End of Life Care Strategy

Third Annual Report

‘How people die remains in the memory of those who live on’

Dame Cicely Saunders

Founder of the Modern Hospice Movement

September 2011

DH INFORMATION READER BOX

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

Document Purpose	For Information
Gateway Reference	16621
Title	End of Life Care Strategy: Third Annual Report
Author	DH
Publication Date	26 Sep 2011
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 third 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Superseded Docs	N/A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 133-155 Waterloo Road London SE1 8UG 020 7972 3958 www.dh.gov.uk
For Recipient's Use	

End of Life Care Strategy Third Annual Report

First published 26 September 2011
Published to DH website, in electronic PDF format only.
http://www.dh.gov.uk/publications

Contents

Foreword

The challenges I observed in last year's foreword have not diminished. There is a risk that quality may suffer as anything which does not immediately and obviously contribute to meeting financial challenges might be squeezed off the agenda.

Thankfully, this has not happened to end of life care so far.

With much support from Professor Sir Alan Craft, I have spent much of last year undertaking a review of palliative care funding for both adults and children, on behalf of the Secretary of State. In July we presented our final report. At the time of writing, the Secretary of State is considering our recommendations and preparing for the piloting needed to take this to its next phase. However, if implemented, they should

- Create a fair and transparent funding system which is based on need, rather than age, disease or where they live;
- Help patients, carers and families know what they can expect;
- Place, assessment and co-ordinate the heart of the patient experience
- Be fair to all providers and follow the patient across all settings – hospital, care home, hospice or home; and
- Create a fair and transparent funding system, which provides better outcome for patients and better value for the NHS.

End of Life Care has been included in the Quality Innovation Productivity and Prevention programme – recognition that improving the quality of end of life care is a key to improving its productivity.

Meanwhile, significant work has been undertaken across the country – led by the Department of Health, the National End of Life Care Programme, SHAs, Dying Matters and many others. This report summarises these, but I highlight just two initiatives:

- Locality end of life care registers – the evaluation of the pilots highlights the potential for excellent co-ordination of care which allows people to be supported in the place of their choice; and
- VOICES – for the very first time, the pilot of the national survey of bereaved relatives provides genuine insights about the quality of care as experienced by patients and their families – and will translate into a national survey.

As I write, the Health and Social Care Bill is before the House of Lords and we are working in a rapidly changing organisational landscape. But the work contained in this report will stand us in good stead to respond to the future, whatever commissioning and providing system is put in place.

I noted last year that turning this strategy into reality is not a task to complete, but an ongoing commitment. That has not changed. Neither have the challenges diminished, nor has the importance of what we are trying to achieve.

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

Executive Summary

Dear Secretary of State

I am delighted to present the third annual report on progress in implementing the End of Life Care Strategy.

Last year I reported that there was a real sense of building momentum, not just in the NHS but also involving the range of other partners and organisations needed to provide high quality end of life care. Previously we had been limited for examples of good practice but now we have gathered together a significant library of solutions and innovative approaches, available for all to use on the National End of Life Care Programme's website. This year colleagues answered the request for contributions to this report with many more examples than we could accommodate. In summary, while there is still a long way to go before we can offer all adults their choices and high quality end of life care, the patches of good practice are growing and spreading.

This is all the more encouraging given the context in which we are working. We have been fortunate in having support from all the Strategic Health Authorities, each of which has had both a clinical and a management lead for end of life care and each of which now has QIPP leads too. As the changes to NHS structures take effect, SHA and PCT input will inevitably diminish though we hope to benefit from their support until 2013. In the meantime, the National End of Life Care Programme is supporting a growing network of local end of life care facilitators who are working from a range of settings to ensure that we maintain progress in improving end of life care outcomes.

End of life care is also a part of QIPP, with a dedicated work stream aiming to improve the quality and productivity of care for people approaching the end of life. This will be achieved by implementing the aims of the Strategy as a whole, enabling more people to be cared for in the place of their choice – at home, which can also mean a care home. This is supported by the launch of the QIPP *Find your 1%* campaign, which aims to encourage GPs to commit themselves, and encourage colleagues, to find the 1% of their patients who are likely to die over the course of the year. Once these individuals have been identified they and their GP can have the right conversation, plan for their care and record and share care preferences. The Key Performance Indicator for QIPP is the same as the overall outcome measure for progress on the Strategy – deaths in usual place of residence.

We have amended our previous Vital Sign (which is now a supporting measure in the NHS Operating Framework 2011/12), deaths at home, to deaths in usual place of residence. This recognises that care homes are an important part of the Strategy. Once someone moves to a care home that becomes their home and they should be able to expect to receive end of life care there unless there is a medical reason for caring for them elsewhere, such as in hospital or in a hospice.

The latest outcome data show that we are continuing to make steady, if slow, progress in reducing the proportion of people who end their days in hospital and increasing those who die in their usual place of residence. However, we also know, from a recent report by Cicely Saunders International[1], that there is still a large gap between where people say they would prefer to die and where they actually do die.

