. As a minimum, practices might expect to record the preferred place of care on the primary care record, the palliative care register and out of hours handover summaries.

The most common preferred places of care were people's own homes, care homes and hospices (see Figure 15).

Figure 15: preferred place of care for those on register, where recorded
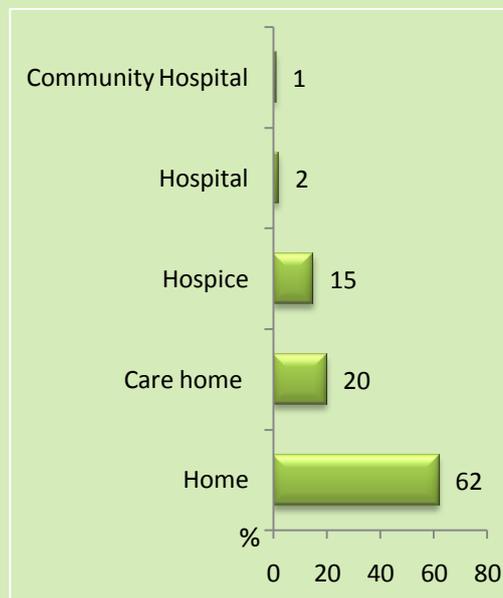
Note: data were available from 661 records

People tend to want to die in their own homes or in care homes or hospices. Those on a register were equally likely to die at home or in hospital.

Almost no one said they would prefer to die in hospital yet this is where half of people died (see Table 6 and Figures 16 and 17).

Practices said that 42% of people on a register died at their preferred place of care, 14% were recorded as not dying at their preferred place and all other records did not know or were left blank.

Of those where a definite yes, no or don't know answer was recorded for this question 75% said the person died in their preferred place of care. However the positive figures reported by practices are somewhat at odds with comparisons of the preferred versus actual place of death (see Figure 16).

Table 6: actual place of death

	% on register	% non register	% all deaths
Home	31	16	20
Hospital	28	59	51
Hospice	18	1	6
Care home with nursing	15	14	14
Care home	4	4	4
Community hospital	3	2	2
Other	0	2	1
Don't know	1	2	2

On a positive note, people on a register were equally likely to die at home and hospital. This suggests that when practices are aware that people are nearing the end of life, teams are making an effort to support people in their preferred place of care.

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

Figure 16: preferred versus actual place of death for people on register
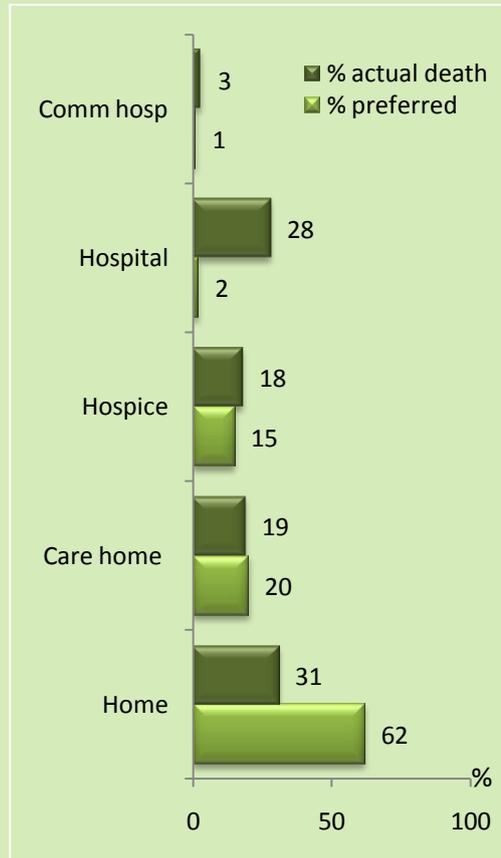
Key theme: practices are taking steps to support people in their final days but there is room for continued improvement. Around one third of people on the register are not asked where they want to die and for those that are asked, their wishes are not always recorded robustly.

Figure 17: proportion of people with preferred place of care recorded that practices said died in their preferred place

Region	%
Yorkshire	51
West Midlands	42
South West	46
South East Coast	45
South Central	27
North West	42
East Midlands	38
London	29
East of England	40
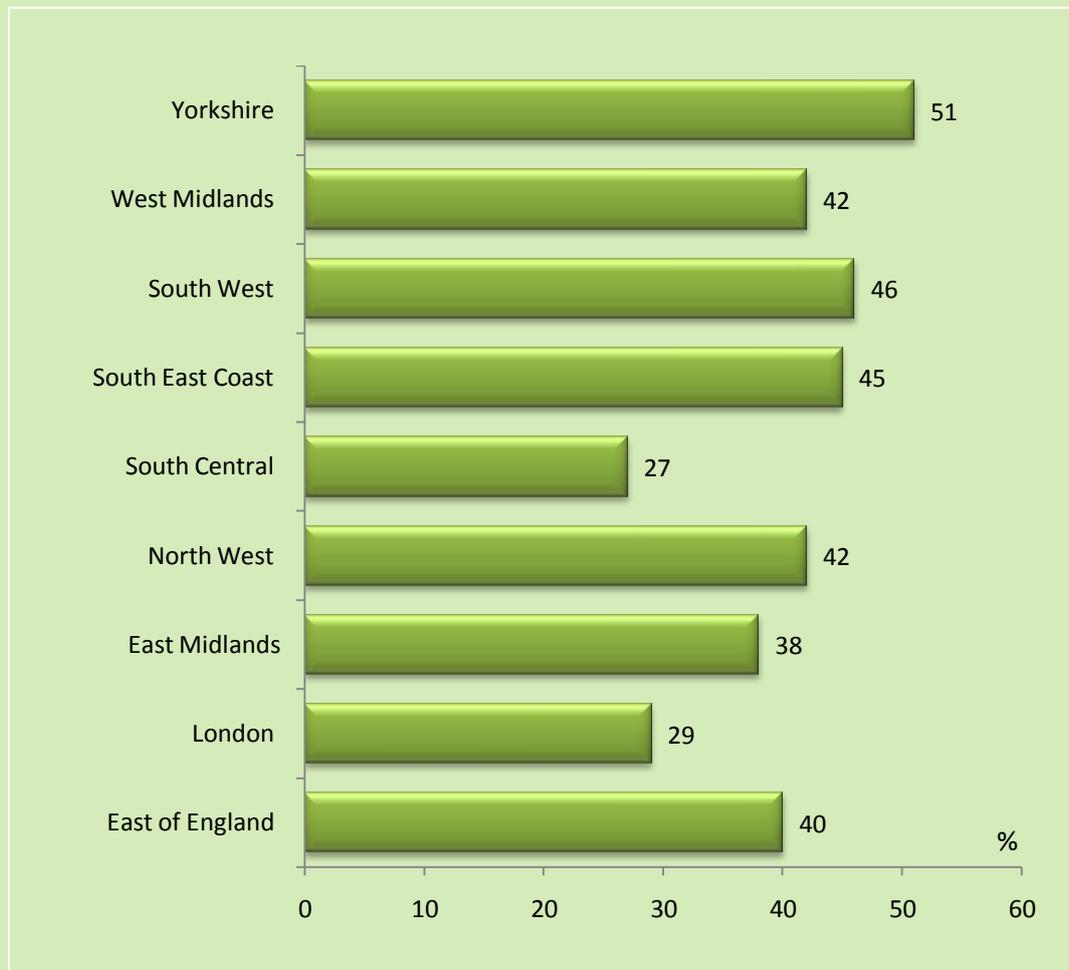
Supporting carers

The End of Life Care Strategy and Gold Standards Framework both emphasise the importance of carers and family members in supporting people at the end of life – and the information and support that carers themselves may need.

