

End of Life Care Strategy

Second Annual Report



*'How people die
remains in the memory
of those who live on'*

Dame Cicely Saunders

Founder of the Modern Hospice Movement

August 2010

DH INFORMATION READER BOX

Policy	Estates
HR / Workforce	Commissioning
Management	IM & T
Planning /	Finance
Performance	Social Care / Partnership Working

Document Purpose	For Information
Gateway Reference	14462
Title	End of Life Care Strategy: Second Annual Report
Author	DH
Publication Date	August 2010
Target Audience	PCT CEs, NHS Trust CEs, SHA CEs, Care Trust CEs, Foundation Trust CEs , Medical Directors, Directors of PH, Directors of Nursing, Local Authority CEs, Directors of Adult SSs, PCT Chairs, NHS Trust Board Chairs, Special HA CEs, Directors of Finance, Allied Health Professionals, GPs, Communications Leads, Emergency Care Leads
Circulation List	Voluntary Organisations/NDPBs
Description	The End of Life Care Strategy was published in July 2008. This is the second annual report on progress in delivering the strategy.
Cross Ref	End of Life Care Strategy
Superseded Docs	n/a
Action Required	n/a
Timing	n/a
Contact Details	End of Life Care Team Department of Health Room 402, Wellington House 135-155 Waterloo Road London SE1 8UG 0202 7972 3958 www.dh.gov.uk
For Recipient's Use	

Contents

Contents.....	3
Foreword.....	5
Executive summary.....	7
Meeting the challenges of end of life care.....	12
Section 1 - The Department of Health	12
Section 2 - The Coroners and Justice Act	16
Section 3 - Care Quality Commission.....	16
Section 4 - The National End of Life Care Programme.....	17
Death, Dying and Society.....	19
The end of life care pathway	26
Step one – Identifying people who are approaching the end of life	26
Step two – Assessment and care planning.....	29
Step three – Co-ordination of care.....	32
Step four – Delivering high quality services	37
Step five – Last days of life	38
Step six – Care after death	40
Care in different settings	42
The King's Fund's Enhancing the Healing Environment Programme	42
Environments for Care at the End of Life.....	42
Hospice capital grant	49
Routes to Success.....	49
Extra Care Housing	51
Support for carers and families	52
Bereavement	53
Spirituality	55
The end of life care workforce	56
What we have achieved.....	57
The next twelve months.....	61
Measurement and research in end of life care	63
Intelligence Network	63
VOICES.....	65
Research into end of life care	66
Making change happen	68
The Quality and Productivity Challenge - QIPP	68
Commissioning	68
Monitoring investment.....	69
Quality Markers	72
Appendix 1	
Review of palliative care funding, to be chaired by Tom Hughes-Hallett, Chief Executive, Marie Curie Cancer Care	74
Appendix 2	
National End of Life Care Programme's summary of Advance Care Planning, care planning, DNACPR.....	75
Appendix 3	
Enhancing the Healing Environment	
List of participating organisations	76

Appendix 4	
Hospice Capital Grant Scheme for 2010/11 – successful applicants.....	77
Appendix 5	
Summary of end of life care projects recently funded by the SDO programme in 2009/10.....	83
Appendix 6	
Results of the Department of Health’s monitoring of new investment in end of life care, 2009/10.....	84
Appendix 7	
Strategic Health Authority End of Life Care Clinical and Management Leads	88

Foreword

In my capacity as Chairman of the End of Life Care Implementation Advisory Board it is my pleasure to endorse this report from the National Clinical Director for End of Life Care and acknowledge the progress that has been made in improving care and support for people at the end of their lives. Death and dying have never been fashionable subject matters but the tide is turning. This report is testimony to much good work across England.



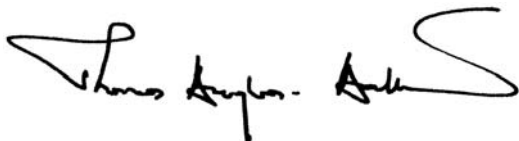
However, there are many challenges facing us, particularly inevitable changes to the NHS in response to the need for financial constraint. We know that circumstances will get tougher. We also know that over the coming years we face a significant increase in the number of people dying in England. In short, there will be less money and more demand. Now is our moment to plan for the future. All those with a commitment to improving end of life care must accept the challenge of finding ways to do more for less. However, this must not distract us from the need to assure and improve the quality of our care and support to people at the end of their lives.

It is critical that we build up an informed picture of the need for care of the dying, as well as mapping the provision of services. Fundamental to this is the systematic collection, analysis and use of robust data and information in order to effectively direct our efforts. Alongside this it is important to know how and where money is being spent on care at the end of life. The first year of funding to support implementation of this strategy has come to a close and the audit trail for this additional money is not wholly satisfactory. Some areas of the NHS are investing and some aren't. As planned, rigorous scrutiny is needed to track the use of the second year's allocation of end of life monies.

Even in times of economic challenge it must be possible for people at the end of life to get the high quality care and support they need, where they need it. The NHS, social services, voluntary organisations, community groups and the independent sector must continue to come together in partnership. It is most important that we take this time now to learn from one another and to share our knowledge and expertise.

We cannot overestimate the impact of continuing to make strides in developing a more educated workforce. Training and education remains vital and not just for those professionals already working to give care and support to people at the end of life. There are millions of people providing care to their loved ones and supporting carers more effectively will help us in responding to people's preferences for how and where they want to be at the end of their lives.

The pressures facing us are immense. It is absolutely imperative that we maintain momentum to ensure sustainable change. As this report demonstrates, turning this strategy into reality is not a task to complete but an ongoing commitment.

A handwritten signature in black ink, appearing to read 'Tom Hughes-Hallett', followed by a large, stylized capital 'S'.

Tom Hughes-Hallett
Chief Executive, Marie Curie Cancer Care
Chairman, End of Life Care Implementation Advisory Board

Executive summary

Dear Secretary of State

Last year I submitted the report on the first year of implementation of the End of Life Care Strategy. We had made a very encouraging start. Nationally, and across the country, the foundations and systems were being put into place to support service development and I was able to highlight a wide range of individual projects which were already making a difference.



This year I can report a real sense that momentum is building. Where last year's examples concentrated on infrastructure, this year we have some important developments along the entire end of life care pathway, and at national, regional and local levels. Nationally,

- e-learning for end of life care, free to all health and social care staff, was launched on 21 January 2010;
- The Dying Matters Coalition ran its first National Awareness Week from 15-21 March 2010 and its website has been developed;
- The successful hospices for the £40 million capital grant were announced in April 2010;
- The National End of Life Care Intelligence Network has started work and its website has gone live;
- The VOICES Survey pilot is ready to begin;
- The locality registers pilots started work in October 2009;
- The Department's Chronic Obstructive Pulmonary Disease Strategy was launched for consultation in February 2010, with a chapter on end of life care;
- We have begun development work for both bereavement services and spirituality, starting with literature reviews;
- Two deputy National Clinical Directors for End of Life Care, Dr Teresa Tate and Professor John Ellershaw, have been appointed to help raise the impetus of delivering the strategy.

The Vital Sign for End of Life Care continues to show a slow rise in the number of people dying at home. However, it has become apparent that the current wording is unhelpful, in that it talks only about deaths "at home". This has led some people to assume that care homes are not an important part of the strategy. Clearly, this is wrong. High quality end of life care for people in care homes means looking after them where they are actually living, just as it does for people in their original homes. Following the Spending Review, any future indicators which measure end of life care should reflect this.

Last year's report also noted the increasingly challenging financial climate and emphasised how important it would be that Primary Care Trusts (PCTs) made the most of the new money available to invest in end of life care over 2009/10 and 2010/11. Unsurprisingly, this theme is now a large part of the agenda, alongside the imperative to improve quality.

For end of life care the two are interlinked, since most people would prefer to die in their own home. High-quality community-based services cost no more, and can cost less, than hospital-based care.

The NHS Operating Framework for 2010/11 published in December 2009 encouraged PCTs to use resources to the best effect locally in order to provide quality end of life care, such as enabling choice of place of death.

We have the results for 2009/10 of the financial monitoring of the new end of life care money. In total for 2009-10 we had £88 million, which went largely to PCTs. The monitoring has shown a mixed picture, with some PCTs investing significant sums in a range of end of life care services and activities, others apparently using the money to support additional posts in services which they were already running, and others making very little or no investment. Results suggest that, in the main, although total new spend on end of life care across the country (including at national level) appears to be approaching the £88 million mark, those PCTs which have spent the most in 2009/10 are those which have historically been good at investing in end of life care and vice versa.

We are in an exceptionally privileged position for 2010/11 in that we have the balance of the £286 million still to invest. So we shall be repeating the monitoring exercise for 2010/11, alongside another iteration of the exercise we undertook ahead of the strategy to collect information on spend on specialist palliative care. The work programme beyond 2010-11 is subject to the next Spending Review which covers financial years 2011-12 to 2014-15. This means that plans highlighted in this report which extend into the next spending round are contingent on the outcome of the Spending Review in the autumn.

The Coalition's programme for government includes a commitment to *introduce a per-patient funding system for all hospices and providers of palliative care*. This is also picked up in the White Paper, *Equity and Excellence: Liberating the NHS*, with a commitment to

review payment systems to support end-of-life care, including exploring options for per-patient funding;

To take that work forward Tom Hughes-Hallett, Chairman of our Implementation Advisory Board, has been invited to lead a review of dedicated palliative care funding and to come up with recommendations which are fair, affordable, and which provide the financial incentives to deliver the right care in the right place for patients.

The White Paper also says

*In **end-of-life care**, we will move towards a national choice offer to support people's preferences about how to have a good death, and we will work with providers, including hospices, to ensure that people have the support they need.*

This theme is central to the End of Life Care Strategy and its linkages with other key policies such as QIPP.

The Department of Health's Quality and Productivity Challenge (QIPP) has been developed to help identify where and how the NHS can make £15-20 billion of productivity savings by 2014 while improving, or at the very least maintaining, quality. End of life care is one of the first twelve QIPP workstreams and Sophia Christie, Chief Executive of Birmingham East and North PCT, has been invited to lead it. QIPP is working with the strategy to accelerate work on the first steps of the end of life care pathway – identifying people who are approaching the end of life, and carrying out effective care planning with them.

We know that very few people would choose to die in hospital but that that is still where the majority spend their final days. We also know that hospital care is likely to be more expensive than care at home or in a care home, though it is difficult to put precise figures on the difference. But care out of hospital will meet more people's preferences, and medical needs, improving their and their family's experience of end of life care.

The QIPP sense of urgency itself chimes with the feeling of the Implementation Advisory Board and Strategic Health Authority (SHA) colleagues about implementation to date. This report has much to say about national, regional and local initiatives which largely meet the ambitions outlined in the strategy and in last year's Report. It is important that we get the infrastructure right and make sure that there is robust information, guidance and tools available to all who need them. But there is also a clear appetite to go further, faster, so that we can demonstrate real improvements in services and experience for individuals.

To do this we need to encourage the NHS to learn quickly from pilots and experience across the country. In the past the adoption process has often been slow and patchy. This has often been frustrating but now it is also unaffordable.

The National End of Life Care Programme has been collecting and publicising examples of good practice as a key part of its role since the strategy was published. It will continue to do so, with an added emphasis on productivity as well as quality, and will be working with SHAs and through a regenerated group of local end of life care facilitators to help spread adoption of interventions with a proven record of effectiveness.

Over this last year the National Programme has collaborated widely and supported other teams to produce a wide range of supportive material. Their work has:

- published the first practical guides in the *Route to Success* series, for care homes and acute trusts;
- published, with the National Institute for Health and Clinical Excellence (NICE), a commissioning guide for end of life care for people with dementia;
- developed, with the Department's dementia team, good practice guidance to support the NICE guide;
- developed, with NHS Improvement, a guide to end of life care for heart failure;
- published a summary guide to care planning, advance care planning and related topics;
- supported the Omega survey of GP practices;
- supported the Liverpool Care Pathway (LCP) National Care of the Dying Audit - Hospitals;
- developed a user involvement network;
- set up an end of life care facilitators' network to support local implementation;
- established a currency project with NHS East Midlands;
- supported test sites for acute hospitals;
- published a social care framework for end of life care;
- supported the development of e-learning for end of life care.

Each SHA has chosen to concentrate on specific aspects of the strategy or on specific steps on the end of life care pathway. This means that we are well placed to spread their learning quickly across the country. For example, NHS South Central has invested a great deal of time and effort in a unified, region-wide DNACPR (Do Not Attempt Cardio-Pulmonary Resuscitation) policy which they launched in March. Other SHAs who are in the process of starting this work for themselves will be able to borrow from South Central rather than do all the work themselves. This will not only save time, but will minimise future problems with cross-boundary working by encouraging a consistent – or at least compatible – approach nationwide.

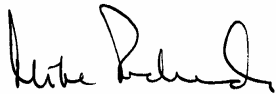
So where last year's report summarised progress on infrastructure, this year we have gone a great deal further on developing and launching the tools to support delivery of the strategy.

It is also becoming clear where we still have a long way to go, and where we need to harness the QIPP sense of urgency. The After Death Audit (ADA) report very helpfully showed us how far we are from fully engaging primary care in end of life care. Those figures suggest that even Gold Standards Framework (GSF) Practices deliver preferred place of death for a small minority of their patients.

Similarly, while the LCP's National Care of the Dying Audit - Hospitals showed that the Pathway is being used in more hospitals and more wards, the media debate at the beginning of 2010 about its value showed that there are still many people who do not understand what it is for, how it is used, or what benefit it offers to patients. The audit itself pointed to communications and care after death as two key areas for continued effort. So we have more to do still in the acute setting.

And the third area where we need to redouble our efforts is in care homes. Many people are still needlessly sent to hospital to die simply because care home staff do not know what else to do. 17% of people currently die in care homes and, since a care home in effect becomes home for its residents, we should be making every effort to increase that figure, just as we are working to increase the numbers of people supported to die in their own home.

These are the themes we shall be pursuing over the next year.



Professor Sir Mike Richards
National Clinical Director for End of Life Care

Chapter 1

Meeting the challenges of end of life care

Section 1 – The Department of Health

The Vital Sign

The key measure of progress against the End of Life Care Strategy is the proportion of all deaths that occur at home. If this figure continues to rise it suggests that more people are able to receive care and to die in the place of their choice.

“At home” has always been a proxy for choice in end of life care. For many people in care homes, that itself becomes their home and they would no more wish to leave there at the end of their life than they would their own home. Following the Spending Review, any future indicator for end of life care should take into account the fact that people may choose to die in care homes, in order to remove any ambiguity about choice at the end of life.

Before making any such amendment we need to be certain that our definitions are as accurate as possible. The Office for National Statistics (ONS) uses a lengthy list of possible places of death, not all of which fit obviously into the broad categories against which we have been measuring progress. We are therefore conducting an exercise to revisit the categorisations decided by the Analytical Working Group for the strategy. For this year’s report, however, we are continuing to use those original categorisations.

Oxfordshire: Lawrence Home Nursing Team

This charity was set up to enable people to stay in their own homes at the end of life. District Nurses and GPs had highlighted the fact that patients were being admitted to hospital at the end of life because there was no support at home. Families became tired and were not able to cope.

Lawrence Home Nursing Team (LHNT) has a team of registered nurses who all work on a bank system to provide the care needed to enable people to stay at home at the end of life regardless of diagnosis. Care is planned with each patient, their family and carers, both formal and informal, to meet their individual needs. The majority of the work is overnight.

LNHT was set up as a charity supported by one of the local GP surgeries. Surgery GPs and other members of the community lead on the management committee making this a very well supported and respected local organisation. Raising money in the first place was very successful with the support of the local community. This year under the auspices of the End of Life Care Strategy Oxfordshire PCT has put a contract in place which provides a small amount of annual funding to support the service.

LNHT does not to replace existing services but works with them. They work very closely with Katharine House Hospice who provide specialist advice and support. They use the district nursing notes and the district nurse remains the key worker.

Feedback has been very positive – “We, my family and myself would like to thank every one involved for the very much appreciated help you gave us in our troubled time. First class service, first class people.”

LNHT also gathers data on numbers using the service and number of days stay to measure effectiveness of the service each year.

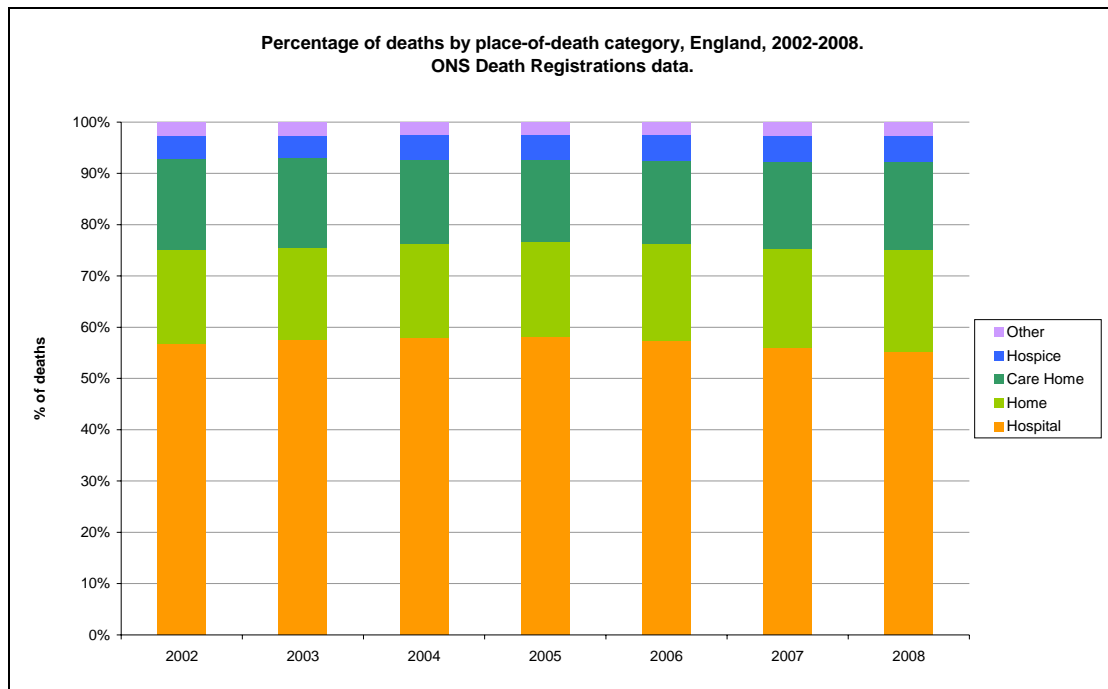
The practice which is central to this service has much smaller numbers for admission to hospital to die (by GP or 999 emergency admission) than other surrounding practices.

The GPs involved are keen to promote and encourage other practices in end of life care work, while the team who leads this service is keen to support and inspire others in developing similar services in their own areas.

Contact: Nursing Co-ordinator/ Registered Manager Jenny Nolan 01608 641549 jennylhnt@yahoo.co.uk www.lawrencehomenursing.org

The latest ONS figures continue to show a very slow trend away from deaths in hospital (55%) towards death at home (20%). This is encouraging but we need to see it speed up if end of life care is to deliver its potential quality and productivity gains.