We also know that locally and nationally we are still a long way from being able routinely to track the stated preferences for end of life care and actual experience of individual patients and families. This year, though, we have made major strides towards being able to do so.

- The National End of Life Care Intelligence Network, now a year old, has already produced a range of publications which are resources which could help all relevant organisations understand how end of life care is provided for people with different conditions and in different areas.
- We have completed the pilots and the evaluation to pave the way for a national VOICES survey which will allow us to understand the actual experience for patients and carers of end of life care, comparing different conditions, different care settings and different geographies. VOICES will be the source of the data for the end of life care Indicator in development for Domain 4 of the NHS Outcomes Framework.
- The NEoLCP is working on a core data set for the content of Electronic Palliative Care Coordination Systems (EPCCS) and other end of life care records. The EPCCS, or locality registers as they are also known, will capture people's preferences for where to be looked after at the end of life and their actual place of death.

This report includes detail about how PCTs invested the new money made available for the End of Life Care Strategy. The allotted sum was £286 million to be spent over the two years 2009/10 and 2010/11. Some of the funding went to SHAs for education and training but most went into PCT baselines. A small amount went for central teams and, in 2010/11, £40 million was reserved for the hospice capital grant. When all reported spending is added the overall investment comes to more than £292 million – ie. more than the allotted sum. However, the detail continues to show wide variations between PCTs.

These data have contributed to the work of the Palliative Care Funding Review, which, as you know, draws attention to the major data gaps in end of life care, in particular for costs.

The Review makes a series of recommendations for how dedicated palliative care should be funded in the future through a per-patient tariff system. The next steps in testing the recommendations will involve development of a number of pilot sites to generate the

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[1] *Local preferences and place of death in regions within England 2010*, Barbara Gomes, Natalia Calanzani, Irene J Higginson August 2011

information we shall need to develop a robust tariff for dedicated palliative care, applicable across all care settings and covering care for both adults and children.

This report, as last year's, is able to point to progress along the entire end of life care pathway, from discussions about end of life care through to help for the bereaved. It is essential that we continue to work across all these fronts as all are interdependent: this is how we shall achieve the goals of better outcomes for all those needing end of life care, and their families and carers.

At the beginning of the pathway, *Dying Matters,* the national Coalition set up through the National Council for Palliative Care (NCPC) with funding from the Department of Health to address the societal taboo on discussing death, dying and bereavement, has made major progress this over this year. It is building momentum for a social movement to de-stigmatise the subject of death, with more than 15,000 member organisations from a wide range of fields. Dying Matters aims to work through its members and has produced a range of excellent materials to support local community engagement and to reach out to those who might not naturally come across them. This year's Awareness Week in May attracted significantly more media attention and local activity than last year's and the Coalition's work has generally been well received.

Towards the end of the pathway the National Care of the Dying Audit Hospitals (NCDAH), which now includes over 80% of Acute Trusts in England, has been included in the NHS Quality Accounts.

And at the very end of the pathway the National End of Life Care Programme and National Nurse Consultant Group (Palliative Care) have revised and published *Guidance for staff responsible for care after death (last offices)* which will be a resource for training, as well as for informing the development of organisational protocols for this area of care. The guide, with its new title, aims to provide a consistent view that accommodates England's diverse religious and multi-cultural beliefs.

Bereavement and spirituality are two areas where we knew we needed to make progress. We have developed draft Quality Markers for both areas, published on the National Programme's website, and which have been submitted to NICE as part of their Quality Standard development work. Quality Markers are designed to complement NICE's Quality Standards. In due course the NHS Commissioning Board will provide its own guidance for commissioners. The NEoLCP has also worked with the Bereavement Services Association and others to revise existing guidance for bereavement services. *When a Person Dies* will be published in the autumn.

The National End of Life Care Programme (NEoLCP) has continued to play a major role in a wide range of work to support the Strategy. This year the Programme's main outputs and resources, largely developed in collaboration with partner organisations, include:

- GP pilots (with NCPC and Dying Matters) to support GPs, building confidence in initiating end of life care conversations;
- Growing and supporting the End of Life Care Facilitators Network;

- Social care (Phase 1 of Social Care Framework) - nine regional road shows, attended by more than 900 people, eight pilot sites supported, now in the evaluation stage;
- Advance Care Planning and assessment (with health and social care professionals and led by Professor Jane Seymour): updated guidance for health and social care staff on advance care planning and commissioning of an economic study by the Institute for Health Service Management of the impact of ACP;
- Peer educator pack (with Sue Ryder Care Centre (University of Nottingham) and the Dying Matters Coalition) in collaboration with older people: a training resource pack focused on advance care planning for older people;
- Communication skills: *Talking about end of life care: right conversations, right people, right time* brings together the lessons of 12 pilot sites;
- Tool kit of resources for care homes;
- The *Six Steps to Success* programme - developed by the North West End of Life Care Home Coordinators and produced by the NEoLCP;
- *Route to Success for Domiciliary Care* (with the United Kingdom Home Care);
- *Route to Success for Environments* (with the Kings Fund);
- *Route to Success for Learning Disabilities* (with a number of organisations including Enfold and GOLD (Growing Older with a Learning Disability));
- *End of life care – achieving quality in hostels and for homeless people: a route to success*;
- Care towards the end of life for people with dementia: an online resource guide;
- *Difficult conversations: making it easier to talk to people with dementia in end of life care* (with NCPC);
- *End of life care in long term neurological conditions: a framework for implementation* (with the Neurological Alliance and NCPC);
- *Act early or A and E: initial actions for new commissioners* (with NCPC);
- *Finding the Words*: a DVD with supporting workbook, developed by users for health and social care staff.