Carers and relatives provide valuable care for dying people and play a key role in enabling them to remain at home. Carers are entitled to have their own needs assessed and should be referred for a formal assessment if appropriate. Knowing how to seek support, both during normal working hours and out of hours, can help carers avoid crises.[15]

It is also important to have a system in place to ensure that bereavement support and information is offered following all deaths. This may be in the form of a letter or card enclosing information about local support or a telephone call.

Signposting to benefits

The end of life can be a very expensive time for people and their families. People who are stressed financially tend to suffer more symptoms. They may also restrict their lifestyle and be more isolated, and carers can feel stressed and unsupported.

There are financial benefits available but many benefits lay unclaimed. Benefits are often paid from the date contact was first made, rather than retrospectively, so it is important for practices to signpost people early.

The national snapshot found that among those on a register, 46% of people or carers had been signposted towards benefits or were receiving benefits.

"The family, including children, close friends and informal carers of people approaching the end of life, have a vital role in the provision of care. They need to be closely involved in decision making, with the recognition that they also have their own needs."

End of Life Care Strategy

Providing information

The national snapshot asked practices whether tailored information was given to carers or family members, including crisis care contact details.

For those on a register, practices said tailored information was provided to carers in 69% of cases. In 10% of cases, practices had not provided information and the rest were unsure. 12% of families not on a register received tailored information too.

Whilst it is extremely positive that seven out of ten were provided tailored information, there is scope for further development. This snapshot occurred before the launch of the Department of Health's Caring with Confidence programme for carers of people near the end of life. It is hoped that this programme of facilitated support for carers will help to address some of these proactive support issues for carers.

Assessing needs

50% of those on a register were recorded as having their carer's needs assessed. In 29% of cases, practices said they had not assessed carers needs and the rest were uncertain. 8% of those not on a register also had carer's needs documented.

Bereavement support

Following the death of someone on a register, practices reported offering bereavement support to family members in 52% of cases. Practices said that 36% of the time bereavement support was not offered and the rest were uncertain. Bereavement support was offered to the family members of 27% of people not on the register too. **Overall, only 34% of families were offered bereavement support**.

Key theme: practices reported that they had provided tailored information to seven out of ten carers of people on the palliative care register, but there appears to be a significant gap in bereavement support.

Figure 18: regional differences in support for carers of people on a register

Legend:
- % bereavement support offered
- % carer assessment done
- % tailored info given

Region	% bereavement support offered	% carer assessment done	% tailored info given
Yorkshire	57	61	78
West Midlands	49	49	69
South West	58	49	67
South East Coast	49	58	77
South Central	51	46	67
North West	45	42	72
East Midlands	44	45	62
London	51	43	66
East of England	55	49	69
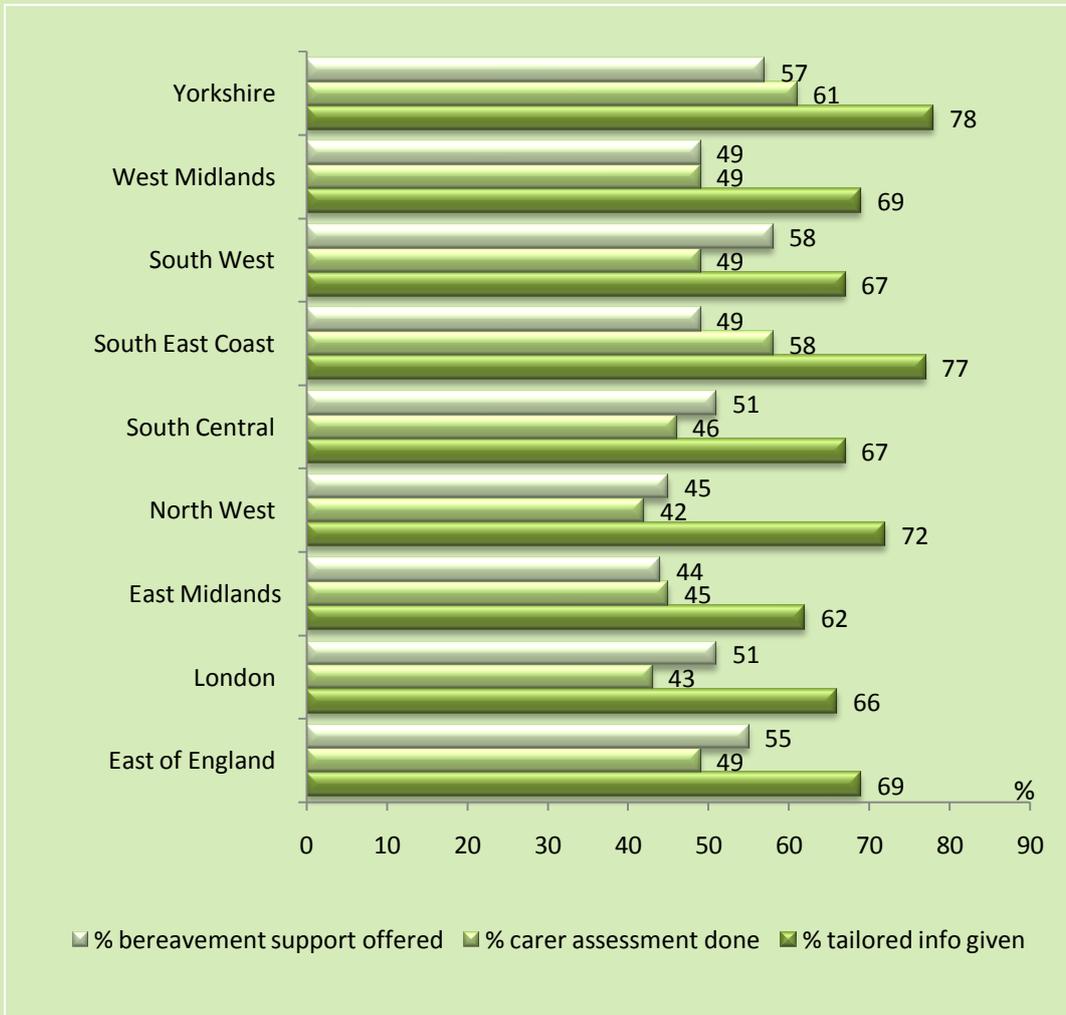
Quality implications

In 2009, the Department of Health launched Quality Markers for end of life care, including suggested approaches for primary care.[10] These Quality Markers are not mandatory and local areas are encouraged to select those that best meet their needs. Feedback from the national snapshot provides an ideal benchmark (see Table 7).