End of Life Care Strategy: Second Annual Report



My husband was suffering from cancer, he was in [hospital] 3 Feb 2010. Doctors said nothing else they could do for him, I said he's going home. Macmillan nurses got everything arranged and he was home 4 Feb 2010... This service from all concerned was absolutely brilliant, cannot fault them, in every way they were all very caring and thoughtful.

comment posted on the Patient Opinion website www.patientopinion.org.uk

The NHS Operating Framework

End of life care continues to feature in the Operating Framework for the NHS published in December 2009. For 2010/11 the Framework concentrated on effective use of resource -

"Providing quality end-of-life care, such as enabling choice of place of death, is another area where PCTs will want to ensure they are using resources to the best effect locally."

The Revision to the Operating Framework for the NHS in England 2010/11 published in June 2010 does not affect end of life care or its Vital Sign, which continues to be current for the remainder of 2010/11.

NHS Worcestershire: whole systems redesign of the end life care pathway.

We are working collaboratively with providers and stakeholders through the Worcestershire end of life and palliative care network to implement a whole systems redesign of the end of life care pathway. The work is supported by the Marie Curie Delivering Choice Programme.

- We are recruiting to ensure district nursing has the capacity and capability to respond rapidly 24/7 to patients at the end of life;
- Communication between providers (especially out of hours and ambulance) enhanced through introduction of a new communication form;
- Local enhanced service for primary care to ensure better identification of patients at the end of life (especially in nursing and care homes and for those with dementia), better advance care planning and communication. Most importantly, all lead GPs who have signed up have received a whole day's training on end of life and palliative care issues and all GPs received training on care pathways and symptom management;
- About to launch rapid access to appropriately trained carers to support patients to remain at home when care needs change (initiative will be delivered in partnership with hospices);
- Access to specialist palliative care drugs improved in the community ('just in case' boxes launched).

Contacts: Debbie Westwood, Programme Lead, End of Life and Palliative Care, NHS Worcestershire (Debbie.westwood@nhs.net)

Payment by Results

The Coalition's programme for government includes a commitment to introduce a per-patient funding system for all hospices and providers of palliative care. As the first step for this we have set up a review of dedicated palliative care funding, looking at how this care might be costed and paid for across all the relevant sectors. The review will develop recommendations for a system which will be fair to all providers and encourage the development of community based services. Although the End of Life Care Strategy itself applies only to adults the review will also be looking at funding for children's dedicated palliative care. Tom Hughes-Hallett has agreed to chair this review which is due to make an initial report in the autumn and a final report in summer 2011. Terms of reference are at Appendix 1.

The review will be able to build on the work already undertaken to develop Health Resource Groups (HRGs). Currencies (units of payment for care), which underpin tariffs, have been developed for in-patient specialist palliative care in hospitals and hospices, but not community services. As part of the work on Transforming Community Services we have explored some of the issues for working up currencies for community-based specialist palliative care and the review will take this as its starting point for these services. The National End of Life Care Programme is working with NHS East Midlands on currencies and costing for end of life care in the community which is due to be completed later this year.

Personal Health Budgets

In 2009, the Department launched a three-year pilot programme to explore the potential of personal health budgets in the NHS, as a way to give people greater choice and control over the care that they receive. This could include

choosing different treatments, for example to support pain relief; choosing non-traditional services such as aromatherapy; or choosing non-NHS providers of care. A personal health budget is based on a care plan that is agreed between the PCT and the individual. A PCT or a third party can hold the budget and arrange the care on the person's behalf, or an individual can do this themselves (via a direct payment). Regulations, which came into force on 1st June, allow approved pilot sites to offer direct payments in the NHS for the first time.

Around half the PCTs in England are involved in the pilot programme and the first people are starting to be offered personal health budgets. Some pilots are looking at the use of personal health budgets for end of life care. This is a group that will be studied in more detail in the independent evaluation, which is due to report in autumn 2012.

Integrated Care

The programme of Integrated Care Pilots is a two-year Department of Health initiative designed to explore different ways in which health and social care could be provided to help drive improvements in local health and well-being. "Integration" may refer to partnerships, systems and models as well as organisations; the pilots are crossing boundaries between primary, community, secondary and social care.

Following a robust two-stage assessment by a team of clinical, professional and managerial assessors, 16 sites were selected as pilots and announced on 1 April 2009. These included Cambridgeshire Assura LLP which is looking at how different organisations across the health, social care and third sectors can better communicate and co-ordinate end of life care to enable people to be cared for and die in the place they choose. The pilot aims to improve public and patient engagement and thus ensure services are fully sensitive to people's needs.

The pilots are still in the early stages of implementation and evaluation. A progress report is expected to be completed by the evaluation team by August 2010 and the final evaluation report is expected by December 2011.

Section 2 - The Coroners and Justice Act

The Coroners and Justice Act received Royal Assent in November 2009. Among other measures, it creates a new national coroner service, led by a new chief coroner. The timetable for implementing the reforms is currently being discussed with Ministers.

Section 3 - Care Quality Commission

From April 2010, the Care Quality Commission (CQC) began to operate a new registration system, initially covering NHS providers. From October 2010, the CQC will register private and voluntary healthcare and adult social

care providers under the 2008 Act, replacing the existing registration of these providers under the Care Standards Act 2000.

The CQC has issued its *Guidance about Compliance*, which explains in more detail how providers can comply with the registration requirements. This guidance is not itself enforceable, but providers must have regard to it in complying with the registration requirements, and it must be taken into account by the Commission when any decision about registration is taken. The guidance fits with the Quality Markers for end of life care.

Section 4 - The National End of Life Care Programme

As the NHS-based delivery arm for the End of Life Care Strategy, complementing the Department's policy team, the National End of Life Care Programme has contributed to many of the developments recorded in this report. The National Programme's core role is to identify and share best practice to support and empower staff at local level. It does this by working in partnership with organisations across the statutory, voluntary and private sectors for both health and social care.

While we have good professional engagement, it can sometimes be challenging to involve the actual people who are dealing with end of life care issues, whether as individuals or carers. This report includes a selection of comments, split between praise and criticism, posted on the Patient Opinion – a not-for-profit social enterprise - website www.patientopinion.org.uk. The National Programme is developing a user involvement network and will be publishing vignettes of actual experience. This will keep the strategy focussed on what is really important to the people it was designed to benefit.

It should not be down to 'luck' and where we live in the country as to how we die, we all know death happens and we should be more prepared, human and caring.
comment posted on the Patient Opinion website www.patientopinion.org.uk

The National Programme's main channels for dissemination are an electronic newsletter, which has been increased to a monthly circulation to about 1,500 recipients, to accommodate the growing number of examples and the speed of local developments, a series of useful practical resources to support local delivery, and a revised website (www.endoflifecareforadults.nhs.uk).

Although end of life care spans health and social care services, joining these up has proved challenging. We have made progress to address this through encouraging organisations to work through initiatives such as the e-learning project, where Skills for Care and Skills for Health collaborated. The National Programme has now identified two social care leads to join the team. This in itself has taken longer than expected but already they have developed a practical social care framework.

The social care framework, developed by a multi professional group, was published in July. It sets out a direction of travel and recommends a series of actions to tackle the barriers to good end of life care. It emphasises how end

of life care is relevant to all 1.5 million workers in social care and aims to develop the structures and tools to help deliver it. One of the framework's key actions is to raise awareness of, and to clarify, social care's central role in end of life care – both within the workforce itself as well as working with other sectors and with the general public. Education and training will be the essential factors required to make progress.

This framework is being disseminated through a series of regional road shows and conferences. A series of test sites, supported by the National Programme, will pilot different approaches recommended in the framework.

There is also a need at local level for more resource to support implementation. This has been highlighted by the acceleration to implementation of the strategy through its relationship with the QIPP programme. The National Programme is therefore supporting and working with a network of local facilitators whose role is to implement the changes and service redesign needed in their area.

The National Programme has also commissioned a detailed external evaluation of its own role and contribution which will report in December 2010.

Chapter 2

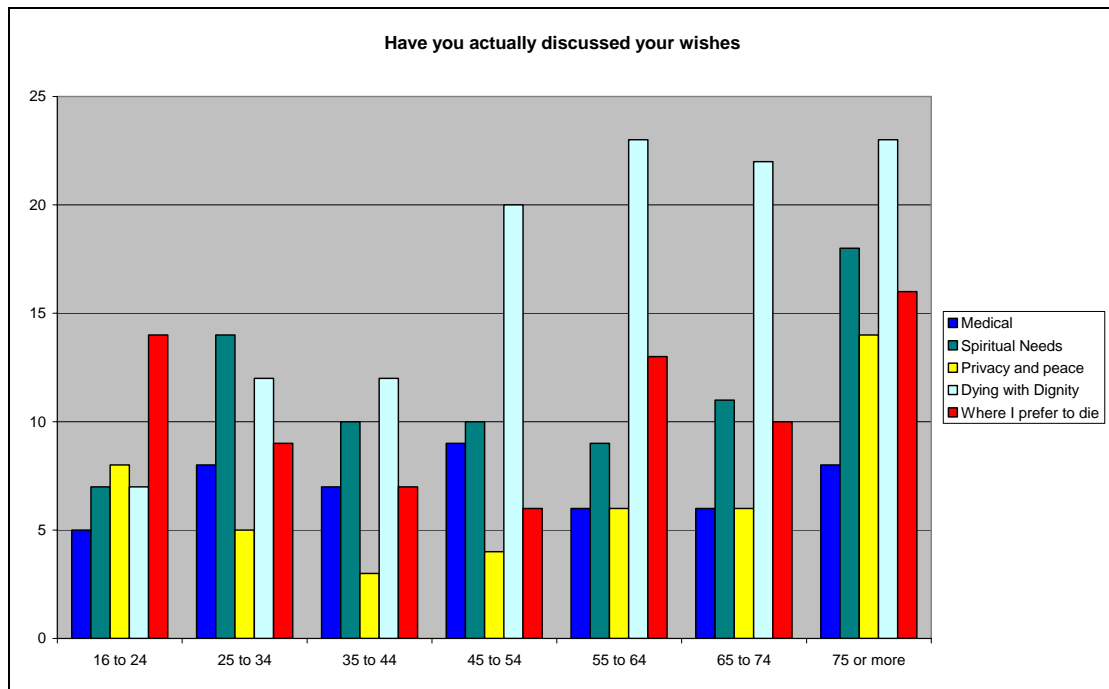
Death, Dying and Society

One of the most challenging aspects of the End of Life Care Strategy is to change public attitudes to death, dying and bereavement. The taboo on discussing death is a major barrier preventing people from receiving the sort of care they would prefer at the end of life.

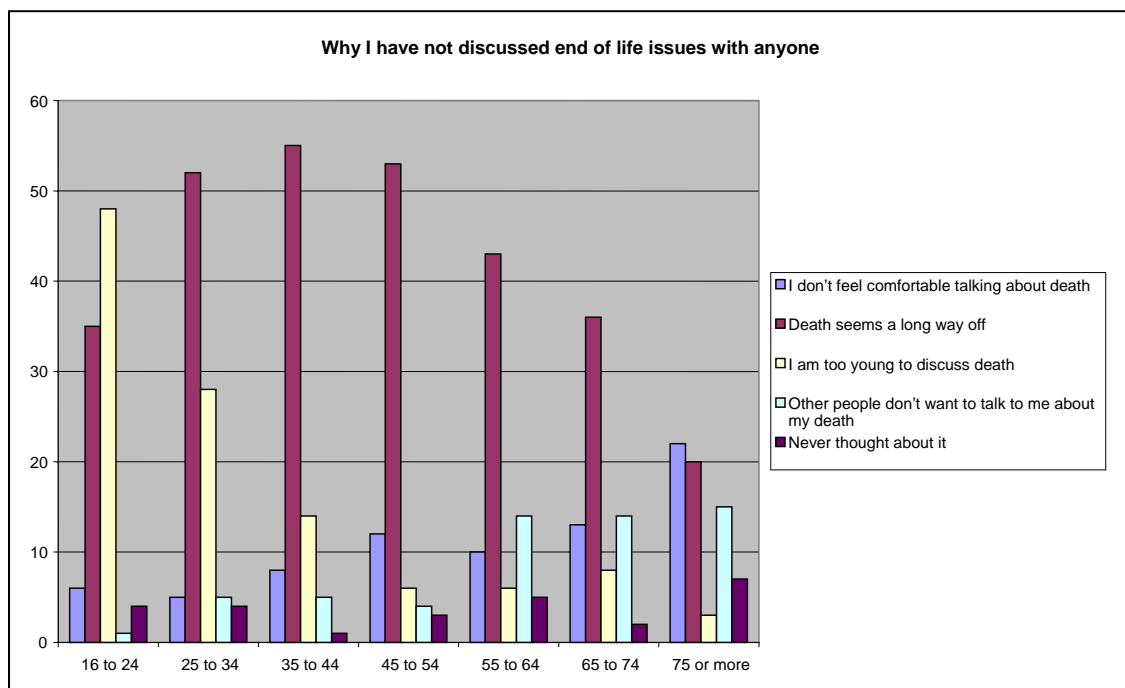
The strategy is tackling this head on through the Dying Matters Coalition led by the National Council for Palliative Care (NCPC). The Coalition has been running since April 2009 and has already gathered more than 10,000 members from a diverse range of backgrounds. Initial interest came, as expected, from the palliative care and hospice world and has spread rapidly across health and social care and other organisations. The English Community Care Association and the National Care Forum have joined all their care homes and housing organisations en bloc, raising membership by about 5,000. In addition, the Church of England, Liberal Judaism, British Humanist Association, the Quakers, the Muslim Women's Network, the National Secular Society, the National Pensioners Convention and the Probate Section of the Law Society and many others have also signed up.

As its first major piece of work the Coalition conducted a survey of public attitudes using the National Centre for Social Research (NatCen). The results showed that less than a third (29%) of people had discussed their wishes around dying and only 4% had written advance care plans. Despite this, more than two thirds (68%) of people questioned said that they were comfortable talking about death.

End of Life Care Strategy: Second Annual Report



Of those people who had not discussed any aspect of their end of life care, 45% felt it was because death felt a long way off, and a further 18% said they were too young to discuss it. Even 8% of 65-74 year olds thought they were too young to discuss dying.



The Coalition has launched a website with a range of information and specially designed materials. This includes a five-minute film which introduces Dying Matters and the aims of the Coalition through real-life stories. The site also signposts visitors to other appropriate sites. Over the Dying Matters week the site received 4,712 hits, while the Dying Matters Facebook site has 357 members.

Dying Matters held its first Awareness Week in March. This was supported by a wide variety of activities across all the health regions as well as extensive media coverage, both national and local. A Coalition Launch Event was held in London on the 15th March which included presentations, analysis and findings from a range of experts and the public. A practical resource pack with targeted literature to help having the conversation about dying and death was presented. The day included a display of painted urns in Trafalgar Square involving a range of celebrities. The launch concluded with a sketch on dying well by Amanda Waring, Virginia McKenna and David Simeon and also the launch of the publication *Dying to Know*, by Jane Tewson and presented by Dame Julia Cleverdon (Vice President, Business in the Community).



Display in Trafalgar Square

The Dying Matters key messages were heard across the media during the Awareness week, including: 65 separate slots of TV and radio coverage; four articles in the national papers; 13 in the newswires and trade titles; and 30 regional pieces across the country. More than 1.5 million listeners heard the Dying Matters message on radio alone.

The Coalition has agreed from its survey analysis that its key target groups are 55-65 year olds, 65-75 year olds and general practitioners to raise confidence about having the sensitive conversations. It will also work with a range of community groups such as schools and pensioners in order to reach the target groups.

The Coalition is working to four key performance indicators to measure progress by 2014 with people aged 55-75 regarding how comfortable they feel talking about death; if they have discussed their wishes; and if they have some form of written plan. The extent to which GPs are discussing their own end of life care will also be measured.

NHS North East: Developing a compassionate community approach to A Good Death

In the north east, the *Better Health, Fairer Health* strategy established end of life as a public health priority and responsibility. Our approach has been to focus on the development of a public health charter for *A Good Death*, with a

statement of the rights and entitlements both for the individual preparing for death, and for their carers and families. We stress the need to 'normalise' death, build public health capacity, and create a compassionate community approach to end of life. Paradoxically, this is not principally about dying - it is about living with dying - and indeed ensuring we live to the fullest of our potential with meaning and value in whatever time we have.

Our progress so far

We have produced a draft charter in partnership with health, social care and other organisations in the north east. Extensive public consultation provided an opportunity for the public and professionals to make a real contribution to the charter's final scope, content and tone. We received 2,500 on-line and on street responses to our consultation and carried out detailed focus group and face to face research. The findings of our consultation are now available. In summary, there is public and professional support for a charter, subject to minor refinement and rewording. We now have a mandate to proceed to embed the charter approach into all organisations dealing with end of life issues and wider society.

Sharing the lessons learned

We have 18 months' experience of developing, refining and consulting on our draft charter and have learned some valuable lessons along the way - both good and bad – about partnership working and public engagement. We are keen to share our experiences with other SHAs, PCTs and partners who are considering a similar approach.

Our plans for implementation

Our approach is to promote, implement and evaluate the charter, and raise awareness by developing a community response to death, dying and bereavement. We will pilot the development of workforce training and capacity building for staff in a range of health and community settings. Our aim is to build a society where death is accepted as a 'normal' part of life, individuals recognise their responsibility to be compassionate to those who are dying and their loved ones, and the policies and practice of all organisations are sympathetic to the needs of dying people.

Developing a 'Compassionate Community' unit

It is neither cost effective nor desirable to see death as the province of clinical medicine. Through NHS innovation funding we have established a Compassionate Community Unit at Teesside University in partnership with NHS Tees.

The new unit will implement the charter, stress the need to 'normalise' death, build public health capacity and aim to create a compassionate community approach to end of life. It provides an opportunity to establish the north east as an innovative test bed for charter ideas. In establishing a dedicated unit we are the first region in the country to implement a plan to use public health approaches to transform end of life services. We are fully supported by the National Council for Palliative Care and the Dying Matters coalition and are jointly disseminating our findings.

Project staff are in the process of developing an action plan which includes:

- building awareness of and support for the charter by engaging with defined and diverse communities;
- redeveloping practices of informal care that will support professional care;
- developing support systems for those caring for others at end of life;
- developing and evaluating courses or training that meets these needs;
- working with major employers to develop compassionate HR policies;
- disseminating nationally and internationally the lessons learned from the innovation.

Contacts: Moira Davison, Programme Director 'Our Vision, Our Future' (moira.davison@northeast.nhs.uk); Keith Aungiers, Head of Projects and Intelligence, Public Health North East

The Dying Matters Coalition GP pilot project

The Coalition has embarked on an exciting new pilot project to support GPs to improve palliative and end of life care for their patients and build their confidence. It will focus on raising awareness and knowledge of GPs as key influencers of the public as identified in the national surveys. A small team including three GPs, chaired by Professor Mayur Lakhani, will advise the project which began with three training workshops in April and early May and will run for four months. 25 GP practices have joined the project from the North East, Midlands, London, the South East and the South West. Materials have been provided to support their awareness raising. The project will be evaluated on completion and if successful it will be rolled out further.