The National End of Life Care Programme has itself undergone an independent evaluation to test its performance and value for money. The report from Nottingham University is clear that the NEoLCP has had and should continue to have a vital role in supporting and facilitating implementation of the Strategy.

As we continue to work to realise the aims of the Strategy, we will build on all of this progress and support the continued improvement in both quality of outcomes and productivity through the next year.

Data and intelligence will be key themes, both for the Strategy itself and for moving forward the work to create a tariff for palliative care following the publication of the Palliative Care Funding Review.

The National End of Life Care Intelligence Network will press on with improving the use and value of data, and with refining its locality profiles: as the VOICES survey and the

Electronic Palliative Care Coordination Systems begin to provide detail on quality and outcomes that will be able hugely to enrich the local pictures.

We shall work to support our partners to use the tools and information we now have, whether that is to roll out Electronic Palliative Care Coordination Systems or to use the Routes to Success, notably those for the Acute Sector and for care homes.

Those will be the core themes for the coming year, as the NHS continues the process of reform set out in Liberating the NHS.

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

Chapter 1: Meeting the challenges of end of life care

The End of Life Care Strategy set out an extensive programme of work when it was published in July 2008. The two previous progress reports have charted significant progress and a building momentum. The Coalition Government has recognised both the importance of this area of care and the analysis underpinning the Strategy itself. They have said that they wish to build on the existing Strategy and to take it further. Implementation has therefore pressed ahead in 2010/11, building on the foundations laid down in the previous two years.

This chapter summarises the central developments and initiatives which provide the context within which the Strategy is now operating.

Liberating the NHS

End of life care has been a running theme in the Department's major policy documents. The White Paper *Liberating the NHS* included the following text -

> "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.
>
> "The previous administration made progress in developing payment by results in acute trusts. The mandatory scope has changed little since 2005/06, and has not incentivised results throughout the system. The Department will review payment systems to support end-of-life care, including exploring options for per-patient funding."

The Coalition Agreement

The Coalition Agreement included a specific commitment on funding for palliative care:

> "And so that proper support for the most sick children and adults can continue in the setting of their choice, we will introduce a new per-patient funding system for all hospices and providers of palliative care."

This was followed up with the detailed commitment in the White Paper, set out above.

To make this a reality, in July 2010 Tom Hughes-Hallett agreed to chair an independent review of dedicated palliative care funding. As the review covers both adults' and children's services Professor Sir Alan Craft, a former President of the Royal College of Paediatrics, has been providing input and expertise on the children's side.

The review published its interim report in December 2010. This outlined its emerging thinking about packages of care stratified according to the level of specialised care needed. It noted the significant level of challenge in developing a funding mechanism given the gaps in available data, but recognised the potential benefits of doing so. It included one key recommendation about the importance of access to 24/7 community-based services.

From December the review team undertook a major engagement exercise with all stakeholders. This involved meetings with 760 individuals from over 380 organisations. The two online questionnaires attracted 334 responses. In addition, the team commissioned King's College London and partners to undertake a piece of research work which estimates the total cost of providing the elements of specialist and core palliative care for adults at the current level of provision. This financial modelling and analysis underpins their recommendations for a funding mechanism for palliative care across all sectors and for both adults and children.

The recommendations are that the NHS should fully fund, through the per-patient tariff:

- an assessment, on a regular basis, of the needs of a patient;
- all the clinically assessed palliative care needs of a patient irrespective of setting, as in any other branch of clinical care;
- a coordinator for the patient who will guide them through their journey, signposting patients and families to the full range of services including those provided by society and not funded by the state;
- at the end of life, as an addition to the tariff, the social care needs of a patient after they are added to the end of life care locality register (also known as Electronic Palliative Care Coordination Systems).

The review recommends that the following should not be included in this tariff:

- episodes of care by either type or duration which are not assessed as a clinical need;
- support for families and carers;
- bereavement care (except for a pre-bereavement assessment);
- spiritual care;
- complementary therapies;
- information and advice;
- respite care for adults;
- play therapy, and other similar interventions.

It says that these services can continue to be supported by either the state or society as they are now, outside the palliative care tariff.

The King's College work underlined the key fact that "There is a stunning lack of good data surrounding costs for palliative care in England". The review team emphasised the point that "This is the first time a per-patient tariff for community services is being created for any health care intervention in England. Only Australia has developed such a tariff for palliative care for adults and none exist for children internationally". This leads them to conclude that there needs to be extensive piloting over two years, including collecting reliable and consistent data, leading into a shadowing period for currencies and tariffs and full implementation, they suggest, from April 2016.