The snapshot found cause for celebration among participating areas, including discussing people nearing the end of life regularly at multidisciplinary meetings (78%) and seeking to co-ordinate care via a key worker (74%).

The Quality Markers recommend adopting a structured approach such as the Gold Standards Framework or similar. The 'GSF Primary Care' was revised and relaunched in 2009 to support practices further. The majority of practices felt that they were applying some GSF principles (92%).

As well as positive aspects of care, the snapshot also highlights some areas for particular focus in future, with policy and practical implications. Key areas include sharing information with out of hours and other teams, supporting people to die in their preferred place of care and supporting carers.

On average, practices had given information to out of hours teams for 46% of those on a register. This could impact on continuity of care and also the extent to which people are able to die in their preferred place.

Practices estimated that 42% of people on a register died in their place of choosing, yet there were few good reasons why this could not be achieved.

Only 32% of all families (and 52% of those with a family member on a register) were offered bereavement support. This is a key area in need of further development.

"NHS and social care services are not meeting the basic needs of many people approaching the end of their life... people approaching the end of their life are not always afforded the dignity and respect they deserve."

National Audit Office

Table 7: Comparison of performance with Quality Markers (primary care section)

Quality marker	Status	Snapshot
Quality marker 2.1: developing strategy and plans		
100% of practices develop action plan & evaluate		Not measured
Quality marker 2.2: mechanism to assess and document		
100% of practices adopt GSF or similar approach	🟧	92% using
% whose preferred place of care is recorded	🟧	56% on register
% who die in their preferred place of care	🟥	42% on register
Quality marker 2.3: mechanism to assess and document carer needs		
% whose carer is recorded		Not measured
% carer's assessment / carers needs recorded	🟧	50% on register; 20% overall
Quality marker 2.4: use of multidisciplinary team meetings quarterly		
% dying discussed at a multidisciplinary team meeting in final year	🟩	29% all deaths; 78% on register within 3 months
Protocols for sharing information with others		Not measured
Quality marker 2.5: communication with out of hours		
Protocols for sharing information with out of hours		Not measured
% on register with info given to out of hours	🟥	46% on register
Quality marker 2.6: nominating a key worker		
% with a key worker identified	🟩	74% of those on register
Quality marker 2.7-9: awareness and action regarding training needs		
Awareness of 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	🟧	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	🟧	60% of those invited
% who die at home	🟥	31% register; 20% overall
% who die in their preferred place of care	🟥	42% on register
% of carers who receive bereavement support	🟥	32% all deaths; 52% register
Audit of complaints and compliments		Not measured

For each individual death, practices reflected on what went well and what did not go so well using the significant event audit component of ADA. The most important perceived factors that influenced the quality of care and the overall outcome were:

- being clear about people's wishes so the practice can take steps to address these

- communication between the practice, district nurse, out of hours service, care homes and hospitals

- frequency of visits and telephone support provided

- communicating and working in partnership with family members

- time to plan and make arrangements (linked to identification)

- support to use a structured approach such as GSF or similar or support from a PCT facilitator so practices feel confident about what constitutes high quality care

- appropriate record keeping and monitoring

- gaining feedback from family members after the death to help reflect on what went well and what could be improved

- reflecting and learning for the future as a practice team

GSF levels of adoption

The Gold Standards Framework aims to facilitate high quality end of life care by promoting systematic clinical and organisational processes. Such process changes have been found to be one of the many components required to improve end of life care.[16]

The national snapshot wanted to understand the extent to which practices are adopting GSF principles. There are four levels of adoption of the GSF for Primary Care: Foundation Level, Higher Level, Advanced Level and Accreditation. Previously ADA has been used to help determine which level of the Gold Standards Framework practices are achieving. In 2009, the levels were revised as part of a relaunch of the Next Stage GSF. This occurred after the snapshot so ADA does not allow exact mapping to the new GSF levels. However it is possible to provide commentary about the extent to which practices are achieving core components.

Foundation Level

Components of Foundation Level GSF covered by the ADA tool include

- use of a palliative care register
- multidisciplinary meetings
- out of hours handover

Quality and Outcomes Framework data suggests that almost all practices nationally are claiming points for having a palliative care register and 85% are claiming points for having a multi-disciplinary team meeting at least every three months. However, the snapshot suggests that whilst identifying people for the register is gradually improving, only 27% of all deaths were people on the register. Having a practice palliative care register alone is not enough – the register must be actively used and there must be a focus on identifying people an appropriate period prior to death.

The snapshot found that 78% of people on a register that died in February and March 2009 were discussed at a multidisciplinary team meeting within three months of their death. Whilst this is positive, practices did not know whether 8% of people had been discussed and 14% were definitely not discussed.

Only 46% had documentation that handover information was sent to out of hours teams, so there is room for improvement here.

The snapshot found that while there were positive trends in some aspects of Foundation Level GSF, a significant proportion of practices are probably not achieving all of the components of this most basic level.

Higher Level

Components of Higher Level GSF covered by the ADA tool include:

- whether everyone added to the register is offered advance care planning
- whether people's preferred place of care is documented
- whether all aspects of care are considered, including using a symptom assessment tool and signposting to benefits
- keeping written records about patient care
- use of the Liverpool Care Pathway or equivalent
- providing tailored information and support to carers
- providing bereavement support

As outlined in other sections of the report, there is much scope for improvement in these areas. The snapshot suggests that most practices are not offering everybody on their registers advance care planning discussion or documenting people's preferred place of care. In fact, 58% of people on registers had an advance care planning discussion and 56% had their preferred place of care recorded.

Around four out of ten deaths on the register were recorded as being on benefits or having been signposted to benefits.

Practices reported that they used a symptom assessment tool with only 40% of people on the register. However in evaluation feedback practices also noted that they were unclear about this terminology and were not sure what this entailed.

This may mean that a greater number of people are supported with symptom assessment tools but that practices wouldn't recognise or name them as such. Alternatively, it could mean that the concept of symptom control tools is not well known in some practices, suggesting scope for exploration here.

60% of people dying at home were supported using the Liverpool Care Pathway or similar.

Positively, tailored information was provided to 69% of carers of people on the register, but only 52% of these (and 32% of all deaths) received any recorded bereavement support.

These trends show that very few practices are likely to be achieving most components of the Higher Level GSF.

Advanced Level

The Advanced GSF encourages practices who are fulfilling the basic requirements to look at the proportion of people with non-cancer diagnoses on their register and ensure they are using available tools to identify the right patients at the right time. Ideally people are added to the register when they are likely to have 12 months or less to live or as soon as they have a diagnosis of a life limiting illness if prognosis is likely to be less.