Hard to Reach Communities

The Coalition has developed a joint project with NCPC to engage with hard to reach groups in communities. They held workshops with homeless projects in March and early April, to complement feedback from project workers. A collaborative workshop is being planned with the Policy Research Institute for Ageing and Ethnicity, to explore the views of BME people, which will complement work already carried out with South Asian Elders. A meeting has been set up with the team who produce *Books Beyond Words* for people with learning disabilities to gain feedback and explore opportunities for joint working. Feedback from all of these will to inform ongoing Dying Matters work.

Schools project

A joint project with NCPC and the Dying Matters Coalition saw the development of a lesson plan and resource pack for secondary school teachers created by students following their successful engagement with St Joseph's Hospice. The students were keen to create a Dying Matters resource pack to help facilitate open and honest conversations about death

within the school environment. The lesson plan was launched in the House of Commons during the Awareness Week.

NHS North West

One of the key recommendations of the North West End of Life Care Clinical Pathway Group is that:

“A public campaign should be established to raise awareness about end of life care resulting in a more open conversation within society which also engages people’s views about death and dying.”

We developed a guide for health and social care workers across the North West to suggest partners for collaboration in shared awareness events for the Dying Matters week in March 2010. This was supported with a “Check List” leaflet and other supporting material for events.

Our snapshot evaluation of just 26 of these events suggested over 9,000 people attended and a real desire to continue this work over the years to come.

With this evidence, we are now working on a comprehensive North West strategy, making links with Public Health and measured through our Quality Markers and the Dying Matters survey data.

Contact: Andrew Khodabukus, NHS North West Leadership Fellow in End of Life Care, Royal Liverpool University Hospital
[*\(Andrew.Khodabukus@rlbuht.nhs.uk\)*](mailto:Andrew.Khodabukus@rlbuht.nhs.uk)

Plans

Over the next year the Coalition will be working on a range of activities with members to raise awareness, including community outreach projects in different parts of England. These will involve a wide range of organisations, as illustrated in the diagram below, to promote compassionate communities and to ensure their sustainability. This will include community projects in the North East, North West, in the Midlands and in London and the South.



The Coalition will be disseminating the targeted leaflets already produced to support conversations on dying, death and bereavement in a range of settings and evaluating and developing further materials to support conversations and encouraging planning for end of life care.

The Coalition will be working in partnership with the National End of Life Care Programme to produce guidance to help the public better understand advance care planning and to prepare their plans in a practical way. This will support the QIPP agenda.

Further work with schools and our target groups working with hospice and care homes is planned on intergenerational understanding and support in communities. On the 1st November it is proposed to hold a further national event to promote the work underway in these community outreach projects. This will be linked to celebrating with other communities to showcase a range of community outreach projects, as part of the Day of the Dead, all Hallows, Halloween and All Souls. There will be further raising awareness activities planned for May 2011.

Dying Matters website: www.dyingmatters.org

Chapter 3

The end of life care pathway

The end of life care pathway continues to provide the framework for a wide range of activity from identifying the right people who need end of life care through to supporting bereaved families and carers. It is essential that service redesign continues – in particular, to make sure that the right services are in place to support people at home and in care homes. This improvement in the quality of people's experience is intimately linked to the productivity gains offered by end of life care. And while the productivity gain is offered by minimising the numbers of people who spend their last days and weeks in hospital, we recognise that there is an irreducible core for whom hospital will continue to be the appropriate setting. This means that we also need to continue to improve the quality of end of life care offered in the acute sector.

For QIPP we have identified the early part of the pathway to be highlighted and accelerated, since this will itself help to build momentum for the rest by making it clearer how many, and which, people need these services and what their actual choices are for care.

Step one – Identifying people who are approaching the end of life

... We knew she was going to die, she knew she was going to die, but just wanted it to be pain free. The staff on the whole carried on as if she was going to get better and seemed unable to recognise the inevitable and change their tone and planning accordingly.

comment posted on the Patient Opinion website www.patientopinion.org.uk

This essential first step is often the most difficult and the evidence suggests that we need to do more here. The After Death Audit (ADA) of Gold Standards Framework (GSF) GP practices conducted through the Omega survey found that 42% of deaths were considered to be sudden. This contrasts sharply with the National Audit Office's finding from the Sheffield study published in its 2009 End of Life Care report that unexpected deaths made up only 8% of the total. Since GSF practices can be expected to be the best performers here this raises questions about the way primary care approaches end of life care.

We are also concerned that the acute sector should receive the help it needs to identify people who are approaching the end of life. The National End of Life Care Programme, in collaboration with NHS East Midlands and St Thomas' Hospital London, are supporting three sites to test out the transferability of the AMBER model. AMBER stands for "Assessment, Management, Best Practice, Engagement of patients and carers, for patients

whose Recovery is uncertain". This has been developed by the modernisation initiative at St Thomas' Hospital, London to support clinical staff to identify patients who are in the last few months of life. The test sites - Northampton General Hospital, University Hospitals Leicester and Nottingham University Hospitals - will report in spring 2011.

The "surprise question", where a health professional asks themselves "Would I be surprised if this patient were to die within the next year (or three months, or six months)?" is one simple and effective tool which needs to be applied to a range of conditions. The long-term conditions QIPP workstream will adopt this into its own plans to be sure that people with conditions such as heart failure and Chronic Obstructive Pulmonary Disease (COPD) are identified at the right point.

An audit of nursing home patients' end of life care in North Bristol NHS Trust

This retrospective audit aimed to establish whether people who died within seven days of admission to hospital were appropriately admitted from nursing care homes, when it was recognised that they were dying, and by whom.

The care of patients from nursing homes admitted to North Bristol NHS Trust (Southmead and Frenchay sites) who died within seven days was reviewed by a senior staff nurse and a registrar to see what lessons could be learned.

All patients who were admitted from a nursing home in the period October 2008 to September 2009 were identified (N=85); 31 sets of case notes (36%) were available and the medical notes for these final admissions were analysed. Subjective judgements about the appropriateness of a patient's medical admission were made by an experienced doctor and senior nurse.

Primary care physicians and the homes themselves would be in a good position to have discussions with these people so that they are not rushed into hospital for the last few days of their lives. The 'surprise question' as identified in the End of Life Care Strategy may help clinicians to identify people whom this discussion would benefit.

When these patients are admitted to the acute hospital they are looked after by doctors who do not know them. As a result there appears to be a tendency for quite aggressive treatment, and a delay adopting palliative measures, causing distress as well as being a poor use of healthcare resources.

The cost of providing seven days of end of life care, including emergency admission, in North Bristol NHS Trust has been estimated by Trust accountants as £3,787. The need for this could be reduced by better communication between primary and secondary care. A higher degree of planning around predictable end of life issues for nursing home patients would improve their terminal care and save increasingly stretched healthcare resources.

Contact: Abigail Bartlett, End of Life Care Research Nurse, North Bristol NHS Trust, Cancer Services, Southmead Hospital, Bristol (Abigail.bartlett@nbt.nhs.uk). 0117 959 5245

While the end of life care pathway itself is generic, different types of condition need more tailored approaches. Cancers, for example, while themselves a heterogeneous group, are a different proposition from dementia. It will not be possible or necessary to devise specific pathways for every single disease but it will be helpful to have a range applicable to the broad groupings. Last year we noted the work on kidney disease which provides a model approach for other organ failures.

Palliative care for advanced chronic kidney disease at the low clearance renal clinic Leeds Teaching Hospitals Trust, West Yorkshire.

Recent evidence has suggested that patients over 75 years with significant co-morbidities may not benefit from dialysis. The aim of this service was to offer a choice of 'no dialysis' in the regional renal low clearance clinic; to change the emphasis of care for patients who chose this pathway to more holistic, supportive care led by a multidisciplinary team, consisting of a palliative medicine consultant, pre-dialysis nurse and social worker. This service is referred to as the 'conservative renal clinic'.

The main challenge has been to change the emphasis of care from interventional medical treatment to a more holistic, supportive role. This was achieved by working in partnership with the renal team. As the conservative clinic was *within* the renal low clearance clinic and all other aspects of care were still treated, 'no dialysis' felt like a choice for patients rather than a discharge from the service. Earlier involvement with palliative care services increases patient acceptability.

A further challenge was to disseminate knowledge and education to the wider regional palliative care services and to maintain good communication with primary care teams who cared for these patients in their local communities. This has been achieved by several teaching events for multidisciplinary staff.

By September 2009, we had achieved the following objectively measurable outputs:

- A total of 126 patients had been regularly reviewed by the service;
- 100% top mark in every question from every service user in a patient satisfaction survey;
- The clinic staff have received numerous thank you cards, flowers and chocolates from grateful relatives and thanks expressed by primary care teams;
- Only 7/126 (5.5%) patients changing their mind from non-RRT to receiving RRT following referral into the service;
- 82/126 (65%) receive input from social services (43% advice/support/signposting; 26% care package; 18% housing/benefits advice; only 8%

fast-track continuing health care support; all offered bereavement counselling).

Future plans, as the numbers of patients continue to rise, are to develop satellite conservative clinics throughout the region modelled on this central service so that patients can receive this treatment nearer to home. This will involve training of regional staff by the current service leaders and some funding. The first of these satellite services has been set up in Calderdale with regular support and feedback from the Leeds clinic staff.

Contact: Dr Lynne Russon, Consultant in Palliative Medicine, Sue Ryder Care, Wheatfields and Leeds TH Trust, Wheatfields Hospice, Leeds LS6 2AE lynne.russon@suerydercare.org. 0113 2787249

As a next step, the National Programme has worked with the Heart Improvement team at NHS Improvement, to test whether the kidney approach could be replicated for heart failure. An expert group explored alternatives before deciding that the kidney model would be suitable. The document was published in June 2010.

The Department has consulted on a Chronic Obstructive Pulmonary Disease (COPD) strategy, published in February. This outlined the specific difficulties in identifying when people with the condition were likely to enter the end of life phase, and made specific recommendations aimed at improving access to end of life services and ensuring appropriate information was available to carers and those who are bereaved. It also recommended that, working with NHS Improvement, further work should be undertaken to pilot markers of a prognostic indicator to identify the end of life care phase for people with COPD, and to develop an end of life care pathway and evaluate different models of support for carers. This work is supported by the National End of Life Care Programme.

The National End of Life Care Programme is developing a pathway for neurological conditions working in collaboration with the National Council for Palliative Care, clinical champions, an expert clinical reference group and the Neurological Alliance. This will be published later this year.

Step two – Assessment and care planning

This is the second strand selected for the QIPP end of life care workstream. The concept of personalisation is central to the Department's approach to care for people with long-term conditions, including their care at the end of life. It means putting people at the centre of decision making about their own care and planning their care, regardless of the actual condition or combination of conditions people are living with. While there is a growing number of examples where this happens there is still significant scope for improvement in practice, using the existing and developing guidance.

NHS East of England: Single Holistic Assessment in end of life care: developing an assessment pathway

This project aims to develop an assessment pathway for end of life care to ensure that :

- Patients receive appropriate assessments at the right times in their journey;
- Assessments are performed by an appropriate professional with the right competences;
- Professionals undertaking assessments can access an assessment tool that is fit for purpose.

The project will:

- Identify which assessments an individual approaching the end of life may need and when they should be done;
- Identify the appropriate care professional to work with the patient to carry out the assessment;
- Guide the professional towards nationally used tools or those benchmarked against national standards where they exist;
- Integrate the quality markers for assessments;
- Ensure the use of any assessment pathway is integrated into the education and training strategy for end of life care and that this is rolled out to both health and social care professionals;
- Integrate the pathway into other relevant care pathways e.g. long-term conditions and cancer survivorship;
- Develop electronic access to both the pathway and assessment tools which can be both locally and nationally agreed;
- Integrate the pathway into the Common Assessment Framework once this has been established.

A subgroup of the East of England (EoE) Palliative and End of Life Care Clinical Programme Board was established with representation from health and social care professionals across the EoE with the aim of:

- Undertaking a baseline assessment of current regional and national practice;
- Identifying what constitutes best practice;
- Assessing the feasibility of implementing a standard policy, procedure and documentation for single holistic assessments across the EoE.

A joint project between the National End of Life Care Programme team and the EoE End of Life Care Programme Board has now been established to take forward the development of an assessment pathway.

Contact: Catherine O'Doherty, Consultant in Palliative Medicine, Basildon and Thurrock University Hospital NHS FT, Nethermayne, Basildon, Essex SS16 5NL; 01268 593088. catherine.o'doherty@btuh.nhs.uk

On 30 March 2010 the Department published a patient leaflet on personalised care planning which explains to patients with long-term conditions what they should expect from the process.

In January 2010 the Department published *Improving the health and well-being of people with long-term conditions: World class services for people with long-term conditions – Information tool for commissioners*. It aims to share a common vision of what a good service is for people with long-term conditions and provides practical suggestions for commissioners to help them achieve that vision.

End of life care pilot studies using Gold Standards Framework (or GSF equivalent) tools in a 'whole systems' approach in the East of England

This work aims to demonstrate improvements (patient care and costs) to PCTs to encourage them to continue and sustain the end of life care training across the region.

We shall use independent evaluation to measure the difference in outcomes for the three approaches being tested. This will be done by the Public Health Action Support Team (PHAST) who link with Imperial College, London. The research part of the project will last two years.

Pilot 1 (shared pilot)

NHS Peterborough and NHS Beds/NHS Luton will implement a standard version of the Gold Standards Framework (GSF) in up to 35 care homes and up to 50 primary care providers. This study will be run over one year.

Pilot 2

NHS Suffolk will implement a shortened version of the GSF in up to 35 care homes and up to 50 primary care providers. This study will be run over a maximum period of nine months.

Pilot 3

NHS Hertfordshire will implement their own end of life care toolkit (GSF equivalent) in up to 35 care homes and up to 50 primary care providers. This study will be run over one year.

Two End of Life Care facilitators will be recruited for each pilot.

As set out in the End of Life Care Strategy, the GSF (or GSF equivalent) will cover the following subject areas in the training of staff:

- Communication skills
- Assessment of the person's needs and preferences
- Advance Care Planning
- Symptom control
- End of life care tools (GSF, Preferred Priorities for Care, Liverpool Care Pathway)

The pilot studies are due to start in May/June 2010.

Contacts: Vanessa Convey, Programme Manager for Palliative and End of Life Care Education & Training, NHS East of England, Victoria House, Cambridge CB21 5XB. 01223 597500. vanessa.convey@eoe.nhs.uk

The Preferred Priorities for Care (PPC) team are undertaking a pilot to test out if posters and information leaflets encourage individuals to initiate discussions about their preferred needs for end of life care. The pilot will report its findings in September 2010.

Last year the National End of Life Care Programme published a guide on advance care planning for the public, *Planning your future care*. This proved very welcome and has had to be re-printed to meet demand. The National Programme has now commissioned an evaluation to see if the guidance has brought about any measurable changes to match its popularity. The evaluation will be published in August 2010. The National Programme has also commissioned an economic evaluation of advance care planning itself, due to report in January 2011.

Throughout his various and extensive treatments, the medical and nursing teams involved in his care was absolutely second to none. He was made to feel comfortable and treated with respect at all times. The nurses and doctors always found the time to talk to relatives and we were therefore fully understanding of the issues facing him.

comments posted on the Patient Opinion website www.patientopinion.org.uk

It had become evident that there was confusion in the field about the differences between care planning and advance care planning, including the relationship with Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR), and the legal status of all of these things. The National Programme has produced a summary of the defining characteristics of each, reproduced at Appendix 2, suitable for a notice board.

Step three – Co-ordination of care

The communication between different departments/wards was not ideal.

comment posted on the Patient Opinion website www.patientopinion.org.uk

End of life care locality registers

The End of Life Care Strategy advocated the development of locality registers as a way to improve the co-ordination of care for people at the end of life, and their families and carers. Over this year we have made important progress in this key area.

The locality registers are electronic records where important details are recorded about all those people in an area who have been identified as approaching the end of life. Relevant organisations in an area, such as Out of

Hours (OOH) and ambulance services, will have access to the register, so that details of a person's care plan, medication and preferences can be accessed immediately when the person presents to a service.

In July 2010, eight pilot sites were selected to develop and test out a variety of approaches to the development of a register. The sites are:

- Camden PCT Provider Services
- Royal Marsden NHS Trusts and Connecting for Health
- Sandwell PCT
- Salford PCT with Salford Royal NHS Foundation Trust
- Weston Area Health Trust (for South West SHA)
- NHS Brighton and Hove
- Leeds Teaching Hospital
- NHS Mid Essex.

The approaches, and consequently the technologies, adopted by the pilots have been informed by the extent of Summary Care Record (SCR) roll out in the local area, the strategic plans of the SHA and PCTs, and the types of systems being utilised by local GP practices, OOHs, and acute trusts. The main system chosen is Adastra (Camden, Royal Marsden, South West SHA and Mid Essex). SystmOne (Sandwell), SCR (Brighton & Hove), and locally devised systems are also being employed.

South West SHA: Web based end of life care register

Organisations across NHS South West are introducing a web based, electronic patient register for end of life care. The project was initially developed by Dr Julian Abel, Consultant in Palliative Care, Weston Area Health Trust and Weston Hospicecare, and piloted in conjunction with GP practices and secondary care providers within North Somerset and Somerset PCTs.

The register is designed to be simple and easy to use. It contains information on patients' wishes about their end of life care that can be seen by professionals across the health community. It is accessed via a secure IT link, and governance arrangements are in place to ensure confidentiality and patient consent. The register is hosted by Adastra and will be available 24 hours a day, 7 days a week to all who need to access it, including GP surgeries, community matrons, hospice and hospital teams, specialist nurses, ambulance services, NHS Direct, and potentially also care homes.

The South West is one of eight national pilot sites for the development of an electronic register and this is so far being adopted across 13 of the 14 PCTs in the region. Training in the use of the register has been supported by use of the Multi-Professional Education and Training allocation, and is going hand in hand with education on advance care planning to ensure that it is embedded in clinical practice.

The register will be important in achieving the NHS South West ambition of ensuring all localities are able to identify patients who have a plan for their death and whether their preferences around place of death were achieved. It has a reporting function that will be able to provide up to date figures on preferred place of death, actual place of death, and reasons for variance. It is hoped to cross match this information with anonymised analysis by the Public Health Observatory to identify any groups who may not be benefiting from an advance care plan, to inform further work on end of life care pathways.

Contacts: Julian Abel, Consultant in Palliative Care, Weston Area Health Trust and Weston Hospicecare, Weston Area Health Trust, Weston Super Mare BS23 4TQ. Julian.abel@nhs.net. 01934 636 363

The first sites are now operational. A minimum data set has also been agreed, to which each of the sites is working. Some are also using a wider set with currently optional fields. We will make available the final version of the data set when the pilots have completed.