Next steps

The Secretary of State is currently considering the review's recommendations. There is agreement about the need to develop the evidence base to be clear about the costs and impact of a tariff as described in the report, as well as the viability in England of a patient classification system like that developed in Australia, before final decisions are taken. We will be developing pilots to collect this information and will work with local and national stakeholders as the work progresses as rapidly as possible.

Commission on the funding of care and support

In parallel with the Palliative Care Funding Review, the Commission on Funding of Care and Support, chaired by Andrew Dilnot, was working on recommendations on the future funding of care and support. The two teams met during the process to discuss common issues**.**

In relation to end of life care, the Commission's report, published on 4th July 2011, says:

> "For those reaching the end of their life, we think that there should be better integrated health and social care services, and that there is a strong case for these being free at the point of need. At this time, the last thing that individuals and families need are arguments over who funds care, and where care is provided. Given this, the Commission is broadly supportive of the direction of travel being taken by the independent Palliative Care Funding Review, which is looking into the funding of end-of-life care."

On 15 September, the Government launched *Caring for our future: shared ambitions for care and support.* Through events run by both the National Council for Palliative Care and the National End of Life Care Programme we will be seeking views on how we can improve the delivery of end of life care services through care and support reform and are particularly interested in how we can innovate through current best practice.

Choice

Choice and personalisation is a constant theme in policy developments across both health and social care. The *Liberating the NHS* consultation on choice set out the Department's ambition in this area

> "…we propose to establish a national choice offer for those people who choose to die at home (including a care home) to receive the support that they need. A lot needs to be done to improve end of life care services to make this possible, so we will undertake a review in 2013 to decide when this national choice offer could be introduced. In the meantime, commissioners and providers should seek to improve both the range and quality of end of life care services and the choices available to patients and their families. For example, the availability of 24 hour community nursing services is crucial in supporting people who choose to die at home."

The consultation asked three questions on end of life care, seeking views on some of the issues that would need to be taken into account if specific commitments on choice were to be made for care at the end of life.

The Department's response to the consultation will be published in the near future.

The NHS Outcomes Framework

A further common theme of the reforms is measuring the outcomes from services, rather than the processes of delivering them. The Department of Health consulted on the outcomes framework for the NHS, which followed up *Liberating the NHS*, with the result that end of life care is included in Domain 4 *Ensuring that people have a positive experience of care*. The outcome we are striving towards is that people have a good experience of end of life care. We are developing an indicator based on the VOICES survey and will be able to monitor progress through regular use of the national survey.

Information revolution

This consultation document stated -

> "Our vision is of an information revolution in which people have the information they need to stay healthy, to take decisions about and exercise more control of their care, and to make the right choices for themselves and their families. This includes an accurate record of their care, available to them electronically. Health and adult social care information will be liberated from a closed, bureaucratic system in order to serve patients and the public, and to help drive better care, improving outcomes, innovation and the better use of resources. Transforming the way information is collected, analysed and used by the NHS and adult social care services will be critical to achieving this information revolution."

Responses to the consultation, published in August 2011, include references to the need for information to be shared across organisational boundaries and to the IT training needs of staff in the diversity of organisations providing end of life care

End of life care has historically been an area where data were few. It also requires good communication of information between professionals, and between professionals and patients and families.

There has been significant progress in this area. The National End of Life Care Intelligence Network (see Chapter 2) has established its website and has made an excellent start on turning a range of diverse data sources into rich end of life care intelligence, providing a resource to support local commissioners and providers of services.

The National End of Life Care Intelligence Network has supported the development of a single electronic resource, available nationally, for monitoring, benchmarking and comparing progress against the end of life care Quality Markers.

The end of life care locality register pilots (see Chapter 4) have developed a range of local solutions to electronic sharing of key information about individuals' end of life care plans and preferences, so that they can be supported to realise their choices for care.

The VOICES pilot (see Chapter 2) has tested a national version of the VOICES survey of bereaved relatives, so that we are now in a position to commission the first national survey.

Public Health White Paper – Healthy lives, healthy people

The new public health White Paper recognises end of life care as a public health concern, as well as a service issue for the NHS, social care and the voluntary sector. It says -

> "The taboo about discussing death and dying means that too many people can reach this critical point of their life unprepared, without having thought about how or where they would like to be cared for. This in turn affects their family and carers as a poor death can lead to a traumatic bereavement, with associated mental and physical health issues. The Department of Health will continue to promote the implementation of the End of Life Care Strategy and in particular the societal strand being led by the National Council for Palliative Care and the Dying Matters national Coalition."

NHS Operating Framework

While end of life care requires concerted action by a wide range of partners the NHS plays a central role. End of life care has therefore featured in successive NHS Operating Frameworks. For 2011/12, the Operating Framework continues to emphasise the Strategy itself and, in common with the Palliative Care Funding Review, the importance of 24/7 community based services.