The snapshot found that the proportion of people on the register with a primary diagnosis other than cancer was small (29%). The majority of people were added to the register within one to six months of their death.

These figures suggest that only a small proportion of practices are operating at Advanced Level GSF.

Accreditation

Practices can become GSF accredited by taking part in a training and development programme. The programme was not launched at the time of the snapshot.

Overall, comparing of the national snapshot data with the Quality Markers and the levels of adoption of GSF illustrates that there is much scope for continued development. Whilst there have been important advancements in the prioritisation of end of life care, it appears that many people who die are not receiving the best possible primary care. The snapshot does not purport to represent all practices and all deaths, and the validity of the data depends on how the questions were asked and answered. However, the trends suggest cause for both quiet optimism and renewed vigour in supporting practice teams to develop care further.

Reflections

Development

One of the key objectives of the national snapshot was to gain a picture of how practices in selected regions are supporting people near the end of life. A second and equally important objective was to test the feasibility and value of using an online 'After Death Analysis' tool to collate feedback of this nature. This section addresses this question. It is divided into three areas:

- an outline of how the snapshot process and tool was developed and how practices and PCTs were supported to use it

- an overview of feedback from practices and PCTs about the feasibility and value of taking part

- a description of some of the changes practices said they have made as a result of taking part in the snapshot

Tools and processes

The snapshot used a modified version of the 'After Death Analysis' tool originally developed by the Gold Standards Framework Centre. The Omega team significantly revised the tool and developed a new, easy to use online platform especially for this snapshot. The tool was used under license.

All participating practices had unique log in details to provide information online. This is the first time the ADA online tool has been used on a large scale for benchmarking the quality of primary care. Redevelopment of the tool followed consultation with clinicians and the administrative team from the GSF Centre, feedback from practices and previous users and researchers at the University of Birmingham and The Evidence Centre. The aim was to provide a user friendly tool that collected a wide range of information.

The ADA online tool was redeveloped for the national snapshot. Lessons learned will help modify the tool to be even more effective in future.

An online platform was developed to ensure ease of use and to reduce the need for any subsequent data inputting. This allowed questions to be hidden based on practices' answers and for an interactive 'help' function to be used.

The order of the questions was reviewed to ensure they were more intuitive and to save practices time when reviewing their case notes.

Some new questions were also added to reflect the End of Life Care Strategy and draft Quality Markers (DNAR forms, care records and key workers) and to account for the broad scope of the snapshot. In the past, ADA focused on use of GSF for predicted or expected deaths but the snapshot included all deaths and all practices, not just those using GSF. Questions were added to establish what proportion of deaths clinicians thought were predictable and this has proved enlightening.

A full data set was collected both for patients on the palliative care register and for those not on the register whom clinicians felt in retrospect they could have been identified as nearing the end of life. For sudden deaths a minimal dataset was completed, including questions about offering bereavement information and support.

The tool was developed to use tick boxes and pre-set responses, with a small number of open ended questions related to the significant event audit (What went well? What didn't go well? What could be improved?). Detailed questions about primary and secondary diagnosis, cause of death and ethnicity were included to test the feasibility of this approach but the data was of limited use in the final analysis. These questions might usefully be removed or shortened in future iterations. In fact, the Omega team may be able to significantly revise and reorder all of the questions to enhance future effectiveness.

The interface was pilot tested prior to launch and the screen layout, password reminders and help functions were tailored to meet the needs of practices. Steps were taken to ensure none of the information was attributable to individuals and confidentiality was secured in line with best practice guidance.

An important function of the system was that feedback and findings were displayed every time a practice entered a record. Practices could therefore see a live display of all of their data mapped out, alongside graphical comparisons to all practices taking part in the national snapshot. This immediate feedback aimed to show practices that their information was valuable and to give them tips for ongoing development. A pdf print out of up to date figures was also sent to every practice during the snapshot to encourage sharing amongst practice teams and remind them of the value of participating.

When a PCT area was selected to participate, all practices within that area were automatically entered onto the software, ready for practices to input information. Whilst this saved practices time it also meant that many did not provide the additional information requested regarding their practice characteristics. In future, the first time a practice logs into the system they could be asked to complete some basic information including the practice size, use of the Gold Standards Framework and other core details before being able to input data about their patients.

PCTs and practices were encouraged to share their views throughout the development and implementation of the snapshot. PCT representatives attended meetings and received regular telephone and email updates, practices took part in interviews and received regular communication, and a full time helpline was available for anyone with queries about using the tool.

Selecting a sample

The snapshot asked practices to provide information about all deaths during a two month period rather than just a sample. The rationale was to gain a comprehensive picture of both sudden and predicted deaths whilst also minimising the time commitment for practices. In the past, sometimes practices or other organisations have been asked to provide information about their most recent five deaths or to undertake other sampling. The Omega team felt that this would limit the usefulness of data because it would not all be from the same time period and may not reflect the variation within practice populations. It might also encourage 'gaming' by using only the most suitable patients rather than including all sequentially.

A two month period was selected because it would help overcome these limitations whilst maintaining feasibility for practices.

As 1% of the population dies each year, an average GP may be supporting 18-20 deaths per year. During the two month window of the snapshot, 3-4 deaths would be expected per full time GP. The small numbers involved enabled a comprehensive snapshot to be undertaken and given that slightly more deaths may be expected in the winter months, individual practice reports would be more meaningful.

It was estimated that the time taken to complete each record would be about 15 minutes. This would be shorter for sudden deaths and perhaps slightly longer for predicted deaths. Practices confirmed this estimate, with 52% suggesting that it took less than 15 minutes on average to complete each record, 27% suggesting an average of 16-25 minutes and 21% suggesting that on average it took more than 25 minutes to provide information.

The methods for the national snapshot were designed to be least intrusive for practices whilst still providing robust information. This was successful, with a high participation rate.

Timing

The national snapshot asked practices to provide information about all deaths during a two month period and practices were given up to six months to provide the information. The snapshot focused on deaths in February and March 2009 in order to avoid asking practices to undertake any additional work during Christmas and the summer period when staffing may be at its lowest. This timetabling overlapped with the Quality and Outcomes Framework reporting in March, but allowed practices to spend up until July-August 2009 providing information if necessary.

There will never be a 'best time' to conduct a snapshot of this nature given the competing demands on practices' time, however the February-March period allowed enough time for practices to provide information after their QoF reporting, avoided times of peak staffing shortages, and allowed collation of information during the end of the winter season to enhance numbers and variation.