Ipsos MORI has been commissioned to undertake a national evaluation of the pilot programme, which will be published in March 2011. When we have an agreed model(s) localities will be able to spread the benefits well beyond end of life care to support work on managing long-term conditions. They will also be able to begin developing the sort of routine data on practice in end of life care which will underpin more sophisticated planning and service delivery.

Continuing Healthcare (CHC) fast track Marie Curie case co-ordination

This project was set up to redesign end of life care within NHS Dorset for Continuing Healthcare (CHC) fast track patients to ensure the patient receives a high quality, consistent service in their own home (where safe to do so) meeting their needs and outcomes, whether it is for one hour per week or a 24/7 package.

We set up a joint case co-ordination role for all fast track end of life CHC eligible patients, undertaken by a Marie Curie nurse. The nurse works with the key worker for the patient (generally a district nurse) to ensure care is put into place for the patient which is safe and meets their needs and outcomes.

This has ensured a 'streamlined' service in terms of response times for requests from the key worker to a maximum of two hours, whereas previously it could be up to three days before a change was instigated.

This has led to an increase in patients receiving end of life care from a Marie Curie trained carer, appropriate to their needs and wishes and, where necessary, independent domiciliary providers working with Marie Curie to ensure the care requirements are met effectively.

The project required a substantial change in current working practices in order to streamline the process and become more responsive to individual patient

needs. But it has delivered the ability to offer a greater number of patients the opportunity to die in the place of their choosing.

Contact: Strategic Manager Continuing Healthcare, NHS Dorset, Ground Floor, Vespasian house, Bridport Road, Dorchester, DT1 1TS. 01305 213536 nita.hughes@dorset-pct.nhs.uk

Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR)

There are critical points in a care pathway where, in the past, incompatible systems have led to difficult decision making and sometimes to poor care. If a patient is in a condition where they may need to be resuscitated time is of the essence: instant information sharing is critical. Inappropriate resuscitation is not only futile but can lead to a painful and undignified death for the patient and distress to the family. NHS South Central has learnt from the experience of NHS Lothian to undertake a major piece of work to co-ordinate DNACPR policies across the entire region. Other regions are now able to learn from their experience and their documentation.

NHS South Central unified Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) policy

Of the 31,000 deaths a year occurring in NHS South Central 21,000 (64%) take place in our hospitals. Of these hospital deaths approximately 4,000 (19%) undergo attempted CPR, 85% of all those on whom CPR was attempted. An audit from a resuscitation team in an acute hospital in Lothian suggests that up to 40% of such attempts are inappropriate in the first place. We do not have accurate data to tell us the exact number of patients receiving CPR in our community or what the outcomes of these attempts might be. We do know however that only 5-10% of patients receiving CPR in the community survive this experience.

The aim of the South Central End of Life Care Steering Group was to establish a unified DNACPR policy and documentation across the SHA. This documentation has been developed and is currently being rolled out to all sectors and settings of care to ensure it will become common to all areas of care including the patient's home, care homes, hospices, ambulances and acute hospitals and will be readily transferable between these settings. The documentation specifically relates to the individual patient and their needs and preferences and is not specific to the service delivering their care at any given time.

The DNACPR policy also needed to comply with the requirements of the Mental Capacity Act 2005.

The South Central Ambulance Trust stated that their ability to meaningfully support a successful end of life care strategy would be greatly dependent on the development of a robust unified DNACPR policy (with accompanying documentation). Having a cross-SHA ambulance service raised the challenge of trying to achieve this considerable goal throughout the region. The

ambulance service's Executive Director of Clinical Services, Fizz Thompson chaired the project group and sits on the End of Life Care Programme Board.

Progress to Date

Following discussion with Juliet Spiller (author of the Lothian policy), Mark Roland presented a discussion document to the Professional Executive Committee Chairs and Medical Directors of all the PCT's and Acute Trusts in South Central in August and September 2008. Having gained their permission to proceed with the project, as well as that of the Critical Care Network, each Trust was invited to nominate representatives to contribute to the project. The group met for the first time in October 2008. Five working subgroups were established:

- Main adult policy document
- Decision documentation and communication group
- Patient Information Leaflet
- Children's and adolescent policy group
- Education group

The process commenced with a standardised review of existing policies in the region. We also discussed the process with the Resuscitation Council (UK) and took advice regarding their template documents being reassured that regional adaptation was acceptable to them. Two full day events started to shape the policy and a part time project consultant was recruited.

Version 9 of the adult policy was issued for consultation in December 2009 and the children's and adolescent documents were sent out in February 2010. Following feedback the SHA group met several key stakeholders to work through practical issues and a final version of the policy was completed in March 2010. The policy can still contain minor local amendments and formatting but the DNACPR decision document itself will be common throughout the region.

The adult and children's policies were formally launched at the Kassam Stadium in Oxford on March 18th. Every Trust in the region has now signed up to use the adult policy with children's policy decisions taking longer as launched a little later. The policies are working through Trust governance processes at varying pace, with some Trusts (e.g. Royal Berkshire NHS FT) already using it, but all anticipated to be using it by September 1st 2010.

It is intended that local resuscitation officers will use forms to conduct local audits as with existing documentation but we also intend to collate and review regionally on an annual basis and to refresh and update documentation biannually. As this process has taken over two years to complete, we are encouraging other SHAs, who are approaching us to share our experience, to simply adopt our completed documents as they stand and join us in the review and refresh process in two years' time.

Contact: Dr Mark Roland, Clinical Director for End of Life Care, South Central SHA, mark.roland@porthosp.nhs.uk

East of England SHA is also embarking on a similar development with plans to evaluate the impact

Step four – Delivering high quality services

The scope of activity here has been maintained from last year. There are many well-evaluated initiatives publicised on the National End of Life Care Programme's website. The urgency imposed by the current financial position means that we need to see the pace of change increase. The NHS has often been characterised as slow to adopt models which have proved their worth elsewhere – “not invented here”. The QIPP programme will be urging a more flexible and innovative approach.

The East of England Marie Curie Delivering Choice Programme

Aims of the programme

The aims and objectives of the Marie Curie Delivering Choice Programme (MCDCP) are to provide:

- Patient-focused 24 hour service models that serve local needs and ensure:
 - The best possible care for palliative care patients
 - Choice in place of care and death is available to all
 - Improved equity of access to services
 - Appropriate support services to palliative care patients and their carers
 - Information on choice is available and known to all
 - Improved co-ordination of care among stakeholders
- Evaluation of the economic impact to healthcare services of more patients receiving palliative care at home as compared to hospitals
- Dissemination of findings to other health and social care providers leading to the replication of solutions across the region

Six out of the thirteen PCTs in NHS East of England (EoE) are now undertaking a MCDCP with two, Norfolk and Great Yarmouth & Waveney, already two thirds of the way through their projects and due to complete at the end of 2010. The Peterborough, Cambridgeshire, Suffolk and West Essex MCDCP was launched in October 2009 to complete by September 2011.

Progress

Both Norfolk and Great Yarmouth & Waveney are utilising a joint health and social care model and are looking at joint commissioning opportunities as a result of the service redesign phase of their projects. The EoE therefore has two of the first areas in the country to undertake the MCDCP using a joint health and social care approach.

The project network is also exploring larger pieces of work that require a strategic focus such as the Ambulance Service (emergency and Patient Transport Service); Education and Training; Equipment; DNACPR and IT, linking in with the other strategic palliative and end of life care projects and workstreams underway across the region as appropriate. This work will

include looking at joint/collective commissioning and service delivery opportunities that could enable economies of scale.

Each project site has access to the MCDCP methodology and electronic toolkit and is supported by a MCDCP Expert Adviser who provides advice, guidance and support. Stakeholders from across all levels of the commissioning and provider community and from patient/carer groups participate in the investigative phase of the project which identifies the barriers and issues to providing the best possible care and choice in place of care and death for palliative and end of life care patients.

The EoE MCDCP is jointly supported by the SHA and the participating PCTs. The SHA fund the MCDCP toolkit licence and support of the MCDCP Expert Adviser for each of the PCTs and also provides an overall programme manager while the PCTs resource their local project teams.

Outcomes

The MCDCP methodology includes an independent evaluation phase. The plan for the EoE is to develop and/or commission an evaluation of all the participating projects.

The results from the independent evaluation of the first MCDCP in Lincolnshire carried out by The King's Fund showed:

- Deaths at home up from 19% to 42%
- Deaths in hospital down from 63% to 45%
- Total costs for end of life care – neutral

The expectation is that similar outcomes will emerge from the evaluation of the EoE MCDCP. In addition, the emphasis across the EoE projects is on the use of the MCDCP as a key commissioning tool, providing a robust and rigorous evidence base across the entire system which will enable the commissioning and de-commissioning of palliative and end of life care services and ensure the best use of available resources.

The EoE approach ensures the dissemination of findings and the sharing of knowledge and lessons learned across all of the projects, and also enables collaboration across project and PCT boundaries, avoiding duplication of effort and exploring areas for joint commissioning and delivery of services with potential for cost savings through economies of scale.

Contact: Dee Traue, Chair Palliative & End of Life Care Clinical Programme Board, NHS East of England. Dee.traue@nhs.net

Step five – Last days of life

The palliative care team were very special people. What training is it that they receive? Can you give it to everyone?

comment posted on the Patient Opinion website www.patientopinion.org.uk

The strategy continues to support the Liverpool Care Pathway (LCP) as the key tool for delivering and improving care in the final hours and days of life. The pathway is subject to a continuing programme of evaluation and revision: Version 12 was published this year.

The Liverpool Care Pathway

1 Aim To improve care of the dying in the last hours or days of life	4 Domains of Care Physical Psychological Social Spiritual
2 Themes To improve the knowledge related to the process of dying To improve the quality of care in the last hours / days of life	5 Key Requirements for Organisational Governance Clinical Decision Making Management & Leadership Learning & Teaching Research & Development Governance & Risk
3 Sections Initial Assessment Ongoing Assessment Care after death	

National Care of the Dying Audit Hospitals (NCDAH): Round 2

The second round of this national audit of use of the Liverpool Care Pathway (LCP) has now reported. Key findings are:

- The number of participating hospitals has increased in Round 2 to 155 - 31% greater than the 118 reporting in Round 1;
- 114 hospital trusts – 82% of the total – are now represented;
- The number of patient data sets submitted increased by 46% (from 2672 to 3893);
- The percentage of hospitals able to submit a full sample increased from 44% to 65%;
- The national percentage of wards reported to be ‘using’ the LCP in Round 2 is 68% compared with 44% in Round 1.

The LCP also excited considerable press coverage, most of which misunderstood its purpose and the way it should be used. As with all clinical guidelines and integrated care pathways, the LCP aims to support but does not replace clinical judgement. It can only be as good as the team that is using it. Good, comprehensive, clear communication is pivotal to good care: all decisions leading to a change in care delivery should be communicated to the patient where appropriate and to the relative or carer as well as to the staff involved. The views of all concerned must be listened to and documented.

The responsibility for using the LCP generic document as part of a continuous quality improvement programme sits within the governance framework of an

organisation. For it to be effective it must be underpinned by a robust education and training programme.

Step six – Care after death

The National Care of the Dying Audit - Hospitals found that the areas most in need of attention were communications and care after death. This information will help trusts to concentrate attention on making improvements in these areas.

Death Certification

In these days of financial constraints and heavier workloads it was very gratifying to see such positive human traits as respect, caring and empathy for patients and their relatives... Although my experience was very positive while my mother was alive, I then had a very distressing time trying to obtain a death certificate in a timely manner... The Bereavement Office staff said this was a frequent occurrence.

comment posted on the Patient Opinion website www.patientopinion.org.uk

The Coroners and Justice Act, which gained Royal Assent in November 2009, included reforms of death certification. These will unify procedures for all deaths, whether the body is to be buried or cremated. PCTs in England (and Local Health Boards in Wales) will be required to appoint medical examiners who will scrutinise medical certificates of cause of death (MCCDs), patient records and circumstances of all deaths not investigated by coroners before the deaths are registered. Medical examiners will also ensure that doctors in their area have appropriate training to complete MCCDs accurately and completely. The Act also includes provision for appointment to the statutory post of National Medical Examiner to provide professional leadership to medical examiners. The timetable for implementing the reforms is currently being discussed with Ministers.

NHS North Somerset: Verification of death by nurses: an online learning tool

This project was designed:

- to support nurses in all care settings to develop the competency to verify death, both expected and unexpected;
- to contribute to service improvement and the improved experience of the bereaved;
- to support partnership working, knowledge exchange, and the continuing professional development of nurses.

In partnership with NHS North Somerset and Weston Hospice Care, the University of the West of England (UWE) has developed an online learning resource to support nurses to be competent to verify death. As an online experience that involves assessment of knowledge and practice, nurses in any setting can engage with this resource at any time.

The aim is for free access to all UWE partnership Trusts and organisations. There are no limits to access. There are implications for nurses to have time to access the resource and to subsequently gain clinical support for initial practice. It has been funded by the Bristol, North Somerset, South Gloucestershire Community Strategic Service Improvement Fund.

The project team have been clear in ensuring that the resource outlines the professional, legal and clinical influences clearly.

The project team and UWE marketed the resource through the range of partnership networks within the West of England.

The tool is now available for widespread use and can be obtained via the UWE website.

This resource offers an opportunity to use the template to develop other competency development resources, accessible within the workplace or home, for example, advance care planning.

Contact: Clive Warn, End of Life Care Lead, Senior Lecturer, University of the West of England, School of Health and Social Care, Glenside Campus, Blackberry Hill, Stapleton, Bristol BS16 1DD. 0117 3288939.

clive.warn@uwe.ac.uk

Chapter 4

Care in different settings

The End of Life Care Strategy emphasizes the importance of providing care where people would prefer to be. Very often this means providing care away from the acute hospital setting. However, there will always be people who choose to die in hospital, and others for whom hospital is the only realistic option so it is important that care there improves too.

The King's Fund's Enhancing the Healing Environment Programme

The Enhancing the Healing Environment (EHE) programme was launched by HRH The Prince of Wales, President of The King's Fund, in 2000, as part of The King's Fund's activities to mark the millennium.

The aim of this innovative grants and development programme is to encourage and enable local teams to work in partnership with service users to improve the environment in which they deliver care and consists of two main elements:

- a development programme for a nurse led, multidisciplinary team;
- a grant for the team to undertake a project to improve their patient environment.

Since its launch, 202 teams from NHS Trusts, hospices and healthcare services in HM prisons have or are currently participating in the programme. In addition, The King's Fund has supported over 25 hospices in improving their environments of care. The programme has been independently evaluated and recognised with a number of local, regional and national awards.

Environments for Care at the End of Life

Although there are now a large number of research studies and evidence from the UK and abroad showing the effect that the environment has on patients' wellbeing there has, as yet, been little research undertaken on the effect of the environment on people that are dying, their relatives and the bereaved, although there is evidence that it does affect perceptions of care and bereavement journeys. Dedicated bereavement facilities are not universally provided and relatives may need to revisit ward areas or wait in busy corridors to collect death certificates and property. Although there is a reported increase in hospital viewings, mortuary facilities are often desolate places.

Following a successful pilot programme, which directly informed the recommendations in the national End of Life Care Strategy regarding the importance of the environment of care to those that are dying, their relatives and the bereaved, the Department of Health commissioned The King's Fund to extend the Environments for Care at End of Life programme. 20 projects were chosen to reflect the end of life care pathway across all NHS sectors including acute and mental health care and in the prisons service. £1 million was made available to fund the programme, 60% of which has gone directly to the participating organisations to fund their projects.

A full list of projects is at Appendix 3.

Outcomes

All 20 projects will be completed by summer 2010 and the following outcomes are already evident:

- an increased profile for end of life care across the participating organisations thereby enabling and supporting other elements of the implementation of the strategy;
- improvements in service provision for patients, including the creation of specially designed palliative care suites ;
- the provision of private areas for relatives, including garden spaces, so that they can stay within easy reach of the ward but have some time away from the bedside;
- the creation of new facilities – including dedicated parking spaces - for the bereaved, with the establishment of bereavement suites where the necessary administrative processes following a death can be undertaken, including local Registration services, avoiding them having to return to the ward;
- improved mortuary viewing areas which have been redesigned to meet the needs of a multicultural society;
- many new partnerships have been formed with local arts groups, schools and colleges through the projects leading to further joint initiatives.

With the help and financial support of the participating organisations, Leagues of Friends, local charities including SANDS (The Stillbirth and Neonatal Death Society) and extensive fundraising by the local teams additional capital of over £1.8 million has been raised to add to the Department of Health's capital allocation of £600,000. This has again demonstrated that through the EHE programme, with the continuing support and commitment of the Department, teams are able to galvanize enthusiasm and leverage local funds in support of service improvements.

Many trusts have adopted the EHE principles and methodologies for new capital projects in recognition that the impact of service redesign and quality is greater than that typically achieved by investment in environmental upgrading alone.

At the request of the National End of Life Care Programme a case study describing the EHE project at Newham University Hospital has been completed for wide dissemination in the NHS.

Evaluation

The programme has been evaluated by The University of Nottingham who will be providing recommendations for the review of the Department of Health's Health Building Note (HBN) on mortuaries and facilities for the bereaved which is due for review later this year.

The evaluation used documentary analysis of each of the six reports completed by all 20 teams over the development period, and a sample of six in-depth case studies. Case studies included interviews with the teams over the lifetime of the projects, an architectural analysis at each completed case study site, and measuring team ratings of the impact, function, and quality of the build designs (AEDET and ASPECT).

Improvements in AEDET and ASPECT scores were most notable in the areas of (1) character and innovation; (2) comfort and control; and (3) privacy and dignity. All teams highlighted the importance of team composition and cohesion in order to have the right skills for the project and sustain good working relationships. Key to the process were input from estates/capital planning, service providers, access to senior figures within the trust, and a culture of creativity. The ability to integrate these features within the teams appeared to be linked to securing substantial and additional funding and earlier completion. While none of the teams doubted the importance of the physical environment in the provision of end of life care, The King's Fund programme was perceived as enabling team members to articulate and realise their aspirations. That these projects were concerned with the physical space, at a time when policy attention in end of life care was greater than it had been hitherto, gave a focus that could provide end of life care with a higher profile within trusts than could have been otherwise achieved.