> "The NHS should continue to ensure implementation of the End of Life Care Strategy – promoting high quality care for all adults at the end of life, working to offer patients the choice of where to be cared for as they approach the end of life, and where to die, regardless of their condition. It should ensure that staff are trained for this, including using the e-learning modules available as part of blended learning.
>
> The QIPP End of Life Care workstream is driving the first two steps on the Strategy's end of life care pathway – identifying people as they approach the end of life and planning for their care, including asking about their preferences for care. To make that choice a real option requires implementation of the other strands of the Strategy – commissioning the care people want, coordinating care across sectors and training the workforce to provide it. In particular, commissioners need to ensure that adequate 24/7 community services are available in their locality."

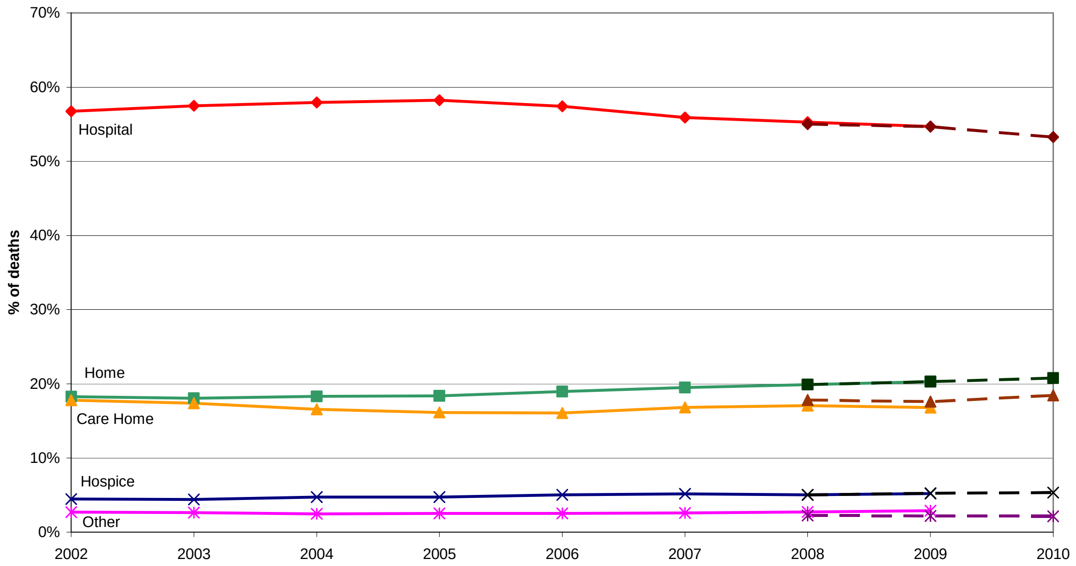
Indicator - "Proportion of Deaths in Usual Place of Residence"

This indicator is a supporting measure in the performance management system, which has replaced Vital Signs - "Proportion of Deaths in Usual Place of Residence". This updates the previous Vital Sign for end of life care which recorded progress on deaths at home. The new indicator covers both people's own homes and care homes, in response to feedback that once someone had moved into a care home this in effect became their home. Good quality end of life care should therefore see more people being cared for to the end of their life in care homes, rather than being moved to hospital to die.

The graph below illustrates progress against both the old and the new definitions. They show a continuation in the slow trend towards a reduction in the percentage of all deaths which take place in hospital and an increase in deaths at home and in care homes. 2010 figures show that 53.3% of deaths take place in hospital, 20.8% at home, 18.5% in care homes and 5.3% in an in-patient hospice bed. Nationally, therefore, 39.3% of people die in their usual place of residence.

As part of the work to change from measuring simply deaths at home as our indicator of progress to “deaths in usual place of residence” we worked with ONS and other colleagues to examine and refine some of the broad classifications. We are therefore reporting against both old and new definitions as below, where the dotted line shows the new. The overlap shown for 2008 and 2009 demonstrates that this has resulted in very little artefactual change and no difference in the overall interpretation of the data.

Percentage of deaths by place-of-death category, England, 2002-2010.
ONS Death Registrations Data



Quality, Innovation, Productivity and Prevention (QIPP)

The end of life care QIPP workstream is now reflected in SHA QIPP plans. The QIPP challenge is to save up to £20 billion by 2015 by improving the quality of care in the NHS. For end of life care, analysis suggests that improvements in productivity will only come about through improving quality, and in particular by supporting people to be cared for in their preferred place of care, in the community.

The QIPP end of life care workstream concentrates on the first two steps of the end of life care pathway – identifying people who are approaching the end of life and planning for their care. Since the entire pathway is interconnected a great deal of the work recorded in this progress report is relevant to the QIPP challenge: for example the electronic palliative care coordination systems (locality registers) are critical to ensuring that care plans are communicated across sectors and between professionals so that they can be acted upon. Early data from the pilots suggest that being on a register greatly increases the likelihood that someone will be able to die at home if that is their preference.

NHS South Central – QIPP

The SHA developed work around Quality Innovation Productivity and Prevention (QIPP) for end of life care early in 2010 so has been able to move forward quickly with the areas that are now picked up in the National End of Life Care QIPP work-stream.