Engaging practices

The Omega team spent considerable time encouraging practices to participate. These activities were worthwhile, with 57% of invited practices choosing to take part. Core activities included:

- providing an information package to PCTs to help engage practices

- distributing a simple guide and information sheet for practices

- running a half day networking and training event for PCT facilitators to share ideas for engaging practices and increasing uptake

- attending events hosted by participating PCTs to explain the snapshot and demonstrate the ADA tool to practices

- emailing an update to PCTs every few weeks listing participation by each practice and common queries so that PCT liaison people could encourage practices locally

- emailing regular updates to practices

- proactive and reactive telephone calls

- providing access to personal guidance through a dedicated helpdesk team

- providing practices with immediate feedback every time a record is entered online as well as an interim comparison with national averages

- disseminating a press release about the snapshot launch and purpose

The extensive promotion of the national snapshot and ongoing feedback means that the team reached a wide range of stakeholders and promoted the principles of the End of Life Care Strategy. Regardless of whether they chose to submit data for the national snapshot, **more than 800 practices received messages regularly over a 10 month period about the importance of end of life care and ways to improve**.

The Omega team also tested the value of having a helpdesk and enquiries line. A full time administrative post was funded for the snapshot and this proved invaluable. The Omega team found that a full time post was not required for dealing with helpline enquiries alone, but this level of staffing was needed to maintain the system, keep in regular contact with PCTs and practices and undertake follow up calls to practices.

Omega chose not to provide full time administrative support during some parts of the snapshot and as a result not all practices received telephone reminders and support (670 practices received one telephone call, meaning that 76% received one call as planned and 0% received two follow up calls as planned). Practices that did receive follow up calls commented on how they were motivated and felt more involved afterwards, so a key learning point is to use administrative resources effectively and to build in sufficient administrative capacity to support regular contact with practices.

The helpdesk recorded 227 telephone enquiries and 271 email enquires during the data collection period for the snapshot (February- July 2009). The most common enquiries were basic questions about how and where to input data. More specifically, 45% of enquiries related to login and password details, 30% were related to technical issues and 25% were other general enquiries.

Feasibility

This section examines feedback from all 15 PCTs and 275 participating and non participating practices regarding the feasibility of the snapshot approach. The next section focuses on some of the changes that practices said they have made as a result of taking part in the snapshot.

Representatives from all PCTs were interviewed by telephone or in person, as were a random sample of 100 participating and 50 non participating practices. Practices were interviewed throughout the snapshot, including before and after receiving interim reports listing their results. In addition 125 participating practices completed an online survey towards the end of the snapshot.

People that provided feedback on behalf of practices were (in order of frequency): GPs, practice managers, practice nurses, palliative care leads and GSF co-ordinators, health care assistants, and administrative and IT support.

Participation

All of the PCTs were positive about being selected to take part in the snapshot and some had actively campaigned to take part because they felt that the information would support local priorities. PCT representatives were positive about the regular engagement with the snapshot team, which ranged from being invited to planning meetings prior to the launch of the snapshot, being sent information and templates to tailor for local use and monthly calls and emails from the Omega team.

"I felt very involved throughout. Receiving a monthly call kept me up to date and the emails saying which of my practices needed to be followed up meant we were working as one team."

Practices and PCTs provided valuable feedback about the ADA tool and snapshot process. The process appears feasible and useful and would be worthwhile repeating in future to monitor changes.

The majority of the practices said they took part because they wanted to review their practice procedures and improve the care offered to people nearing the end of life.

"We thought it was a good opportunity to review our practice procedures and benchmark them against others."

"We thought that if there was anything we could identify from it that was changeable that might help people in terms of end of life care then it couldn't be a bad thing."

Some practices became involved due to encouragement from their PBC group or PCT or due to a personal interest in end of life care.

Those practices that chose not to take part generally felt that the snapshot was a good idea, but that they lacked the capacity or motivation to take part. The most common reasons for non participation were concerns about how long it would take and the lack of reimbursement available, a feeling that this would duplicate QoF work, and a lack of information about the process.

"We didn't participate because we saw it as a duplication of effort of what we are already accomplishing... we already have a limited time resource."

Of the 50 practices spoken to that chose not to participate, 70% said they would have taken part if they had received a telephone call explaining the purpose and value. These practices said they were not well informed by their PCTs but could see the value once explained.

Some practices didn't take part because they did not understand the purpose. In future, even more time and effort could be spent engaging with practices.

Using the tool

In interviews and surveys, participating practices said they found the online tool user friendly. In fact 80% of practices said the tool was easy to use.

In interviews, practices elaborated further, saying they favoured the drop down menus and 'click box' approach.

"The way it has been put together is good and it is easy to use. It was good for our GSF patients, because we keep comprehensive notes on them."

Practices noted that using the tool could be time consuming and required clinical input. The average time taken to complete records was 15 minutes, but in addition, practices sometimes had to find information from other sources such as hospitals or district nurses or spend time reviewing the notes at multidisciplinary team meetings.

Some suggested that the tool should not require a response for every question. Practices said that they wanted to omit some questions but the system did not allow them to do this. As a result, they ended up submitting fewer records than they might have otherwise. In fact, 10% of the practices that provided feedback said they had not submitted records for all deaths during February and March 2009 due to insufficient time or because they did not have the full set of data required by the online tool.

The information required to complete the ADA was mostly easily accessible, however most of the practices questioned had to find the information from various places, including from district nurses and hospitals when a patient had died there.

"The online tool was easy to use. The thing that was tricky was getting the information needed, depending where the person had passed away. It's often not as easy as you might imagine to get information out of hospitals if people have passed away there. Using the tool was easy, but finding the information in some cases wasn't easy."

It was suggested that the tool was more appropriate for asking about expected deaths (ie those on a palliative care register).

"We don't always know about things like whether they're on benefits and things that aren't necessarily with their medical care. If they're otherwise fit and have died in their sleep at 98 for example, we wouldn't necessarily know. But we would for patients who have been on our palliative care register, we know lots more about them. We know about their carers and lots more about those patients."

Practices that had a comprehensive and structured recording system in place found it easiest to complete the online tool.

Technical support

Practices identified some issues for development if the snapshot is repeated in future. Some said that sometimes the system was difficult to access or appeared offline and that it was sometimes difficult to contact the Omega helpline.

Whilst those that contacted the Omega team generally said that the staff were helpful, 23% said they encountered problems contacting the team by telephone due to issues with the telephone number or telecommunications system. A similar proportion felt the helpdesk staff were new or inexperienced and could not answer their queries sufficiently. Omega was unable to keep continuity of staff during the snapshot and this is reflected in the comments made by practices.

Feasibility

The overall message was that the approach used for the national snapshot is feasible and valuable. Figure 19 illustrates the positive perceptions of the snapshot process and the ADA tool amongst 275 practices that provided written or verbal feedback.

The biggest challenge faced by most of the practices was time. A number of practices mentioned that the timing of the audit was not good, coinciding with QoF and year end. For others, obtaining the information required was the factor they found most difficult. Practices appreciated having several months to provide the data, which reduced the burden during the QoF period.

86% of ten practices that provided feedback said that they will be able to use the results to improve their care.