Southend – Bereavement Suite, before development

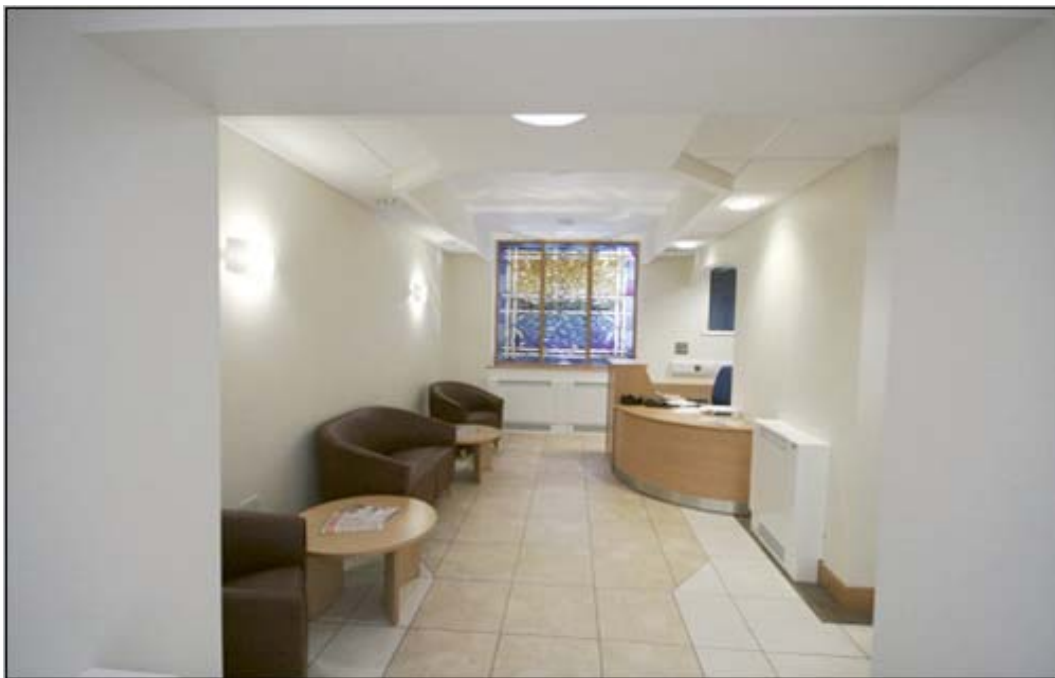


Southend – Bereavement Suite, after development

Photographs © The King's Fund EHE photo library and Southend University Hospitals NHS Foundation Trust



Northampton – Bereavement Suite, before development



Northampton – Bereavement Suite, after development

Photographs © The King's Fund EHE photo library and Northampton General Hospital NHS Trust



Newham – Mortuary viewing facilities, before development



Newham – Mortuary viewing facilities, after development

Photographs © The King's Fund EHE photo library and Newham University Hospital NHS Trust



Salisbury – Mortuary viewing facilities, after development

Photograph © The King's Fund EHE photo library and Salisbury NHS Foundation Trust



Liverpool – Facilities for palliative care for patients and relatives, after development

Photograph © The King's Fund EHE photo library and Liverpool Women's NHS Foundation Trust

Hospice capital grant

As part of the Dignity in Care programme for older people, a £40 million capital scheme was made available for hospices in 2006 to support improvements to their physical environments. Building on the success of this scheme, a further £40 million fund was made available for hospices in 2010/11 through the End of Life Care Strategy.

Hospices were invited to submit applications which would deliver tangible physical improvements in their care environments, and show how this would contribute to improved care provision. The criteria were drawn quite broadly. Alongside traditional areas for improvement, such as the conversion of multi-bed bays to single rooms, other areas, such as the redesign of mortuary and viewing room areas, and investment in outpatient and day therapy areas, were also invited.

Help the Hospices was commissioned by the Department of Health to manage this scheme, arranging roadshows to inform hospices about the details of the scheme, and to assess applications and provide funding recommendations to the Department.

A total of 153 applications from 135 organisations were submitted to Help the Hospices. The outcome of the application process was announced on 2 April 2010. In total, 123 projects from 116 organisations were supported, with 66 of these being funded in full. A list of the successful applicants is set out at Appendix 4.

Routes to Success

The National End of Life Care Programme is developing a series of practical guides called *Route to Success*. The guides focus on the practical implementation of the end of life care pathway and are tailored to the needs of different settings for care. So far the series covers:

- **Care Homes** – published in June 2010, where the National Programme is working with a range of providers on adoption and implementation;
- **The Acute Sector** – published in June 2010. The National Programme is working with a number of partners including SHAs, Acute Trusts and end of life care facilitators to support implementation;
- **Hostels** - to be published late summer 2010;
- **Prisons** – to be published in autumn 2010, subject to finalisation of the prison service order.

Finalised *Routes to Success* are available to download from the National Programme's website (www.endoflifecareforadults.nhs.uk). The benefits are yet to be realised but will depend on the relevant sectors making use of these

materials, which may require support from the National Programme and from the local end of life care facilitators.

Implementation of end of life care initiatives in Her Majesty's Prison Full Sutton, York

Aims: To deliver equity in provision of end of life care across all care settings, specifically HMP Full Sutton, York.

Process: Using outcomes/advice from a PCT investigation following a death in custody and subsequent coroner's inquest, meetings were held within the prison with the Head of Healthcare, prison doctor, pharmacist, and nursing staff to discuss national end of life care initiatives. As a result we:

- developed an end of life care policy for expected and planned deaths within HMP Full Sutton;
- established criteria for inclusion in monthly Gold Standards Framework (GSF) meetings;
- introduced a Care of the Dying Pathway;
- implemented a syringe driver policy with staff training and competency assessments.

Funding: Purchase of syringe driver and oxygen concentrator came from the healthcare budget.

Challenges and solutions:

- Establishing parameters for inclusion on GSF - all inmates who may die within two years to be included on the palliative care register, using "traffic light system" dependant upon extent, complexity and prognosis, with red reviewed monthly, amber two monthly and green three monthly;
- Within the prison environment prescribing practices are significantly restricted - working with nursing staff, prison doctor and pharmacist to ensure prescribing practices ensure safe and effective symptom management;
- Recording the GSF meetings - templates developed by SHA IT lead for SystmOne;
- Lack of end of life care policies in prisons nationally - the Head of Healthcare is exploring practices in other prisons.

Outcomes:

- Monthly GSF multi professional meetings including Macmillan CNS attending;
- Plan of care for each patient established and documented on SystmOne, so providing a robust audit trail;
- Education provision through the Community Macmillan CNS means healthcare staff are equipped to deliver high quality end of life

- assessment and provision of care, via implementation of national end of life care tools within the restrictions of a high security prison;
• Equity of end of life care provision within the restrictions of a high security prison setting.

Contacts: Macmillan Clinical Nurse Specialist in Palliative Care, NHS East Riding of Yorkshire, Alfred Bean Hospital, Driffield YO25 5JR.

dawn.robinson2@erypct.nhs.uk. 01377 208758

Extra Care Housing

The first annual report noted that the National Programme had produced guidance documents for this sector *Is it that time already?*, and a resource pack for staff. These were well received and are now subject to a formal evaluation due to report at the end of the year.

Chapter 5

Support for carers and families

In its report published last year ⁽¹⁾ the Standing Commission on Carers recognised the need to encourage closer links between the implementation plans for the Carers Strategy ⁽²⁾ and other strategies relevant to carers, including the End of Life Care Strategy.

A number of activities were launched last year under the auspices of the Carers Strategy, including Carers Direct, a website and helpline to provide accessible information and advice to all carers. (www.NHS.uk/CarersDirect, Helpline 0808 8020202.)

The Department also set up 25 Carers Demonstrator sites to gather evidence of different ways of providing breaks, health checks and better NHS support for carers. A number of the sites have a particular focus on end of life care – for example, Northumberland Trust is offering health checks to carers who have recently stopped caring for someone with complex needs and Halton and St Helens is focusing on identifying and supporting ‘hidden’ carers within a range of services, including palliative care.

We weren't taken into a private area, we didn't have the news broken to us gently - it was just a case of he's dying and that is pretty much it. If we were told this information earlier we could have had more time with him at home doing what he wanted to do in his final days.

comment posted on the Patient Opinion website www.patientopinion.org.uk

Support for carers is embedded in many of the other strands of the End of Life Care Strategy. For example, the work of the Dying Matters coalition and the National Centre for Social Research (NatCen) Survey highlights that many people's interest in thinking about death, dying and bereavement stems from their wish to spare their family and carers pain and distress. The audit of the LCP showed that communications with carers was an area which needed improvement. A high proportion of the Enhancing the Healing Environment projects involved areas such as mortuaries and viewing rooms which allowed services to offer properly respectful, discreet and sensitive services to bereaved relatives.

(1). *Carers at the heart of 21st-century families and communities – work in progress*. Report of the Standing Commission on Carers 2007 to 2009, DH October 2009

(2). *Carers at the heart of 21st-century families and communities*, DH June 2008

Dorothy House Hospice Care COPE programmes for carers

Dorothy House developed an informal “COPE Carers Support Group” for the longer term support of carers to gain support from others in a similar situation.

The Carers Course was set up by the nurse specialist team using information gained, through research and audit, to ascertain the needs of carers who were unused to caring roles or whose needs changed when providing care at the end of life. It is run three times per year. This is a structured programme of carer education with time provided for informal support.

The COPE Carers Support Group was set up by the family support team and the nurse specialist team, to provide on-going support for carers. This was in response to those who had been on the carers course and requested another forum where they could continue to meet other carers informally, but with professional facilitation.

In both cases the carers defined what the course content should be and what the more informal setting should look like. They also said what help they might need to achieve attendance, the best times of day etc.

The Carers Course is formally evaluated at the completion of each six week course and the course content is adjusted depending on the comments of attendees.

The Carers Support Group is formally evaluated every six months and the written evaluation is submitted to the clinical audit group to ensure needs are being met. Carers have reported that they can now talk about their own feelings as well as have a break from their patient and are better able to cope with their circumstances as a result.

Contact: Julia di Castiglione, Clinical Development and Outreach Manager, Dorothy House Hospice Care, Winsley, Bradford-on-Avon, Wilts BA15 2LE. 01225-722988. Julia.dicastiglione@dorothyhouse-hospice.org.uk

You don't think you need help but you certainly find out you do
comments posted on the Patient Opinion website www.patientopinion.org.uk

The Coalition Government has recently announced that it will undertake a ‘refresh’ of the Carers Strategy, focusing on the key actions that will make the greatest impact on improving carers’ lives. It will be important to ensure that implementation of the two strategies continues to be linked.

Bereavement

When my mother died recently I feared a messy episode of my sometimes severe bipolar disorder...I was assigned a team member to befriend me while I faced up to the daunting prospect of life without Mum... I know Mum would be delighted to see I am getting the help I need.

comments posted on the Patient Opinion website www.patientopinion.org.uk

The National Implementation Advisory Board for End of Life Care and the first Annual Report on the End of Life Care Strategy identified bereavement as an area in need of further development. As a first step we commissioned a literature review on bereavement, bereavement services and bereavement support asking:

- What is known about the current level of bereavement provision across England?
- What models of good practice exist in England and comparable countries?
- What is known about the costs related to service provision?
- How do needs/service requirements vary for different sectors of the population?
- What are the gaps in bereavement service provision?

The findings will inform the development of recommendations for future bereavement care.

A working group, under the clinical leadership of Dr Teresa Tate, Deputy National Clinical Director for End of Life Care, has been established to take forward work in this area. The group's remit is to develop a programme of work and identify priorities for improving the quality and cost effectiveness of bereavement care services, both in the short-term and longer term. It brings together expertise from key bereavement organisations and professionals. It is due to report back to the End of Life Care Programme Board in the autumn with its recommendations.

In June 2010, the Marie Curie Palliative Care Institute Liverpool launched a range of pre-bereavement materials designed to help support children and adolescents when someone significant to them is close to dying. The materials include leaflets written for children aged 5-11, teenagers, and for those supporting toddlers and preschool children. These leaflets are now included in the suite of leaflets provided to support the Liverpool Care Pathway (LCP) for the Dying Patient continuous quality improvement programme.

The Bereavement Pathways Project 'Bridging the Gap' – Solihull Pilot

A one year pilot was undertaken at Solihull Hospital (Heart of England NHS Foundation Trust) as part of the Bereavement Partnership Project; a Department of Health funded partnership project between the Bereavement Services Association and Cruse Bereavement Care. The aim of the pilot was to explore ways of 'bridging the gap' between acute hospital bereavement services and community voluntary bereavement services by utilising bereavement support volunteers to provide 'early intervention' support and guidance following the death of a person in hospital.

It was noted that formal letters of complaint were usually received within the first three months following a death; also that people had contact with bereavement support organisations at around three months following a death.

It was hypothesised that extending care and support to bereaved families through an initial one to one meeting and/ or telephone follow up support over the first eight weeks following the death, may have an impact on these two factors and provide both quality benefits for the bereaved and cost benefits for acute hospital services.

556 deaths occurred during the year and 209 relatives requested the follow up service. The service received an overwhelmingly positive response from all relatives: “comforting to know someone was there for us at such a difficult time”.

This early intervention and support facilitated assistance with financial, social and emotional concerns. As a direct result of early intervention seven potentially formal complaints were resolved at an informal level with an approximate cost saving of £10,059.

The Solihull pilot indicates that early intervention with timely information, signposting and support can extend holistic high quality care to acutely bereaved relatives and reduce the incidence of formal complaints and referral to formal counselling services for non counselling requirements.

Contact: Dawn Chaplin, Project Director Bereavement Care, University Hospitals Birmingham NHSFT, Selly Oak, Birmingham;
dawn.chaplin@uhb.nhs.uk

After my mother in law had died the bereavement service lady was very quick and efficient with practical help but also did not rush us. Leaving your body to science has to be done in a particular way and again has consequences for the family with regard to closure as there is no funeral as such.

comment posted on the Patient Opinion website www.patientopinion.org.uk

Spirituality

Our first Annual Report also recognised that meeting the spiritual needs of those approaching the end of life, their carers and families is an important, although very complicated, area which needs to be addressed.

During the past year, our work on this has concentrated on identifying and obtaining all the available evidence and information and gathering the preliminary views of experts in the field. To do this, the National Programme has commissioned a literature review, due to report in July, and the Department has provided funding support for two conferences, one organised by the National Council for Palliative Care and the other by the British Association for the Study of Spirituality. The findings of the literature review and feedback from the conferences will provide pointers on next steps for this important work.

Chapter 6

The end of life care workforce

During the past twelve months, work has continued to support achieving the cultural shifts in attitudes and behaviour related to end of life care required to enable delivery of quality services to individuals, their families and carers as outlined in the strategy. As we near completion of our three foundation projects (see 'What we have achieved', below) the complexities of implementing our work across the range of health and social care organisations has been challenging. Making change a reality given the scale of workers interacting with the end of life pathway can be daunting but we know that a significant number of projects and initiatives within SHAs and PCTs, with many demonstrating joint working across into social care, are now underway because of funding allocated via the Multi-Professional Education and Training (MPET) Levy.

The MPET funding is set to continue in 2010/11 and we have established a group of SHA End of Life Care Workforce Leads and Skills for Care Regional Leads to promote joint working and help influence regional and national workforce related plans and priorities.

From 1 July 2010 the General Medical Council's new guidance, *Treatment and care towards the end of life: good practice in decision making*, came into effect. Made available to all doctors, this provides very useful guidance to help doctors navigate the complex issues often raised in end of life care, including advice on care planning and improved communication between doctors, patients, family and carers and the healthcare team.

NHS South Central: education and training strategy

The NHS South Central End of Life Care Education Strategy focuses on learning in practice so that alongside improving skills and knowledge it focuses on changing behaviours and cultures which is essential to improve end of life care. The regional education strategy is reflected in local PCT end of life care group education plans and supports the local end of life care strategies and implementation.

Each locality based end of life care group is recruiting practice facilitators to work with staff in their workplace. Many of these are focusing on care homes with some covering hospitals. End of life care e-learning is an element of the blended practice based education approach South Central are taking and rapid roll out of this is initially starting in the acute sector (between June to August 2010) with discussions underway with community and mental health

providers. A care homes project is scoping the best way to support care home staff and rolling out e-learning to this group is likely to be an element.

To capture people early in their career, awards have been given for attendance at end of life care conferences with clear outcomes to shape practice. Rotation posts have been put in place between for example hospitals and hospice to explore the transitions in care and how to improve end of life care. A key part of the education strategy has been to address communication skills across health and social care staff so that all reach level 1. This is being facilitated via a range of blended learning which includes a 'train the trainer' model for Sage and Thyme training (level 1 communications skills) with 30 trainers being trained in June.

Contact: Lucy Sutton, Associate Director for End of Life Care Programme, NHS South Central, Rivergate House, Newbury.

Lucy.Sutton@southcentral.nhs.uk. 01635 275546

What we have achieved

We have maintained strong working relationships with a number of organisations and individuals, which help us to deliver our projects and identify new work to further enhance end of life workforce development.

Competences and Core Principles

Skills for Health (SfH) and Skills for Care (SfC) completed the second phase of the work on competences and core principles in January 2010. This work mapped the competences and core principles against recognised frameworks such as the Knowledge and Skills Framework, National Occupational Standards and enabled updates to be made to the social care Knowledge and Learning Sets as well as influencing development of the new Qualifications and Credit Framework (QCF). Take up of these tools continues to be challenging and work will continue in 2010/11. Further developments are also planned (see 'The next twelve months', below).

e-Learning for End of Life Care (ELCA)

Working with e-Learning for Healthcare (e-LfH) we were able to secure additional access licenses for social care in 2009 and in January 2010 ELCA (End of Life Care for All) for health and social care was successfully launched. This was followed up by ten regional workshops giving a more hands-on experience. Feedback on the content developed has been extremely positive and the initiative has been very well received. However significant frustration has arisen through problems with access which we addressed as a priority issue.

Agreement has now been reached between SfC, the Social Care Institute of Excellence (SCIE) and e-LfH on a process for access registration for social care workers and we anticipate being able to announce the timescale for

implementation in the near future but expect completion by the end of 2010. Work has started with SCIE, SfC and our e-learning Clinical Lead to look at ensuring that ELCA is 'social care' friendly and to amend terminology as required or develop new social care focussed sessions. This work will continue over the next year.

NHS South West: education and training strategy

In the South West a strong network of End of Life Care Implementation Groups across the region have been working towards the achievement of education and training plans to deliver the End of Life Care Strategy. A large part of this work has utilised the skills and expertise available within hospices. An example of this is the collaboration between Dorothy House Hospice and St Margaret's Hospice to provide education and training for NHS Somerset.

NHS Somerset had identified as priority areas for educational provision advance care planning and the key elements of end of life care to enable domiciliary carers and ambulance staff to support clients appropriately. Different models of programme delivery were developed depending on the staff groups, some based on programmes originally developed by Dorothy House Hospice for another PCT (Bath and North East Somerset). The strengths of these programmes were:

- they were locally delivered by specialists in the field, who knew the area and context;
- the delivery was responsive to learners and local needs. For instance, different courses were provided for the domiciliary care agencies' care workers and managers, enabling their differing and specific learning needs to be met and particular issues they experienced to be explored amongst peers;
- the use of hospices in the delivery also enabled the care agencies in particular to develop a greater understanding of the role of the hospice and how the hospices can support them;
- the hospices shared expertise and resources.

Contact: Helen de Renzie-Brett, Dorothy House Hospice Care, Winsley, Bradford-on-Avon, Wiltshire, BA15 2LE. 01225 722988.

Helen.derenzie-brett@dorothyhouse-hospice.org.uk

Problems also arose with access for NHS staff working in Trusts which had not implemented the National Learning Management System (NLMS). In May a national agreement was reached to enable these Trusts to have access to the e-LfH Learning Management System and therefore access to ELCA.

In May issues concerning the future of e-LfH arose. However, we have been assured that a resolution will be found and we are optimistic that we will be able fully to implement our plans for e-learning to support end of life care.