Of particular note is the progress made in each local area to develop action plans for introducing locality registers which will ensure people's wishes can be shared electronically between in and out of hours primary care, the ambulance service and acute trusts to help prevent people being admitted to hospital if this is not what they want and to prevent them having unnecessary interventions at the end of life.

This work has been greatly supported by each local area having QIPP plans that reflect the regional and national plans.

The region has also agreed a CQUIN measure related to advance care planning and people dying in their preferred place and KPIs which support this work.

For further details please visit www.southcentral.nhs.uk/end-of-life-care or contact Lucy Sutton, Associate Director for End of Life Care at lucy.sutton@southcentral.nhs.uk

QIPP has adopted the Indicator for the proportion of deaths in usual place of residence as a reflection of both quality and productivity; since most people say that they would prefer to be cared for and to die at home, and there is some evidence to suggest that this is also the most cost-effective way of providing care.

QIPP will also be adopting new Indicators to capture the quality and effectiveness of services in responding to people's needs and wishes at the end of life**.** These are currently in development to ensure that they are robust, unambiguous, and that they will genuinely help to drive quality as well as productivity.

Dying Matters is important to QIPP in its work to change the climate such that both public and professionals are readier to talk about end of life care. Dying Matters' training for GPs has shown that it can be effective in enhancing their skills in this area and QIPP's campaign *Find your 1%* can build on that work.

Find your 1% is based on the fact that approximately 1% of the population dies each year. It encourages GPs to identify who from their own practice populations are likely to represent their share of the 1%, so that they can have the conversations, do the care planning, and enter the right people on their palliative care registers – and, where they have them, on their locality end of life care registers.

NHS Worcestershire - Primary Care/ End of Life Locally Enhanced Service

This initiative was set up to benefit GPs and Primary Care in a number of ways: improved multi-disciplinary working; providing service models based on better resource utilisation; improved patient outcomes; and improved knowledge.

An End of Life (EoL) Local Enhanced Service was developed by NHS Worcestershire, with support from GPs with an interest in palliative care, based on the Gold Standards Framework (GSF), requiring GPs to undertake the following: adopt the principles of GSF; inform both West Midlands Ambulance Service and Out of Hours (OOH) GP of special notes relating to all EoL patients, via an OOH communication form; use the Liverpool Care Pathway; and attend two, one hour, education modules relating to EoL subjects. Additionally, all lead EoL GPs had to attend one EoL study day, provided by NHS Worcestershire. A GSF Facilitator was also in post to support practices in implementing the requirements of the LES.

Each of the above activities was associated with payment, and as such needed to be Read coded together with other EoL activities in order for a baseline of EoL care data to be established.

In addition to the above the use of the ‘Just-in Case Box’ was also launched, together with education covering symptom management and anticipatory prescribing (part of the training requirements mentioned above).

All of this has led to improved patient outcomes through increased advance care planning, improved communication between all services providing care for EoL patients, timely access to EoL drugs in the OOH period and a reduction in inappropriate transfers to the acute trust.

In addition to improved patient outcomes cost savings have also been seen. In the first six months of the OOH form being used an estimated saving of £74,000 was made, and an audit of the ‘Just-in Case’ box showed estimated savings of £65,000.

Contact: Debbie.westwood@worcestershire.nhs.uk

The National End of Life Care Programme (NEoLCP)

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.

The developments in NHS structures and commissioning arrangements mean that strategic agendas are more than usually crowded. The National End of Life Care Programme (NEoLCP) is key to translating end of life care policy into practice, working with a wide range of partners. The NEoLCP provides information and support to local commissioners and providers, distilling out the practical learning from others' experience to maximise the return on investment in innovation.

The NEoLCP works closely with SHA clinical and management leads and with end of life care leads in PCTs. As the NHS's management structures change many of these key contacts are changing roles. This makes it all the more important to provide a focus and support to local champions, and NEoLCP is now supporting a growing network of local end of life care facilitators. The network currently involves some 200 facilitators across England, variously based in PCTs, cancer networks and elsewhere. They aim to support improvements in end of life care within their localities. In support of these facilitators NEoLCP has initiated two national events, is supporting the development of regional networks, and plans to hold a number of WebExes in order to share knowledge, challenges, ideas and solutions to improve end of life care. The plans are to continue to expand and develop the network to comprise both health and social care, with most support provided remotely.

NEoLCP has continued to develop its role as a communications hub for end of life care. Its revamped website is well used by both health and social care staff, providing up to date news and a growing bank of examples of good practice. As well as contributing to a wide range of news media including national publications such as Nursing Times and the Health Service Journal NEoLCP's own electronic newsletter now goes directly to 2,650 recipients. The Programme is also making use of social marketing tools such as Twitter.

The NEoLCP has focussed on user involvement to support service delivery. Communications is always a key issue so a *Finding the Words* DVD with a supporting workbook has been developed by users as a resource for health and social care staff and was published in July.