Figure 19: feedback about snapshot process and ADA tool (275 practices)

Category	%
Immediate online trend comparisons helpful	87
Will be able to use results to improve	86
ADA is useful overall	83
Tool was easy to use	80
Helpline team were helpful	76
Will use findings to benchmark against average	74
Easy to contact helpline if needed	70
Would recommend using ADA to others	70
Easy to get the info needed to complete	53
Already used findings to make a change	39

Key theme: most practices that provided feedback said they found ADA useful and easy to use, that they will use the results to improve their care, and that they would recommend using ADA to others.

There were some challenges using ADA but **83% thought that the tool was useful overall and 70% of practices said they would recommend the ADA tool and taking part in the snapshot to others.**

66% of practices that provided feedback said they would be interested in continuing using the ADA tool on an annual basis or every two years.

"I have found it interesting. It was interesting to see what we do and what we don't record. I would like to do it again in 12 months time to see what we've changed."

Practices suggested that the questions could be cut down to enhance usability and make them more likely to want to repeat it regularly. Of those who were not interested in continuing, most stated time constraints as the main reason.

Being able to receive immediate feedback and comparisons with the national average after submitting a record onscreen was thought to be particularly useful (87%).

"I found it useful looking at all our deaths... It was good looking at our patients and comparing it with other practices."

86% of practices said they would be able to use the findings from the snapshot to help improve their practice. The interviews and surveys were completed in mid 2009, when the snapshot analysis and reporting was not complete. Even so, more than one third said that taking part in the snapshot had already influenced the care they provide and motivated them to make changes. This number might be expected to increase with later feedback.

"It's a really good thing that it's across the whole of the country monitoring our end of life patients."

Feedback from practice

Suggested changes

Based on all the feedback from practices, PCTs and a process evaluation, a number of changes could be made to enhance the snapshot in future years, including:

- being clear about the purpose and value of taking part in the snapshot and working in partnership with PCTs to contact every practice individually to ensure they are informed

- reducing the number of questions and categories within questions to make it easier to complete the audit

- removing the need for practices to complete every question

- focusing on questions where practices have ready access to information, rather than needing to seek this from other sources

- ensuring that the question wording is clear and unambiguous

- structuring the tool so all aspects of the Quality Markers and End of Life Care Strategy are covered

- asking practices to provide basic registration information when they log on for the first time

- ensuring sufficient administrative support to telephone all practices

- making it easier for practices to access the online system by providing more guidance and technical tips

- revising the navigation of the online tool so that fewer 'clicks' are needed to get through the questions

The feasibility and impact of these changes has yet to be tested by the Omega team.

Making change

The Omega team examined the feasibility of the snapshot process but did not aim to evaluate all the impacts of taking part in the audit in any depth.

Even so, important impacts have begun to emerge and these are reported here. It would be useful to evaluate impacts fully in 2010.

Participating PCTs and practices generally felt that taking part in the snapshot would help to improve the quality of care available to people nearing the end of life. The three core areas of improvement are:

- raising the **profile** of end of life care in primary care

- encouraging **learning** and sharing amongst practice teams

- beginning to make tangible **changes** in how care is recorded and provided

Raising the profile

During interviews, practices said that taking part in the snapshot has helped to raise the profile of end of life care. Some commented that they have a greater understanding of the End of Life Care Strategy and principles of the Gold Standards Framework in Primary Care. Others suggested that they are more aware of the evidence-base and good practice.

"It makes you think about some aspects of end of life care that you maybe would have omitted - like handing over to out of hours and informing ambulance... Sometimes people say that they are following a 'pathway' and are ticking the boxes, but maybe then forget some aspects of the pathway."

Others believe that the snapshot and accompanying information has made them more aware of the needs of dying people and their families.

"It did make us realise that we needed to be more proactive with things like advanced directive and people's end of life wishes in people who you could anticipate the end of their lives."

"This tool has made us even more aware of patients needs, such as their preferred place of dying and we are now able to discuss this at practice meetings. We had not had this information before and so this was not discussed in practice."

Even practices that did not take part felt their awareness was raised as they received regular communications from Omega throughout.

"We didn't take part but I wish we had. We have been kept informed and seen example reports and it's made it a higher priority for us in future."

Sharing and learning

Practices reflected that taking part in the snapshot had encouraged the entire practice team to discuss their approach to end of life care.

Some clinicians said they were considering how to identify more people for palliative care registers in future and how to educate and inform others within the practice team to help with this identification. Practices had also recognised some training needs.

> *"The doctors have found out where we are doing well and where we are not doing so well and now we know where we need more training. We've been looking into how to get more knowledge as a whole practice so we can improve our performance."*

Another key learning point within practice teams is the way documents are organised and records are kept. Practice managers and administrative personnel described how they have initiated conversations with GPs to help make completing the snapshot easier, which has ultimately resulted in improved record keeping overall.

> *"GPs don't always keep good records. This has given us the opportunity to share the deficiencies in our record keeping as a practice and pushed us to do something about it."*

> *"We know we do things but don't always record them on the patient's records or the computer system. This is particularly true of end of life care... This made us aware to document everything."*

Tangible changes

39% ten of the random sample of practices that provided feedback said they had already made a tangible change as a result of taking part in the snapshot and others were waiting to reflect on the final results prior to altering the care provided. This feedback was gained in mid 2009, well before the final results from the snapshot were reported back. Practices had used the immediate online feedback to support change as well as an interim summary sent out to all practices.

Changes being made by practices are primarily around improved communication and reflection and enhanced record keeping. These are changes reported by the practices themselves, rather than changes that have been independently assessed or observed.

Numerous practices suggested that they have changed the way they store information about people nearing the end of life and the support provided as a result of taking part in the snapshot.

"ADA has highlighted our spreadsheet for palliative care was formatted in the wrong way and clinicians were missing entering some data. We have now improved it and we are getting better compliance with GSF standards now."

Practices said they were recording information more regularly.

"All information regarding patients who have passed away will be logged immediately - so that it is readily available in order to use in the future."

But it is important that this is not merely record keeping for the sake of it. Practices indicated that enhancing their record keeping has led to increased staff awareness and confidence, and associated improvements in the quality of care.

"As a result of completing ADA, the practice staff now feel they have more information relating to a patient's wishes, requirements and the family needs than they were before."

Other practices said they had altered the way multidisciplinary team meetings were run and ensured that every death was now discussed and reflected on.

"We are now holding meetings to discuss the care received and to assess if anything could or should have been done differently or was spot on."

"We now have a meeting with Macmillan and other specialist nursing care, on a regular basis."

"We would like to be closer to the national average so we are discussing all deaths to see how care could have been better."

Other changes included inviting district nurses and social workers to attend multidisciplinary meetings each month.

"Audit helped my own practice realise that we didn't quite measure up to the care we thought we were providing. We became more organised and went about care in a more structured way behind the scenes. So every patient and their family get the best we can offer in the last year of life."

Dr Helen Bowden, GP and Assistant Clinical Lead, National GSF Centre

Some said that they had applied what they learnt and this had supported people to die in their preferred place of care.

"It caused us to think about documenting when certain subjects are raised with the patient. For example, a casual conversation with the GP about wanting to die at home is now documented. In one case this meant that a patient died where they wanted, whereas that might not have happened otherwise."