Communication Skills

...although his treatment was excellent he was told that he had terminal cancer on his own without any warning and despite the fact that the staff nurse who told him was aware that he was being visited by his pastor just before he was told. He then had to endure 2 hours on his own before myself and our 15 year old daughter could come and collect him, we were totally unaware of the diagnosis. I thought that it was not done to tell people that kind of news without some support.

comments posted on the Patient Opinion website www.patientopinion.org.uk

Twelve pilot projects are underway across England led by the National End of Life Care Programme, to review the needs and provision of communication skills training for the health and social care workforce delivering end of life care. The sites are building on existing good practice and knowledge and using a whole system approach to consider the training needs and the coordination, planning and delivery of communication skills training.

The pilot sites have each carried out a training needs analysis (TNA) to better understand the local workforce engaged in end of life care, the existing competences in this workforce and the training that is currently being delivered. The pilot sites will next benchmark their TNA findings against the common core competences to determine any gaps in competences and in training. The pilots will then work with local stakeholders to develop training plans.

Key findings from the pilots to date:

- Confirmation that the majority of health and social care workers are involved in end of life care;
- Most staff have received basic communication skills training although this may not be specific to end of life care;
- Staff generally perceived they had some competences but would benefit from further training;
- End of life communication skills courses are provided mainly by higher education institutes, hospices and through in-house training. Some pilots found duplication of courses and gaps in the curriculum;
- Service providers are not always aware of the range of training available for their staff.

The 12 test sites are Berkshire East Community Health Services; Dorset Cancer Network; East of England Cancer Network; Greater Manchester & Cheshire Cancer Network; Lancashire and South Cumbria Cancer Network; St Gemma's Hospice Leeds; Leicestershire and Rutland Hospices (LOROS); North East London Cancer Network; South East London Cancer Network; St Luke's Hospice Plymouth; Teesside University; and, West Essex PCT.

NHS East of England: education and training strategy

To meet the requirements of the Strategic Vision 'Towards the Best Together' requires a significant step change in the ability of staff to deliver palliative and end of life care. About 70% of people in the East of England (EoE) express a wish to die in a place of their own choice. This is not being realised at present for a number of complex interrelated reasons, one of these being a lack of specific skills amongst practitioners. The drive to improve quality, defined as safety, effectiveness and patient experience, requires education and training investments that enable our staff to think differently and behave in new ways.

The target audience for *advanced level communication skills training* is senior generalist health and social care professionals working with patients (adults) and their families in end of life care with a focus on care of the elderly, respiratory diseases, heart failure, renal disease and degenerative neurological disease, as part of their everyday clinical practice. Over the past year, 184 staff out of 400 have attended this three day course and this training will continue until March 2011. These courses are run by the three cancer networks covering EoE - Anglia, Essex and Mount Vernon.

An ongoing problem has been the difficulty in recruiting GPs to attend this training due to the length of the course. Although it is hoped that the national ELCA e-learning programme may be an alternative and a more accessible method of training for GPs, many end of life care experts believe communication skills in particular cannot be taught solely by e-learning.

We have been developing a *basic palliative and end of life care training package* for care home staff which will utilise blended learning, such as e-learning and face to face/mentorship training. It is estimated that 1800 care home staff across EoE will be trained by March 2012. The objectives are to:

- Cover the core development areas highlighted in the strategy as well as existing end of life care tools (GSF, LCP and PPC) incorporating competences developed by SfH and SfC;
- Enable staff to improve their skills, behaviours and knowledge with respect to caring for people who require palliative and end of life care;
- Reduce inappropriate admissions to acute services from care homes;
- Support people's wish to die in their preferred place of care.

EoE SHA is working in partnership with Epic, a learning solutions company, and other key players include the local End of Life Care Education and Training Sub Group, the cancer networks, hospices and care homes.

The facilitation for this training has been awarded to the three end of life care networks within EoE in partnership with their end of life care educational and specialist palliative care providers. It is expected that training will commence from July 2010 and will be completed by March 2012.

Contact: Vanessa Convey, Programme Manager for Palliative and End of Life Care Education & Training, NHS East of England, East of England Multi-Professional Deanery, Victoria House, Capital Park, Fulbourn, Cambridge, CB21 5XB. 01223 597500. vanessa.convey@eoe.nhs.uk

Other work started in the past twelve months

We have been working closely with the Chief Nursing Officer's team and the National Programme to develop a set of nurse sensitive outcome indicators to support nurses in providing high quality end of life care for adult patients. This work is being aligned to the wider work on national indicators and will use national and international evidence such as the International Council of Nurses catalogue for palliative and end of life care as its basis.

As mentioned elsewhere in this report a network supporting end of life care facilitators has been established by the National Programme. The first meeting took place in June 2010.

The next twelve months

Some of the work we anticipate taking forward:

- Work with the National Programme, SfC and SfH to test how well the materials developed to date support the workforce delivering end of life care in learning disabilities, mental health and people with sensory impairment;
- Look to extend our end of life care competences and core principles to cover bereavement and spirituality as well as reviewing the competences for communication skills and advance care planning following feedback that they were not detailed enough;
- Review the evaluation and reports from the communication skills pilot sites and identifying appropriate next steps;
- Continue to prioritise work related to e-learning access issues for all health and social care staff and employers;
- Establish, with the Association for Palliative Medicine and e-Learning for Healthcare, an Editorial and Review Board for e-learning which will periodically review content and commission additional modules or sessions;
- Continue to support wider dissemination and implementation of work undertaken to date eg using ELCA within blended learning by the National Programme;
- Continue to raise awareness with Medical Royal Colleges of our work on e-learning and competences and influence other professional bodies and standards to include end of life care;
- Support and actively work with SHA End of Life Care Workforce Leads and SfC Regional Leads to find solutions and practical ways forward to meet challenges as they arise, eg identify how best to support education and training facilitators, identify how to support staff with the

greatest unmet training needs to access development opportunities including addressing IT infrastructure barriers;

- Ensure that the new Centre for Workforce Intelligence is aware of and linked into our work eg informing the work of the National End of Life Care Intelligence Network;
- Build on the success of the Training Needs Analysis utilised for the communication skills pilots to develop an electronic TNA toolkit.

Evaluation of our work and ensuring it is making a difference is going to be a major theme and challenge in the coming year.

Chapter 7

Measurement and research in end of life care

Compared with many other areas, end of life care is a data-poor field. There are very few routine data collections. One of the few national, annual collections is the mortality figures collated by the Office for National Statistics (ONS), which is why the Vital Sign was devised using that information about place of death as a proxy for choice of place for care.

Intelligence Network

To remedy this paucity of information, the strategy included a commitment to establish a new National End of Life Care Intelligence Network. The National Cancer Intelligence Network and the National End of Life Care Programme were charged with considering how this work might be taken forward. Development was based on the ideas generated from a workshop held in March 2009, which brought together a number of key providers and users of information. It was agreed that the National End of Life Care Intelligence Network would be commissioned based on the National Cancer Intelligence Network model.

The Network aims:

- To improve the collection and analysis of information related to the quality, volume and costs of care provided by the NHS, social services and the third sector to people approaching the end of life;
- To utilise this intelligence to drive improvements in the quality and productivity of services.

Its core objectives are:

- To provide national co-ordination to bring together a national repository of diverse sources of data related to end of life care which will enable people to create intelligence from data and thereby improve quality and productivity;
- To utilise and disseminate existing data sources more effectively for local service planning to drive improvement in standards of end of life care;
- To generate and utilise information on the financial aspects – costs and savings comparing alternative models of end of life care;

- To generate ideas and solutions in relation to ongoing information requirements e.g. end of life care minimum data set;
- To commission and manage new information/data analysis work according to priorities identified in the End of Life Care Strategy;
- To bring together a variety of people including data holders/owners of information, clinicians and key users of this data intelligence to explore better use of data for commissioning, service delivery, research and audit;
- To suggest modifications to existing datasets;
- To promote efficient and effective data collection throughout the end of life care pathway;
- To produce, promote and present expert analysis and robust methodologies for analysing data in end of life care;
- To present and disseminate information in a clear and timely fashion;
- To enable use of end of life care information to support audit and research programmes.

The Network is centrally funded so it is very important that it make rapid strides to demonstrate its worth. There is wide scope for it to offer useful intelligence for both commissioners and providers of end of life care, much of which will be especially valuable for the QIPP workstream.

Already the South West Public Health Observatory has produced a number of publications on behalf of the Network, titled:

- *Variations in place of death in England – inequalities or appropriate consequences of age, gender and cause of death?*
- *Deaths from Renal Diseases in England, 2001 to 2008*
- *Deaths from Neurodegenerative Diseases in England, 2002 to 2008*

The Network is planning additional disease-specific publications, to add to this series.

Early Network products could be:

- End of life care intelligence catalogue (what data are available and where - including research and audit);
- Analysis of quality data on place of death by age, gender, ethnicity, social deprivation and geographical location and cause of death registered on the death certificate (ONS);
- Analysis of hospital episodes ending in death (Hospital Episode Statistics (HES));
- Analysis of hospital resource utilisation in the months preceding death (HES/ONS);
- Analysis of hospice/specialist palliative care service utilisation in the months preceding death;
- Analysis of social care utilisation in months preceding death;
- Analysis of health and social care resource/cost utilization in last three, six and nine months of life;

- End of life care atlas/toolkit providing, for example, comparative information at a PCT or other level on:
 - Number of patients dying of different causes per 100,000 residents
 - Spend on specialist palliative care (per death)
 - Spend on Marie Curie services
 - Number of specialist palliative care leads
 - Number of care home places
 - Deaths in different locations.

Much of this work is already underway.

The Network's website went live in May 2010. (www.endoflifecare-intelligence.org.uk)

VOICES

The End of Life Care Strategy set out a commitment to measure the quality of care for people at the end of life, and their carers, through the development of a survey of bereaved relatives.

The Department of Health has commissioned Professor Julia Addington-Hall, at the University of Southampton, to undertake a pilot project to take this work forward, building on her extensive work developing, and utilising the VOICES (Views of Informal Carers – Evaluation of Services) questionnaire. The pilot commenced in collaboration with South Central SHA July 2009, and is due to complete in January 2011.

Significant progress has already been made on the project. Agreement has been reached to run the pilot in East Berkshire PCT and Isle of Wight PCT. The sampling strategy has been agreed with ONS, and will enable breakdown of responses by location, sex, place of death, and three principal causes of death (cancer, cardiovascular disease, other). Plans are in place to send out the questionnaires in September and October, backed up by a range of awareness raising activities.

Extensive changes have been made to the VOICES questionnaire, ensuring that it is congruent with the strategy, and substantially reducing its length to make it much easier to complete and assess. Cognitive testing of the new version of VOICES will be nested within the pilot.

To maximise response rates, a variety of approaches have been developed to make the questionnaire available, including enabling completion via the internet and providing an interpreting service. An important element of this work has been the development of a strategy to encourage engagement from ethnic minority populations, which in prior VOICES studies have had very poor response rates.

The intention is that, subject to available funding, the pilot will inform regular national surveys of the bereaved. Guidance will also be produced to provide local commissioners and providers with the necessary support to undertake their own surveys.

Research into end of life care

There is a lack of knowledge about what services work best and at what cost. Conducting research into how services work for people at the end of life is difficult and has not been sufficiently developed. The Medical Research Council/National Institute for Health Research Methodology Research Programme has therefore commissioned a two-year research project entitled *Methods for evaluating service delivery models for end of life care: development of best practice guidance*. The principal investigator is Professor Irene Higginson from King's College London. The aim of the project is to identify, appraise and synthesise 'best practice' methods for the evaluation of end of life care, particularly focussing on complex service-delivery interventions and reconfigurations.

Supporting end of life care research

In response to the End of life Care Strategy, the National Institute for Health Research Service Delivery and Organisation (NIHR SDO) programme has funded four new research projects on generalist services for people at the end of life, with a combined value of £1.4 million. This is over and above the £1.2 million already invested by the Department of Health in palliative care research. The four projects, summarised at Appendix 5, are looking at:

- The impact of the Liverpool Care Pathway on care of dying patients in nursing homes and intensive care units in England;
- Factors that influence the place of death for patients with non-cancer conditions;
- How the co-ordination of end of life care could be improved to benefit patients, families and professionals; and,
- The impact of variations in the provision of out of hours end of life care on patients' and carers' experiences and satisfaction.

Three of the four projects have now started with the fourth due to start in early autumn. In connection with gaining ethical approval it is particularly pleasing to see that projects have had a positive experience to date when dealing with this sensitive issue.

Two of the four projects have been successful in applying to the SDO programme's Management Fellowship scheme and have been awarded funding to second a management fellow to join their project teams. Penny Hansford is working with the team led by Dr Fliss Murtagh and Anne Donaldson is working with the team led by Professor Scott Murray.

The management fellows are typically practising managers working in healthcare organisations that are local to the SDO funded research projects.

The SDO programme anticipates that the fellowships will encompass three key objectives:

- to improve the quality and relevance of the respective funded research projects through greater managerial involvement;
- to develop capacity in the managerial community for accessing, appraising and using research evidence;
- to encourage greater engagement, linkage and exchange between the local research producers (usually universities) and potential local research users within the NHS.

Chapter 8

Making change happen

The Quality and Productivity Challenge - QIPP

The Department of Health launched the Quality and Productivity Challenge (QIPP) in summer 2009. It has four strands – Quality, Innovation, Productivity and Prevention. All the Department's work has to be able to show that it fits that framework. QIPP is designed to help the NHS achieve savings of £15-20 billion over the next Spending Review period.

QIPP has adopted an initial twelve national workstreams of which end of life care is one. By improving the quality of care we shall also improve productivity, since high quality care in this case means meeting people's wish to be cared for at home. The paucity of financial information for end of life care means that we have to be cautious about the estimates, but Marie Curie's data from evaluating the Lincolnshire Delivering Choice pilot suggest community-based care is at worst cost neutral compared to care in hospital.

Complaints data about end of life care suggest that better communications and care planning could deliver efficiency gains, possibly worth as much as £100 million per year. This methodology is currently being tested.

Demographic projections show that numbers of deaths are due to start rising. This provides another incentive to minimise the numbers who die in acute hospitals without a medical need or personal wish to be there.

For QIPP we have selected the first two strands of the end of life care pathway – identifying people as they approach the end of life, and planning for their care. The workstream will benefit from the work we already have in hand and it is intended that it will galvanise enhanced progress at local level.

Commissioning

Commissioning is the single key mechanism for making sure that the right services are available to meet local need, and that they are sensitive to the needs of those approaching the end of life regardless of their condition. The ageing population in England, together with improvements in care for many conditions, means that more and more people are likely to live into late old age and so a higher proportion will develop dementia.

The National End of life Care Programme, in collaboration with the National Institute for Health and Clinical Excellence (NICE), has developed a commissioning guide for end of life care with people with dementia. It is

especially important to undertake care planning and advance care planning for these people at an early stage, even though they may still have many years to live, so that their wishes and preferences can be taken fully into account when their condition advances to the point where they lose capacity.

To complement this guide the National Programme has been working with the Department's dementia team to develop a good practice guide for the NHS. This will be published in August 2010.

Monitoring investment

The End of Life Care Strategy is supported with new money for 2009/10 and 2010/11. The strategy said that although the money would not be ring-fenced we would be monitoring how it was used. Sir David Nicholson repeated this commitment when he appeared before the Public Accounts Committee in December 2008.

In 2009/10 the strategy was supported by £88 million, most of which went to PCT baselines. There was a small allocation to SHAs through the MPET levy and a small amount retained for central initiatives including the National End of Life Care Programme.

In consultation with SHA colleagues we devised a template to capture the possible areas of new investment and decommissioning at PCT and SHA levels. By the time this report was finalised we had received 145 returns from PCTs and nine from SHAs. The detailed analysis can be found at Appendix 6, with a further breakdown available on the Department of Health website (www.dh.gov.uk).

The PCTs reported a net total new spend of just about £72 million net new investment. Based on this (and assuming that the remaining PCTs are not significantly different from those which have made their returns), it is estimated that across all PCTs, new investment into end of life care services was about £75 million, which is in line with the PCT baseline uplift for additional investment into end of life care.

Average investment per PCT was about £500,000, or about £9 per person aged over 65. As shown in figure 1 below, the highest proportions of total spend were on Voluntary Hospice (20%), Care Homes (17.5%), Other (15.3%), Specialist Palliative Care Teams (11.9%), and Specialist Palliative Care Resources (8.6%). These were also the services that most PCTs invested in, and together represent over 70% of total new spend. Other services where at least a third of PCTs reported investments were Training, and Support for Marie Curie Nurses or equivalents. These together represented a further 8% of total spend. Nine PCTs reported disinvestment from some end of life care services, representing a total disinvestment of about £1.6 million.