Partnership working

The NEoLCP extends its influence and effectiveness as widely as possible by working collaboratively with an extensive range of partners, supporting their events and co-producing resources. This year these have included:

- The British Geriatric Society's spring meeting afternoon seminar on end of life care. This was led by Dr Jackie Morris and attended by 300 clinicians;
- A Macmillan Cancer Support joint event for GPs focusing on partnership working between health and social care;
- National Council for Palliative Care (NCPC) regional events;
- QIPP regional events with SHA leads and the QIPP team with over 600 people attending;
- The NEoLCP programme has provided input into a NICE commissioning group working on dementia, heart failure and COPD;
- The NEoLCP is working in collaboration with NHS Institute for Innovation and Improvement on new ways of working;
- In collaboration with Dying Matters the NEoLCP has provided a DVD on attitudes of death and dying for people with learning disabilities called *We are living well but Dying Matters*;

- The NEoLCP is working in collaboration with the National Council for Palliative Care and the Institute for Health Services Management to develop a framework for organisations to evaluate and measure the impact of user involvement on practice;
- The NEoLCP supported the NCPC with the development of *Difficult Conversations: Making it easier to talk to people with dementia about end of life care*.

Working Together to Deliver Better End of Life Care for People with Dementia and their Carers in Hull and East Riding of Yorkshire

This project aims to improve end of life care for people with dementia and their carers living in Hull and the East Riding of Yorkshire. It was recognised that there was little joined-up working across organisations within the area and a lack of awareness about the support systems available to patients and carers.

In response to this, a collaborative working group has been established with a wide variety of representatives from relevant sectors, including the Alzheimer's Society, the local hospice, GPs, psychiatrists, local authorities and NHS providers. Working together, the group were able to identify current gaps in provision as well as examples of best practice, which the group has used to create a dementia care pathway. The pathway was developed based on the Stepped Care model used within local mental health services and the real-life journey of a person with dementia. It has five stages, ranging from "Early Signs and Symptoms" to "End of Life", with end of life care being a consistent element throughout. Three sub-groups have been created to support implementation of this pathway; Training, Service Mapping & Information and Annual Health Check, with each working to establish better end of life care through these areas. For example, the training group is developing a "swap shop" which will enable those skilled in dementia care and those knowledgeable in end of life care to "swap" training. This will increase knowledge and skills of both groups while keeping costs to a minimum. The Service Mapping and Information group will build on the current information services provided by the Alzheimer's Society, whilst the Annual Health Check group will develop a more efficient and effective Annual Health Check process for patients.

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Evaluation

The NEoLCP commissioned Nottingham University to undertake an independent evaluation on the programme's impact and effectiveness. Their report clearly identifies the vital role the NEoLCP has had in supporting and facilitating the implementation of the National End of Life Care Strategy.

Chapter 2: The Information Revolution for people approaching the end of life

The work to follow up *Liberating the NHS* included a consultation document on the *Information revolution.* This consultation document stated -

> "Our vision is of an information revolution in which people have the information they need to stay healthy, to take decisions about and exercise more control of their care, and to make the right choices for themselves and their families. This includes an accurate record of their care, available to them electronically. Health and adult social care information will be liberated from a closed, bureaucratic system in order to serve patients and the public, and to help drive better care, improving outcomes, innovation and the better use of resources. Transforming the way information is collected, analysed and used by the NHS and adult social care services will be critical to achieving this information revolution."

Dying Matters

The End of Life Care Strategy highlights the importance of informing both the general public and health professionals about end of life care to break the taboo on discussing death, dying and bereavement. To do this we established the Dying Matters National Coalition, supported by the National Council for Palliative Care (NCPC).

Dying Matters has continued to make real progress in reaching out to organisations and communities to raise awareness and change public attitudes to dying, death and bereavement. The Coalition now has over 15,000 members, including health, social care and housing and care homes providers, from hospices, national and local charities, pensioner groups, funeral directors and organisations from the legal and finance professions. The growing involvement of Coalition members has been one of the most encouraging developments since Dying Matters was set up, notably evidenced by the events and activities held up and down the country during the second Dying Matters Awareness Week in May engaging thousands of people. Dying Matters received considerable national, regional and trade media coverage during the week and radio reach was estimated at 32 million.

NHS South Central Dying Matters Awareness Weeks

The SHA ran a series of events and media campaigns to mark both the 2010 and 2011 Dying Matters weeks. This included:

- a Berkshire Healthcare NHS Foundation Trust roadshow which travelled around Windsor, Maidenhead, Bracknell and Slough;
- Drop in sessions for the public with the specialist palliative care team in Basingstoke; and,

- NHS Oxfordshire's specialist palliative care team ran a Health Bus for the week which visited communities around Oxfordshire.

For more details please visit www.southcentral.nhs.uk/about-us/your-local-nhs/

Dying Matters has produced a range of resources. These include a series of leaflets on how to have conversations on end of life, how to talk to children, practical matters and myth busting, a series of posters, postcards and a pack for Dying Matters Champions. Prior to the Awareness Week 70,000 copies were sent out to members, in addition to downloads from the website. In September 2010 *A Party for Kath*, the short film Dying Matters produced to demonstrate the benefits of greater openness around dying and death were awarded Highly Commended for best video at the 2010 International Visual Communications Association Clarion Awards.