"We've changed the information we are collecting from our patients and we are now having more discussions with our patients. We are taking a totally different approach now and this is helping more people die at home."

Another core theme was the importance of providing additional support for carers and family members.

"We are now focused on earlier consideration of patients' needs. We were shocked to see the gaps in the bereavement support so we now provide information to all relatives."

This feedback, collected from half of participating practices suggests that there have been some immediate tangible benefits from taking part in the snapshot and it is hoped that these will continue as practices and PCTs receive and reflect on the overall national data and their individual practice and PCT reports.

"I'd just like to emphasise that the GPs found it useful and that they're happy with taking part. We were impressed at how quickly the feedback came back to us both on an interim basis and the report."

Feedback from practice

Next steps

Summary

The national snapshot of end of life care in primary care achieved its two core objectives:

1. To provide a snapshot of the quality of end of life care in primary care

502 practices from 15 PCTs and nine SHA areas took part. Practices provided information about 4487 deaths that took place in February and March 2009. 57% of invited practices chose to participate.

More than double the planned number of practices took part and four times as many records were provided. Information was collected about key quality measures including place of death, the proportion of people dying where they choose, and support for carers. The snapshot was not designed to compare areas or practices, but rather to provide a national overview of key trends.

2. To evaluate usefulness and feasibility

An evaluation has assessed the feasibility and usefulness of using an online tool for supporting improvements in end of life care. Participating practices and PCTs had many positive things to say about the process and the ADA tool. Most importantly, a number spoke about things that they are doing differently as a result of taking part in the snapshot, including changes to the way they record and monitor information and changes to the support provided to families. PCTs and practices also identified a number of challenges including the time taken to complete the tool and the desire to omit some questions.

"The provision of end of life care services has become increasingly complex: people are living longer and the incidence of frailty and multiple conditions in older people is increasing. As a result, people approaching the end of their life require a combination of health and social care services."

National Audit Office

Recommendations

The national snapshot process has been a real success, both in terms of collating new information and developing processes to follow up and improve over time. The snapshot has provided a clear vision of areas to focus on in future:

Identify the right people

There is more work to do to identify people near the end of life. Practices said 42% of deaths were sudden or unpredictable, but this may suggest that more work is needed to help practitioners identify that people are nearing the end of life.

Only 27% of people were on a palliative care register. About three quarters of those on registers had cancer as their primary diagnosis. This suggests that end of life care may still be focused disproportionately on people with cancer rather than recognising that palliative care is important for all.

Assess people's preferences

There is also more work to do in terms of asking people about their needs and preferences and helping them plan to achieve these.

Of those on a palliative care register (identified as being near the end of life and in need of supportive care), 43% had an advance care planning discussion document and 56% had a preferred place of death recorded in the general practice notes.

Plan and co-ordinate

The snapshot suggests that some practices are doing well to plan and co-ordinate care within the team. The majority of those on the register had a documented key worker (74%), were discussed at least once at a multidisciplinary team meeting within their last three months of life (78%) and had a record or checklist prepared to ensure the practice covered all aspects of care (80%).

However there is room for development in the communication and co-ordination between different teams. For example, practices had sent handover information to out of hours services for just 46% of deaths on the register. Protocols and infrastructure to support cross boundary communication is a priority for the future.

Deliver high quality services

There will be real value in repeating the national snapshot to establish changes over time. The first snapshot provides a baseline of information about planning and co-ordinating care.

People on a palliative care register had an average of one unplanned hospital admission in their final six months, though this ranged between 0 and 23. The average number of unplanned days spent in hospital in the last six months of life was 13 for both people on a register (range 0-130) and those not on a register (range 0-184).

A lot of people on a register use community and primary care services during the final months of life and it will be important to track whether this influences hospital usage. Information sharing was highlighted as a particular area in need of further development.

Managing final days

Although there is room for improvement in many areas, the national snapshot also shows many grounds for celebration in the end of life care provided in primary care. Of people who have a preferred place of care recorded, 42% die in their preferred place – but when only the responses of those that provided a definite yes, no or don't know answer to this are considered, then the proportion increases to 74%. Those on a register are equally likely to die at home as in hospital.

This suggests that there is a need to concentrate on identifying people at the end of life and establishing their preferences. When these two things are done well, the national snapshot data suggests that primary care teams can support people to achieve their preferences.

Support carers

A key finding from the snapshot is that the majority of families are not offered bereavement support following the death of a loved one. Only 35% of all families who suffer a bereavement were offered such care. This may be due to a lack of available care services in local regions, a lack of confidence amongst practice staff or oversight given competing priorities.

Further investigation is needed regarding the reasons why bereavement support is not routinely offered so that steps can be put in place in both policy and practical terms to address this.
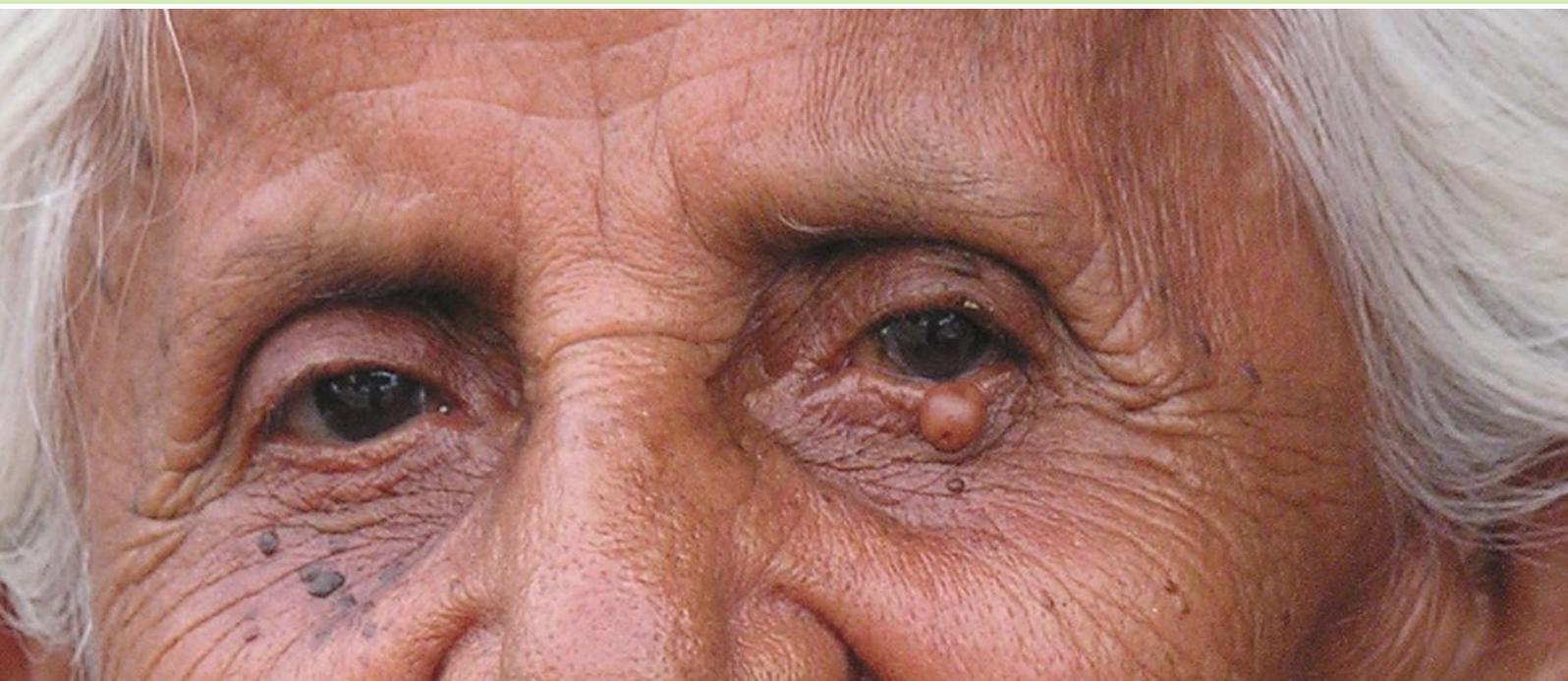
The key recommendations stemming from the national snapshot include:

Recommendations for policy makers

a. Celebrate success

The snapshot suggests that the quality of end of life care may be continuing to improve. 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 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. It is recommended that more 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.

c. Build on strategic vision

It is recommended that policy makers consider how to further support implementation of the End of Life Care Strategy, including helping clinicians identify people near the end of life, ensuring there is training available to help overcome key barriers, and 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.

a. Benefit from available tools

Providing supportive end of life care can help to reduce expensive crisis admissions. A first step is to monitor changes in practice. It is recommended that commissioners continue measuring the quality of end of life care and, since taking part in the snapshot has already lead to improvements and a willingness to change in one third of practices, 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 practice in end of life care. The snapshot also 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 and support for people and carers at all stages. Workforce Deaneries and PCTs could consider making initiatives such as the Gold Standard's Framework's 'Going for Gold' training programme 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. Other potential developments to infrastructure include systems and templates to support cross boundary care such as improving information sharing using the 'passport information' concept and IT links between primary care, care homes and hospitals.

Recommendations for practice teams

a. Spread the word

Practice based commissioning groups and individual practices should share the best practice tips from the snapshot so that, whether or not neighbouring practices participated, the information is disseminated to and useful for all practices.

b. Address gaps

It is recommended that all practices consider what they could do to improve common gaps, including:

- better identification of people nearing the end of life
- including more people on the register
- offering advance care planning discussions to all on the register
- improving cross boundary communication such handover forms
- using a pathway to manage final days
- actively supporting carers
- considering the team's training needs

c. Consider further training

It is recommended that practice teams consider ongoing development 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.

d. Make use of information

It is recommended that participating practice teams use their individual feedback as part of their revalidation process.

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 diabetes or dementia, for example. It is recommended that the findings from the snapshot are used to help shape ongoing research programmes.

b. Refine the snapshot tool

It is recommended that the snapshot tool and process is refined to make it even more user friendly and quicker to implement. It is recommended that the questions are redeveloped so as to align more closely with the Quality Markers and End of Life Care Strategy. Questions 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 in 2010. This will help assess the value of this process as an improvement mechanism once practices and PCTs 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. 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.
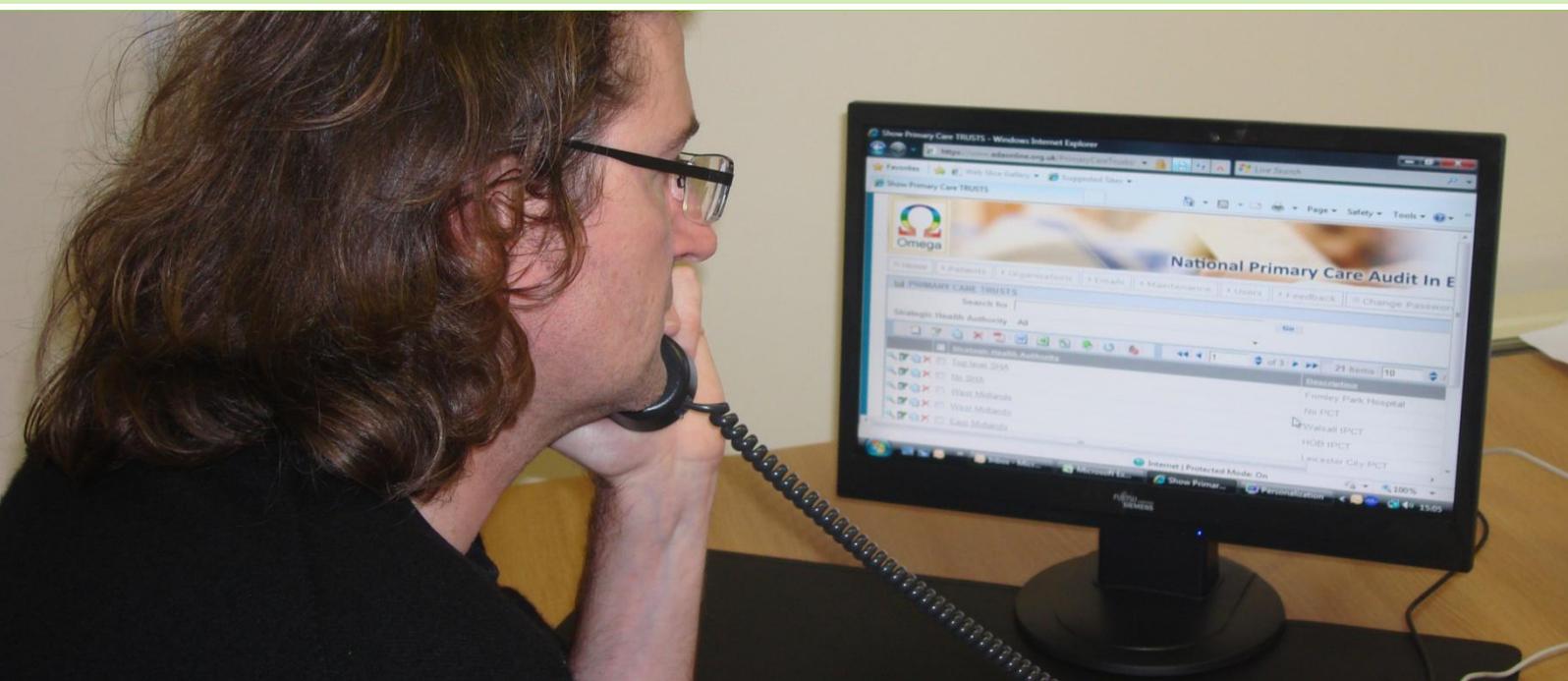
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