End of Life Care Strategy: Second Annual Report

Figure 1: PCT Spend by category

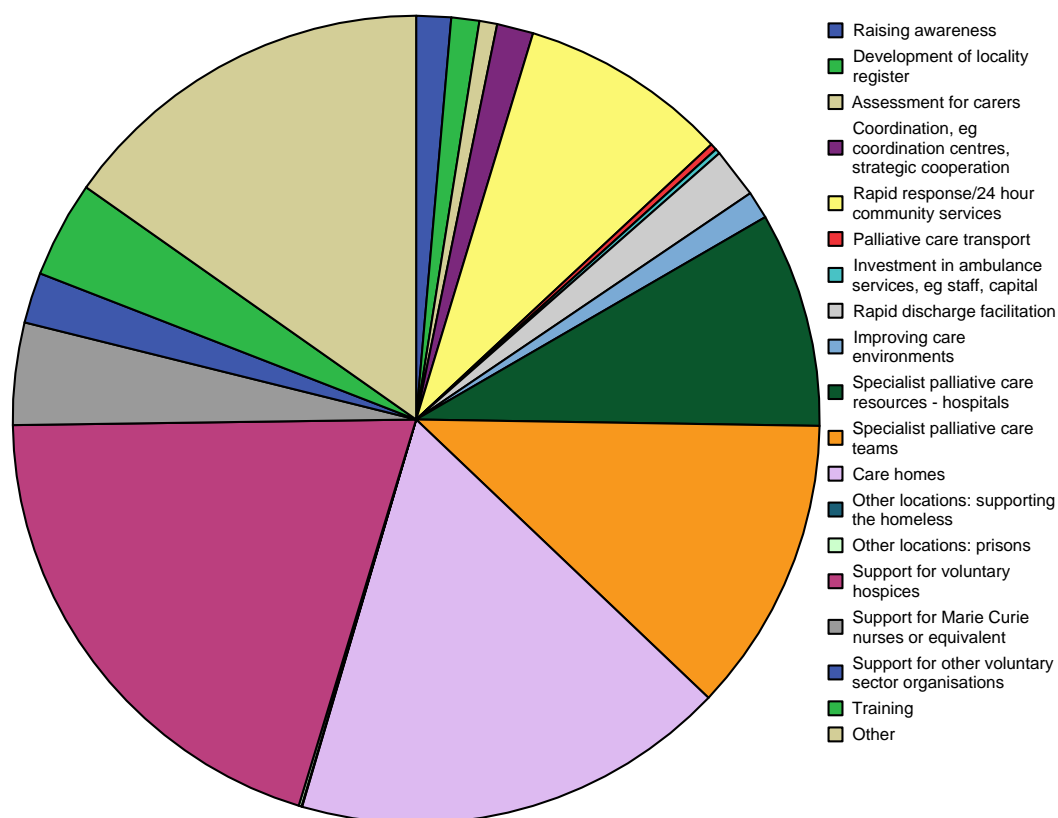
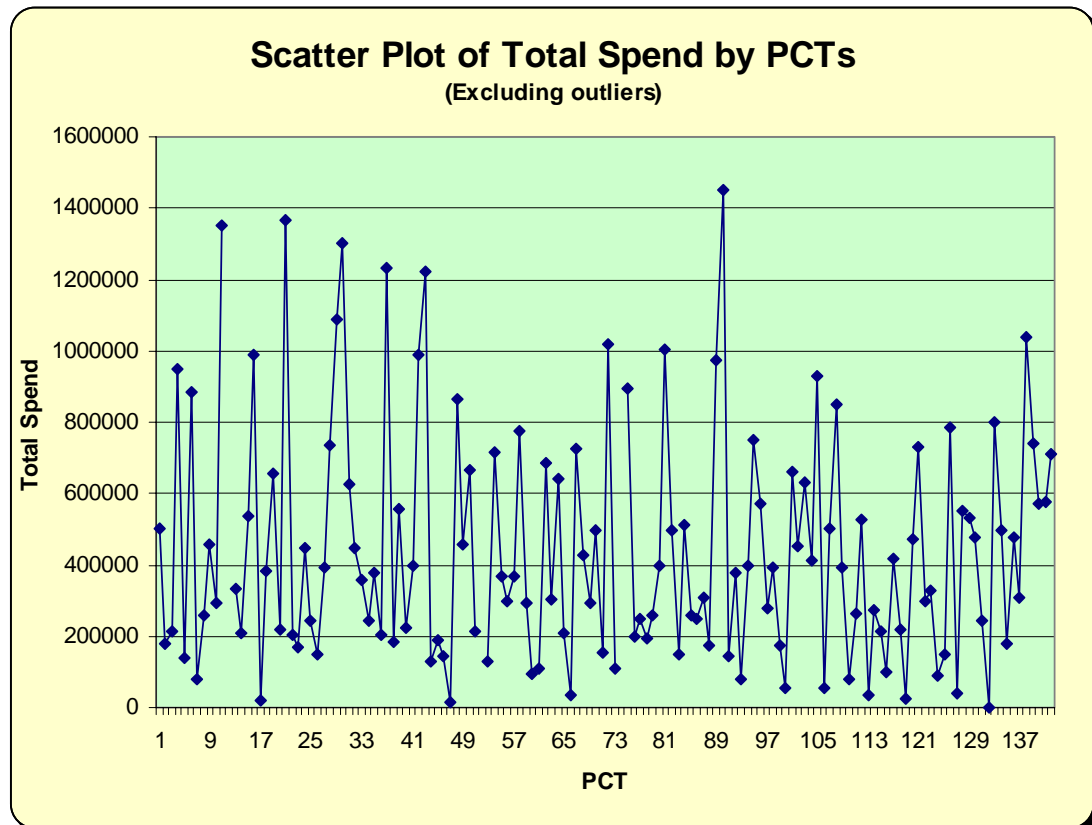


Table 2: NEW PCT INVESTMENT		
Type of Spend	Total Spend (£)	Spend
Raising awareness	1,013,821	1%
Development of locality register	814,000	1%
Assessment for carers	517,010	1%
Coordination, eg coordination centres, strategic cooperation	1,063,904	1%
Rapid response/24 hour community services	6,104,356	8%
Palliative care transport	194,000	0%
Investment in ambulance services, eg staff, capital	148,000	0%
Rapid discharge facilitation	1,850,682	3%
Improving care environments	811,000	1%
Specialist palliative care resources - hospitals	6,266,080	9%
Specialist palliative care teams	8,630,000	12%
Care homes	12,708,322	17%
Other locations: supporting the homeless	20,000	0%
Other locations: prisons	83,000	0%
OTHER NEW PCT INVESTMENT		
Support for voluntary hospices	14,612,867	20%
Support for Marie Curie nurses or equivalent	2,978,965	4%
Support for other voluntary sector organisations	1,473,378	2%
Training	2,801,343	4%
Other	11,166,710	15%
PCT Disinvestment	-1,632,000	-2%

There is a high degree of variation in the level of new investment between PCTs. Some of this is driven by some PCTs that reported either no investment in end of life care or significantly high levels of investment. Of the PCTs that made returns, twelve reported investment of over £1 million with a maximum investment of £5.4 million in Hampshire, which on its own represented about 8% of total spend, while Blackburn reported no new investment at all. Even after excluding the outliers, there is still much variation in the levels of investment between PCTs as shown in figure 2 below.

Figure 2



Some of the variation observed can be explained by the size of the over 65s population within each PCT. However, even after controlling for this, a fair degree of variation still remains. This could be due to several factors including the historical levels of investment, but we are not able to explore this further due to a lack of historical data on total spend on end of life care by PCTs. However, historical data (2006/7) on PCT spend on adult specialist palliative care is available, and indicates a strong relationship between historical levels of expenditures and current spend – in other words, those PCTs which have historically been good at investing in end of life care have continued to be so and vice versa. We need, therefore, to encourage more investment by those PCTs where investment tends to lag behind.

Nine out of ten SHAs returned data on end of life care expenditure at both SHA and PCT levels. Some of SHA budgets were passed to PCTs; depending on the approach taken, PCT- and SHA-reported data on PCT

spend did not always tally. Thus, estimated total new investment by PCTs based on PCT returns (£75 million) differed from the estimate based on SHA returns on PCT spend (£77 million). Total new investment across the nine SHAs that made data returns (including PCT spend) was £74.9 million. Based on this, new investment across all SHAs is estimated at about £83.2 million. Investments by SHAs themselves ranged from zero in East Midlands and South East Coast to just over £2 million by the North West SHA. Average spend at SHA level was about £750,000.

In addition to the above expenditure, the Department of Health and the National End of Life Care Programme invested about £4.35 million in national work and projects.

We shall be running the exercise again next year to monitor investment over 2010/11. At the same time we shall repeat the survey of spending on specialist palliative care which preceded the strategy.

Quality Markers

These are now being used across the NHS. We intend to consult on their effectiveness and to revise them next year.

North West pilot of end of life care quality markers and measures

The North West End of Life Care Clinical Pathway Group (CPG) identified the Department of Health's *Quality Markers and measures for end of life care* as a key standard for the North West to achieve.

These are not mandatory but they are helpful for organisations to formulate end of life care plans with SHAs, Local Authorities and Provider Services.

Commissioners will find them of use in articulating their expectations of service and commissioning against them. They also provide a useful framework to track action plans.

The Quality Markers cover the ten key recommendations cited in the End of Life Care Strategy.

It was agreed to utilise the work already completed by Tom Fairclough, then commissioner for end of life care at Knowsley's Health and Wellbeing PCT. Tom had devised a self assessment tool for each provider, matched to the quality markers and measures, which incorporated North West local and end of life care clinical pathway recommendations.

The North West End of Life CPG agreed to pilot these self-assessment tools across the North West in 2010 with a view to using them region-wide in the near future, if successful. The aim of the pilot project was:

1. To test out the usefulness and reliability of the self-assessment markers and measures across the North West with all the providers;

2. To assess whether the use of the quality markers and measures made a difference at both commissioner and provider level;
3. To see whether the quality markers and measures could make a difference to patient care.

A project team was established, made up of representatives from the Cancer and End of Life Care Networks and the North West SHA. The team, using a defined scoring system, assessed each application and decided who met the criteria to be a pilot site.

The project had a tight timescale of two months. The aim was to have pilot sites representative of the North West. To this end the North West SHA sought formal applications from across the North West to get involved via completion of a scoping document for assessment. The team also sent out the completed scoping documents for external review to ensure that the final decisions made were equitable and fair.

The successful pilot sites were: Central and Eastern Cheshire PCT; Central Lancashire PCT; North West Ambulance Service; Salford PCT; Tameside and Glossop PCT; Western Cheshire PCT.

There were two meetings of all the pilot site leads in January and February 2010, to address any issues/problems and to share experiences during the pilot. During the pilot the Project Lead undertook teaching sessions across all the sites. These were beneficial in ironing out any problems before they arose. The teaching sessions worked really well as attendance was high alongside the commitment to share ideas.

The way forward following the pilot.

Following the successful pilots the North West SHA has decided to take forward the work using the Quality Markers and Measures in two ways. First, provider organisations will be encouraged to use the Quality Markers and Measures to assess their own performance in relation to end of life care. The self-assessment tool developed for the pilots will be amended in the light of experience. This tool will be provided electronically together with a step by step guide for completion. Second, the Quality Markers and Measures are already being used by PCTs as a tool for commissioning high quality end of life care services. If successful, these approaches will be shared nationally.

Contact: Elaine Owen, NHS North West Leadership Fellow End of Life Care, Royal Liverpool University Hospital Trust (elaine.owen@rlbuht.nhs.uk)

Appendix 1

Review of palliative care funding, to be chaired by Tom Hughes-Hallett, Chief Executive, Marie Curie Cancer Care

Terms of Reference

To review the current funding mechanisms for dedicated palliative care for adults and children

To consider and quantify the impact of changes in funding mechanisms, based on an NHS tariff to meet NHS responsibilities, regardless of the choice of provider, on a per-patient basis

To make recommendations on a funding mechanism which is fair to all sectors, including the voluntary sector

Encourages the development of community-based palliative care services

Supports the exercise of choice by care users of provider and of location of palliative care provision

Phase one of the review should offer a definition of core dedicated palliative care services, together with some indicative costs, by autumn 2010

Phase two should make detailed recommendations for the mechanisms for funding the core service across all sectors by summer 2011.

Secretariat will be provided by the Department of Health.

Appendix 2

National End of Life Care Programme's summary of Advance Care Planning, care planning, DNACPR

Web-link access:

<http://www.endoflifecareforadults.nhs.uk/publications/differencesacpadrt>

Appendix 3

Enhancing the Healing Environment

List of participating organisations

Improvements to facilities for palliative care patients and relatives

Barnet & Chase Farm Hospitals NHS Trust, Barnet Hospital, Barnet, Herts
East Kent Hospitals University NHS Foundation Trust, Queen Elizabeth
Queen Mother Hospital, Margate, Kent
Frimley Park Hospital NHS Foundation Trust, Frimley Park Hospital,
Camberley, Surrey
Lancashire Care NHS Foundation NHS Trust, Frank Gardham House,
Specialist unit for sufferer's of Huntington's Disease, Preston, Lancs
Liverpool Women's Hospital NHS Foundation Trust, Liverpool Women's
Hospital, Liverpool
Northumbria Healthcare NHS Foundation Trust, Wansbeck General Hospital,
Ashrington, Northumberland
Nottingham University Hospitals NHS Trust, Hayward House Specialist
Palliative Care Unit - City Campus, Nottingham
Shropshire County Primary Care Trust, Bishops Castle Community Hospital,
Bishops Castle, Shropshire
South Staffordshire & Shropshire Healthcare NHS Foundation Trust, Baswich
Ward (dementia care), St George's Hospital, Stafford
South Tees Hospitals NHS Trust, The James Cook University Hospital,
Middlesbrough
Her Majesty's Prison Isle of Wight (HMP Albany)

Bereavement suites (centralisation of bereavement services)

Cambridge University Hospitals NHS Foundation Trust, Addenbrooke's
Hospital, Cambridge (project also includes the upgrade of A&E relatives
room)
Northampton General Hospital NHS Trust, Northampton General Hospital,
Northampton
Southend University Hospital NHS Foundation Trust, Southend Hospital,
Southend on Sea, Essex,
York Hospitals NHS Foundation Trust, York Hospital, York

Mortuary viewing facilities

Luton & Dunstable Hospital NHS Foundation Trust, Luton and Dunstable
Hospital, Luton, Bedfordshire
Newham University Hospital NHS Trust, Newham General Hospital, Plaistow,
London (project also includes refurbishment of A&E viewing and relatives
room)
North Bristol NHS Trust, Frenchay and Southmead Hospitals, Bristol (two
projects)
Salisbury NHS Foundation Trust, Salisbury District Hospital, Salisbury,
Wiltshire

Appendix 4

Hospice Capital Grant Scheme for 2010/11 – successful applicants

Hospice	SHA	Project
Ashgate Hospice	East Midlands	In-patient unit/Refurbishment
Barnsley Hospice	Yorkshire and Humber	Day care unit/ Refurbishment
Beaumont House Community Hospice	East Midlands	Information centre/Refurbishment
Birmingham St. Mary's Hospice	West Midlands	Day care unit/Refurbishment
Blythe House (High Peak Hospicecare)	East Midlands	Day care unit /New building
Bolton Hospice	North West	Day care unit/ Refurbishment
Butterwick Hospice (Bishop Auckland)	North East	Day care unit/ Refurbishment
Chestnut Tree House Children's Hospice	South East Coast	In-patient unit/ Refurbishment
Compton Hospice	West Midlands	In-patient unit/ Refurbishment
Cornwall Hospice Care (Hayle)	South West	Therapy centre / New building
Cotswold Care Hospice	South West	Day care unit / New building
Derian House Children's Hospice	North West	In-patient unit/ Refurbishment
Donna Louise Children's Hospice	West Midlands	Kitchen / Dining area / Refurbishment
Dorothy House Hospice Care	South West	In-patient unit/ Refurbishment
Douglas Macmillan Hospice	West Midlands	In-patient unit / New building
Dove House Hospice	Yorkshire and Humber	Therapy centre / New building
Dr Kershaw's Hospice	North West	In-patient unit/ Refurbishment
Earl Mountbatten Hospice	South Central	Day care unit/ Refurbishment

End of Life Care Strategy: Second Annual Report

East Cheshire Hospice	North West	Day care unit / New building
East Lancashire Hospice	North West	In-patient unit/ Refurbishment
Eden Valley Hospice	North West	Day care unit / New building
EllenorLions Hospices	South East Coast	Day care unit/ Refurbishment
Fair Havens Hospice	East of England	In-patient unit/ Refurbishment
Farleigh Hospice	East of England	Therapy centre / New building
Greenwich & Bexley Cottage Hospice	London	In-patient unit/ Refurbishment
Halton Haven Hospice	North West	In-patient unit/ Refurbishment
Harris HospisCare with St Christopher's	London	Day care unit/ Refurbishment
Hayward House Macmillan Specialist Palliative Cancer Care Unit	East Midlands	Reception / New building
Heart of Kent Hospice	South East Coast	Day care unit/ Refurbishment
Helen and Douglas House Hospice Care	South Central	In-patient unit/ Refurbishment
Hospice Care for Burnley and Pendle	North West	Hospitality/Refurbishment
Hospice in the Weald	South East Coast	In-patient unit/ Refurbishment
Hospice of St Francis	East of England	Day care unit/ Refurbishment
Hospice of St Mary of Furness	North West	Bathroom / Refurbishment
Hospiscare – Exeter	South West	Day care unit/ Refurbishment
Isabel Hospice	East of England	Kitchen / Dining area / Refurbishment
Katharine House Hospice (Banbury)	South Central	In-patient unit / New building
Katharine House Hospice (Stafford)	West Midlands	Day care unit/ Refurbishment

End of Life Care Strategy: Second Annual Report

Keech Hospice Care	East of England	Day care unit/ Refurbishment
Kirkwood Hospice	Yorkshire and Humber	Day care unit/ Refurbishment
Lindsey Lodge Hospice	Yorkshire and Humber	Hospitality/Refurbishment
LOROS Leicestershire and Rutland Hospice	East Midlands	Hospitality/Refurbishment
Marie Curie Cancer Care Hampstead	London	Hospitality/Refurbishment
Marie Curie Cancer Care Liverpool	North West	Reception/ Refurbishment
Marie Curie Cancer Care Newcastle-upon-Tyne	North East	Chapel / Refurbishment
Martin House	Yorkshire and Humber	Reception / New building
Martlets Hospice	South East Coast	In-patient unit/ Refurbishment
Mary Ann Evans Hospice	West Midlands	Day care unit/ Refurbishment
Mary Stevens Hospice	West Midlands	In-patient unit/ Refurbishment
Meadow House Hospice	London	Therapy centre / New building
North London Hospice	London	Day care unit / New building
North London Hospice	London	In-patient unit/ Refurbishment
Nottinghamshire Hospice	East Midlands	Day care unit/ Refurbishment
Oakhaven Hospice	South Central	In-patient unit / New building
Overgate Hospice	Yorkshire and Humber	Day care unit/ Refurbishment
Peace Hospice	East of England	Therapy centre/ Refurbishment
Phyllis Tuckwell Hospice	South East Coast	Reception/ Refurbishment
Pilgrims Hospice Ashford	South East Coast	Reception/ Refurbishment
Pilgrims Hospice Margate	South East Coast	In-patient unit / New building
Primrose Hospice & Cancer Help Centre	West Midlands	Therapy centre / New building

End of Life Care Strategy: Second Annual Report

Princess Alice Hospice	South East Coast	In-patient unit/ Refurbishment
Prospect Hospice	South West	Kitchen / Dining area / Refurbishment
Queenscourt Hospice	North West	In-patient unit/ Refurbishment
Rossendale Hospice	North West	Day care unit/ Refurbishment
Rotherham Hospice	Yorkshire and Humber	In-patient unit/ Refurbishment
Rowcroft - Torbay & S Devon Hospice	South West	Therapy centre/ Refurbishment
Salisbury Hospice	South West	In-patient unit/ Refurbishment
Severn Hospice	West Midlands	Day care unit/ Refurbishment
Springhill Hospice	North West	In-patient unit/ Refurbishment
St Andrew's Children's Hospice	Yorkshire and Humber	Therapy centre/ Refurbishment
St Andrew's Hospice (Grimsby)	Yorkshire and Humber	Therapy centre/ Refurbishment
St Ann's Hospice (Worsley)	North West	In-patient unit/ Refurbishment
St Barnabas Hospices Worthing	South East Coast	Reception / New building
St Barnabas Lincolnshire Hospice (GIFTS Hospice)	East Midlands	Day care unit/ Refurbishment
St Catherine's Hospice (Preston)	North West	Reception / New building
St Catherine's Hospice (Scarborough)	Yorkshire and Humber	Conservatory / New building
St Christopher's Hospice	London	In-patient unit/ Refurbishment
St Clare Hospice (Harlow)	East of England	In-patient unit/ Refurbishment
St Clare's Hospice (Jarrow)	North East	In-patient unit/ Refurbishment
St Cuthbert's Hospice	North East	Grounds / Landscaping
St Elizabeth Hospice Ipswich	East of England	In-patient unit/ Refurbishment
St Francis Hospice (Romford)	London	Bathroom / Refurbishment
St Gemma's Hospice Leeds	Yorkshire and Humber	In-patient unit/ Refurbishment

End of Life Care Strategy: Second Annual Report

St Giles Hospice Lichfield	West Midlands	Therapy centre/ Refurbishment
St Helena Hospice Colchester	East of England	Day care unit/ Refurbishment
St John's Hospice (Lancaster)	North West	Hospitality/Refurbishment
St John's Hospice (London)	London	In-patient unit/ Refurbishment
St John's Hospice (Wirral)	North West	In-patient unit / New building
St Joseph's Hospice (London)	London	Viewing room/ Refurbishment
St Joseph's Hospice Association Liverpool	North West	In-patient unit/ Refurbishment
St Leonard's Hospice York	Yorkshire and Humber	Bathroom / Refurbishment
St Luke's Hospice (Basildon)	East of England	Therapy centre/ Refurbishment
St Luke's Hospice (Cheshire)	North West	Reception / New building
St Luke's Hospice (Harrow)	London	Reception/ Refurbishment
St Luke's Hospice (Plymouth)	South West	In-patient unit/ Refurbishment
St Margaret's Somerset Hospice Taunton	South West	Grounds / Landscaping
St Michael's Hospice (Harrogate)	Yorkshire and Humber	In-patient unit/ Refurbishment
St Michael's Hospice (Hastings)	South East Coast	Therapy centre/ Refurbishment
St Michael's Hospice (North Hampshire)	South Central	In-patient unit/ Refurbishment
St Nicholas Hospice Care	East of England	Grounds / Landscaping
St Oswald's Hospice Newcastle	North East	In-patient unit/ Refurbishment
St Peter & St James Hospice Lewes	South East Coast	In-patient unit / New building
St Peter's Hospice (Bristol)	South West	Grounds / Landscaping
St Raphael's Hospice Sutton	London	Bathroom / Refurbishment

End of Life Care Strategy: Second Annual Report

St Richard's Hospice Worcester	West Midlands	Therapy centre / New building
St Rocco's Hospice Warrington	North West	Grounds / Landscaping
St Teresa's Hospice Darlington	North East	Day care unit/ Refurbishment
St Wilfrid's Hospice (Chichester)	South East Coast	In-patient unit/ Refurbishment
St Wilfrid's Hospice (Eastbourne)	South East Coast	In-patient unit/ Refurbishment
Sue Ryder Care Manorlands (Keighley)	Yorkshire and Humber	In-patient unit/ Refurbishment
Sue Ryder Care St John's (Bedford)	East of England	Day care unit/ Refurbishment
Sue Ryder Care Wheatfields (Leeds)	Yorkshire and Humber	Day care unit/ Refurbishment
Sussex Beacon	South East Coast	In-patient unit/ Refurbishment
The Rowans Hospice	South Central	Reception / New building
Treetops Hospice	East Midlands	Day care unit / New building
Wakefield Hospice	Yorkshire and Humber	In-patient unit/ Refurbishment
Walsall Hospice	West Midlands	In-patient unit / New building
Warwick Myton Hospice	West Midlands	In-patient unit/ Refurbishment
Weldmar Hospicecare Trust Dorchester	South West	Day care unit/ Refurbishment
Weston Hospicecare	South West	Reception/ Refurbishment
Wigan and Leigh Hospice	North West	In-patient unit/ Refurbishment
Willowbrook Hospice	North West	Therapy centre / New building
Woodlands Hospice	North West	Therapy centre/ Refurbishment

Appendix 5

Summary of end of life care projects recently funded by the SDO programme in 2009/10

Project Reference	Project Title	Principle Investigator	Start date	Funding	Duration
08/1813/256	The Impact of the Liverpool Care Pathway on care at the end of life	Professor John Ellershaw, University of Liverpool	01/01/2010	£474,304	36 months
08/1813/257*	Understanding place of death for patients with non malignant disease: a systematic literature review	Dr Fliss Murtagh, King's College London	01/01/2010	£98,945	12 months
08/1813/258*	Definition and evaluation of models of primary and secondary care collaborative working	Professor Scott Murray, University of Edinburgh	01/10/2009	£406,485	27 months
08/1813/259	The impact of variations in out of hours end of life care provision on patient experience, staff and health systems	Professor Julia Addington-Hall, University of Southampton	01/09/2010	£474,690	36 months

Notes to table:

(i) * projects that have Management Fellowships

(ii) The funding shown is the original funding received for the project and excludes any additional funding the project team may have received for a Management Fellowship where this is relevant.

(iii) The four projects in this table were funded from the same SDO call for proposals, there are other projects in the SDO programme portfolio that also focus on end of life care for more details please visit:

<http://www.sdo.nihr.ac.uk/projbycat.php?cat=sdotheme>

Appendix 6

Results of the Department of Health's monitoring of new investment in end of life care, 2009/10

End of Life Care Strategy: Second Annual Report

Table 1: Total Spend by PCT

	PCT	Total Spend (£)
1	Ashton, Leigh and Wigan	500,000
2	Barking and Dagenham	179,000
3	Barnet	214,000
4	Barnsley	947,000
5	Bassetlaw	139,000
6	Bath and North East Somerset	882,000
7	Bedfordshire	78,000
8	Berkshire East	257,000
9	Berkshire West	459,000
10	Bexley	294,000
11	Birmingham East and North	1,351,000
12	Blackburn with Darwen	0
13	Blackpool	333,000
14	Bolton	206,667
15	Bournemouth and Poole Teaching	535,000
16	Bradford and Airedale Teaching	988,000
17	Brent Teaching	22,000
18	Brighton and Hove City	384,000
19	Bristol	654,000
20	Bromley	220,000
21	Buckinghamshire	1,367,000
22	Bury	202,000
23	Calderdale	169,000
24	Cambridgeshire	446,000
25	Camden	243,000
26	Central and Eastern Cheshire	151,000
27	Central Lancashire	395,000
28	City and Hackney Teaching	733,000
29	Cornwall and Isles of Scilly	1,087,000
30	County Durham	1,301,000
31	Coventry Teaching	624,000
32	Croydon	446,000
33	Cumbria Teaching	360,000
34	Darlington	241,000
35	Derby City	379,000
36	Derbyshire County	202,000
37	Devon	1,233,000
38	Doncaster	185,000
39	Dorset	554,243
40	Dudley	225,000
41	Ealing	400,000
42	East Lancashire Teaching	990,000
43	East Riding of Yorkshire	1,221,000
44	East Sussex Downs and Weald AND Hastings	128,000
45	Eastern and Coastal Kent	187,000
46	Enfield	142,000
47	Gateshead	17,000
48	Gloucestershire	864,000
49	Great Yarmouth and Waveney	0
50	Greenwich Teaching	456,000
51	Halton and St Helens	665,868
52	Hammersmith and Fulham	216,000
53	Hampshire	5,426,000
54	Haringey Teaching	129,000
55	Harrow	715,000
56	Hartlepool	366,000
57	Havering	300,000
58	Heart of Birmingham Teaching	367,000
59	Herefordshire	777,000
60	Heywood, Middleton and Rochdale	291,000
61	Hillingdon	95,000
62	Hounslow	107,000
63	Hull Teaching	683,400
64	Isle of Wight National Health Service	302,000
65	Islington	641,000
66	Kensington and Chelsea	208,000
67	Kingston	33,383
68	Kirklees	724,000
69	Knowsley	428,000
70	Lambeth	291,042
71	Leeds	495,000
72	Leicester City	152,000
73	Leicestershire County and Rutland	1,021,000
74	Lewisham	110,000
75	Lincolnshire Teaching	4,406,630

	PCT	Total Spend (£)
76	Liverpool	896,000
77	Luton	0
78	Manchester	197,000
79	Medway	248,000
80	Mid Essex	0
81	Middlesbrough	195,000
82	Milton Keynes	256,000
83	Newcastle	396,000
84	Newham	1,003,000
85	Norfolk	458,000
86	North East Essex	499,000
87	North East Lincolnshire	150,000
88	North Lancashire Teaching	514,000
89	North Lincolnshire	257,000
90	North Somerset	250,000
91	North Staffordshire	306,000
92	North Tyneside	174,000
93	North Yorkshire and York	973,000
94	Northamptonshire Teaching	1,448,822
95	Northumberland	144,000
96	Nottingham City	380,000
97	Nottinghamshire County Teaching	79,000
98	Oldham	399,000
99	Oxfordshire	750,000
100	Peterborough	0
101	Plymouth Teaching	572,000
102	Portsmouth City Teaching	280,000
103	Redbridge	392,000
104	Redcar and Cleveland	174,000
105	Richmond and Twickenham	56,000
106	Rotherham	662,000
107	Salford	453,000
108	Sandwell	633,000
109	Sefton	414,500
110	Sheffield	931,000
111	Shropshire County	55,000
112	Solihull	503,000
113	Somerset	847,826
114	South Birmingham	393,000
115	South East Essex	78,000
116	South Gloucestershire	264,000
117	South Staffordshire	529,000
118	South Tyneside	34,000
119	South West Essex	0
120	Southampton City	275,000
121	Southwark	213,000
122	Stockport	100,000
123	Stockton-on-Tees Teaching	416,000
124	Stoke on Trent	219,000
125	Suffolk	0
126	Sunderland Teaching	24,000
127	Surrey	474,000
128	Sutton and Merton	729,000
129	Swindon	298,000
130	Tameside and Glossop1	326,000
131	Telford and Wrekin	89,000
132	Torbay	150,000
133	Tower Hamlets	783,421
134	Trafford	40,000
135	Wakefield District	550,000
136	Walsall Teaching	531,000
137	Waltham Forest	479,000
138	Wandsworth	244,000
139	Warrington	2,000
140	Warwickshire	798,000
141	West Essex	0
142	West Hertfordshire AND East and North Herts	498,000
143	West Kent	180,500
144	West Sussex	479,000
145	Western Cheshire	305,600
146	Westminster	1,037,000
147	Wiltshire	740,000
148	Wirral	571,000
149	Wolverhampton City	576,536
150	Worcestershire	712,000

End of Life Care Strategy: Second Annual Report

Table 2: NEW PCT INVESTMENT		
Type of Spend	Total Spend (£)	% of Total Spend
Raising awareness	1,013,821	1%
Development of locality register	814,000	1%
Assessment for carers	517,010	1%
Coordination, eg coordination centres, strategic cooperation	1,063,904	1%
Rapid response/24 hour community services	6,104,356	8%
Palliative care transport	194,000	0%
Investment in ambulance services, eg staff, capital	148,000	0%
Rapid discharge facilitation	1,850,682	3%
Improving care environments	811,000	1%
Specialist palliative care resources - hospitals	6,266,080	9%
Specialist palliative care teams	8,630,000	12%
Care homes	12,708,322	17%
Other locations: supporting the homeless	20,000	0%
Other locations: prisons	83,000	0%
OTHER NEW PCT INVESTMENT		
Support for voluntary hospices	14,612,867	20%
Support for Marie Curie nurses or equivalent	2,978,965	4%
Support for other voluntary sector organisations	1,473,378	2%
Training	2,801,343	4%
Other	11,166,710	15%
PCT Disinvestment		
	-1,632,000	-2%

End of Life Care Strategy: Second Annual Report

SHA	PCT	Total Spend
North East		3494000
	County Durham	1301000
	Darlington	241000
	Gateshead	17000
	Hartlepool	366000
	Middlesbrough	195000
	Newcastle	396000
	Stockton-on-Tees Teaching	416000
	North Tyneside	174000
	Northumberland	144000
	Redcar and Cleveland	174000
	South Tyneside	34000
	Sunderland Teaching	24000
North West		10814635
	Ashton, Leigh and Wigan	500000
	Blackburn with Darwen	0
	Blackpool	333000
	Bolton	206667
	Bury	202000
	Central and Eastern Cheshire	186000
	Central Lancashire	395000
	Cumbria Teaching	360000
	East Lancashire Teaching	990000
	Halton and St Helens	665868
	Heywood, Middleton and Rochdale	291000
	Knowsley	428000
	Liverpool	1133000
	Manchester	197000
	North Lancashire Teaching	514000
	Oldham	399000
	Salford	453000
	Sefton	414500
	Stockport	100000
	Tameside and Glossop1	326000
	Trafford	40000
	Warrington	2000
	Western Cheshire	305600
	Wirral	571000
Yorkshire and the Humber		8950000
	Barnsley	947000
	Bradford and Airedale Teaching	988000
	Calderdale	169000
	Doncaster	185000
	East Riding of Yorkshire	1221000
	Hull Teaching	683400
	Kirklees	724000
	Leeds	495000
	North East Lincolnshire	150000
	North Lincolnshire	257000
	North Yorkshire and York	973000
	Rotherham	662000
	Sheffield	931000
	Wakefield District	550000
West Midlands		9847000
	Birmingham East and North	1351000
	Coventry Teaching	624000
	Dudley	225000
	Heart of Birmingham Teaching	367000
	Herefordshire	777000
	North Staffordshire	306000
	Sandwell	633000
	Shropshire County	55000
	Solihull	503000
	South Birmingham	393000
	South Staffordshire	529000
	Stoke on Trent	219000
	Telford and Wrekin	89000
	Walsall Teaching	531000
	Warwickshire	798000
	Wolverhampton City	576536
	Worcestershire	712000

SHA	PCT	Total Spend
London		12121846
	Barking and Dagenham	179000
	Barnet	238000
	Bexley	294000
	Brent Teaching	22000
	Bromley	220000
	Camden	839000
	City and Hackney Teaching	733000
	Croydon	578000
	Ealing	400000
	Enfield	142000
	Greenwich Teaching	456000
	Hammersmith and Fulham	216000
	Haringey Teaching	129000
	Harrow	715000
	Havering	300000
	Hillingdon	95000
	Hounslow	107000
	Islington	1112000
	Kensington and Chelsea	208000
	Kingston	33383
	Lambeth	291042
	Lewisham	110000
	Newham	1021000
	Redbridge	392000
	Richmond and Twickenham	56000
	Southwark	213000
	Sutton and Merton	729000
	Tower Hamlets	783421
	Waltham Forest	479000
	Wandsworth	244000
	Westminster	1037000
South East Coast		2080000
	Brighton and Hove City	384000
	Eastern and Coastal Kent	187000
	Medway	248000
	Surrey	474000
	West Kent	180500
	West Sussex	479000
	East Sussex Downs and Weald AND Hastings and Rother	128000
South Central		9522000
	Berkshire East	257000
	Berkshire West	459000
	Buckinghamshire	1454000
	Hampshire	5426000
	Isle of Wight National Health Service	302000
	Milton Keynes	256000
	Oxfordshire	750000
	Portsmouth City Teaching	280000
	Southampton City	275000
South West		9826000
	Bath and North East Somerset	882000
	Bournemouth and Poole Teaching	535000
	Bristol	654000
	Cornwall and Isles of Scilly	1087000
	Devon	1233000
	Dorset	554243
	Gloucestershire	880000
	North Somerset	250000
	Plymouth Teaching	572000
	Somerset	847826
	South Gloucestershire	264000
	Swindon	298000
	Torbay	150000
	Wiltshire	740000
East Midlands		8207452
	Bassetlaw	139000
	Derby City	395000
	Derbyshire County	202000
	Leicester City	152000
	Leicestershire County and Rutland	1021000
	Lincolnshire Teaching	4406630
	Northamptonshire Teaching	1448822
	Nottingham City	380000
	Nottinghamshire County Teaching	79000

Appendix 7

Strategic Health Authority End of Life Care Clinical and Management Leads

Elizabeth Kendrick - GPwSI Older People; Chair End of Life Clinical Innovation Team, NHS North East (elizabeth.kendrick@nhs.net).

Moira Davison – End of Life Care Management Lead, NHS North East (moira.davison@northeast.nhs.uk).

Fiona Hicks - Consultant in Palliative Medicine, Leeds TH NHS Trust; Joint Clinical Lead End of Life Care, NHS Yorkshire and the Humber (fiona.hicks@leedsth.nhs.uk).

June Toovey - Nurse Director, Yorkshire Cancer Network; Joint Clinical Lead End of Life Care, NHS Yorkshire and the Humber (June.Toovey@ycn.nhs.uk).

Catherine Wardle - SHA End of Life Care Management Lead, NHS Yorkshire and the Humber (catherine.wardle@yorksandhumber.nhs.uk).

Robin Graham-Brown - Director of Services for Older People/Consultant Dermatologist, University Hospitals of Leicester; End of Life Care Pathway Chair, NHS East Midlands (robin.grahambrown@uhl-tr.nhs.uk).

Amanda Rolland - SHA End of Life Care Management Lead, NHS East Midlands (amanda.rolland@nhs.net).

Dee Traue – Medical Director, Isabel Hospice; Chair, Palliative and End of Life Care Clinical Programme Board, NHS East of England (dee.traue@nhs.net).

Penny Lavis – SHA End of Life Care Management Lead, NHS East of England, (penny.lavis@eoe.nhs.uk).

Rob George - Consultant in Palliative Medicine, Guy's and St Thomas'; Pan-London Clinical Lead for End of Life Care, Commissioning Support for London (rob.george@gstt.nhs.uk).

Eileen Sutton – SHA End of Life Care Management Lead, NHS London (eileen.sutton@london.nhs.uk).

John Omany - Medical Director and Consultant in Palliative Medicine, Woking and Sam Beare Hospices; End of Life Care Clinical Adviser, NHS South East Coast (john.omany@surreypct.nhs.uk).

Karen Devanny - Senior Nurse, Clinical Developments, Clinical & Workforce Directorate; SHA End of Life Care Management Lead, NHS South East Coast (karen.devanny@southeastcoast.nhs.uk).

Mark Roland – Clinical Director for End of Life Care, NHS South Central; Consultant Respiratory Physician, Portsmouth Hospitals NHS Trust (mark.roland@porthosp.nhs.uk).

Lucy Sutton - Associate Director for End of Life Care Programme, NHS South Central (Lucy.Sutton@southcentral.nhs.uk).

Will Warin - Professional Executive Committee Chair, NHS Bristol; Joint Clinical Lead for End of Life Care, NHS South West (will.warin@bristolpct.nhs.uk).

Julian Abel – Consultant in Palliative Care, Weston Area Health Trust and Weston Hospicecare; Joint Clinical Lead for End of Life Care, NHS South West (julian.abel@nhs.net).

End of Life Care Strategy: Second Annual Report

Julia Chisnell - Programme Manager Cancer, End of Life Care, Urgent & Emergency Care, NHS South West (Julia.Chisnell@southwest.nhs.uk).

Pauline Smith - End of Life Care and Dementia Lead, Transformation Team, NHS West Midlands (pauline.smith@westmidlands.nhs.uk).

Nicole Woodyatt – Workforce Development Lead, NHS West Midlands (Nicole.Woodyatt@westmidlands.nhs.uk).

John E Ellershaw - Professor of Palliative Medicine, University of Liverpool; End of Life Care Pathway Chair, NHS North West (J.E.Ellershaw@liverpool.ac.uk).

Liz Matthews - SHA Joint End of Life Care Management Lead, NHS North West (liz.matthews@northwest.nhs.uk).

Jane Cummings - SHA Joint End of Life Care Management Lead, NHS North West (jane.cummings@northwest.nhs.uk).