To support conversations Dying Matters released a series of films in May:

- *Why Dying Matters to Me,* with people from different walks of life talking about why the way in which they will die is important to them, a compilation of the Talking Heads project which captured the views of over 80 people for the website and YouTube;.
- *We are Living Well but Dying Matters* (with the National End of Life Care Programme) with people with learning disabilities talking about the importance of including them in decisions being made around end of life - especially their own; and
- *Dying for a Laugh* produced by PictureWise to support Awareness Week, with leading comedians including Ardal O'Hanlon and Ricky Tomlinson and consultant physician-turned-comedian Kevin Jones (on staff at Royal Bolton Hospital), tackling the taboo on talking about dying.

The Dying Matters website provides a comprehensive range of information and resources and also signposts visitors to other appropriate sites. A community forum launched in May now enables visitors to discuss and share their views and experiences about dying and includes a section dedicated to health and social care workers. Over 8,800 people visited the site during Awareness Week 2011. Dying Matters can also be followed on Facebook and Twitter.

Further research on attitudes by Dying Matters indicates that progress is being made but people continue to be reluctant to discuss issues related to dying. Dying in pain appears to be people's biggest fear, highlighting the importance of palliative care and access to 24/7 pain relief – people are more scared of dying in pain (83%) than of being told they are dying (67%), dying alone (62%) or dying in hospital (59%). Most people have avoided using the terms "dying" and "death" when talking about the death of someone close to them – with "passed away" the most used euphemism.

The Dying Matters Coalition Community development programme

As a society we need to talk more about dying, death and bereavement and it is in communities that the taboo of talking about dying and death needs to be tackled. In Devon, Lewisham and Essex Dying Matters is supporting members to work closely with each other and bring on board a range of diverse organisations, professionals and

Community Champions who are working on the different aspects of dying, death and bereavement in their area. Information about the programme was shared with members at the Day of the Dead event on 1 November 2010 and the Awareness Week event when members had the opportunity to hear examples of good practice and engage directly with professionals from different sectors.

Building on the successful *Don't Die at Home Alone* campaign which Lewisham Pensioners Forum led for Dying Matters in December 2010, Age Concern Lewisham & Southwark launched a new pilot drop-in service in partnership with the Lewisham Pensioners Forum and Dying Matters. The pilot aims to open up discussion and engage with older people in the local community. The pilot project will run for six months and there is keen interest expressed by other groups in setting up a parallel service.

To support community engagement Dying Matters has produced several resources including a community engagement pack with information and tips from different sectors on how best to work together.

Peer educator pack

Sue Ryder Care Centre (University of Nottingham) have been working with the NEoLCP and the Dying Matters Coalition, in collaboration with older people, to develop a training resource pack focused on advance care planning (ACP) for older people. The pack is one of the outcomes of a two-year action research project which involved working with 173 older people and health and social care staff. A training programme in ACP and associated end of life care issues was then developed and delivered to 32 volunteers (24 older people and eight health and social care staff) who were committed to raising awareness of ACP among their peers.

The original training programme has now been revised into a training resource pack with four modules:

- Module 1: Learning from each other: understanding peer education;
- Module 2: Supporting ourselves and others;
- Module 3: Advance care planning: what it means and how to do it;
- Module 4: Putting it into practice.

Spiritual Support

As Dying Matters succeeds in supporting and encouraging more people to talk about their dying, death and bereavement, and that of people close to them, many wish to talk about the things that are most important to them. Spiritual support is vital to that. Dying Matters is working closely with NCPC to address the spiritual needs of people at the end of life and has set up a meaning, faith and belief group encompassing a broad range of different faith and worldview perspectives. A key priority for the group is exploring how to strengthen and extend spiritual support in community based settings. The profile of spiritual support was raised through two well-attended national conferences held by NCPC and Dying Matters in March and October 2010, and a discussion document, *The Missing Piece*, was published identifying key challenges and opportunities for developing spiritual support at the end of life.

Hard to reach communities

The Coalition has worked with a range of organisations to reach out to those who might not naturally come across Dying Matters resources, relate to them or understand them:

- with St Mungo's and Marie Curie to produce leaflets aimed at homeless people and those who care for them and with Homeless link to ensure distribution to all homeless shelters;
- with CHANGE and the NEoLCP to produce a film highlighting the importance of including people with learning difficulties in discussions around death, dying and bereavement;
- with the Barnsley Black and Ethnic Minority Initiative, the LGBT Consortium and Social Action for Health to create joint messages and images targeting different communities. This has resulted in a four new posters and a number of talking heads; and
- with the LGBT Consortium to produce a report and associated film highlighting the inequalities faced by some LGBT people in discussing and accessing appropriate end of life care services as well as good practice which can be learnt from. Both will be available in July.

Future plans

The Coalition will be expanding its community engagement work with activities to reach out to its target groups and GP project over the next year in different parts of England. Events are planned for 1st November and Dying Matters Awareness Week in May 2012 and the successful "Don't die Home Alone at Christmas" campaign will be run again in December 2011. The Coalition continues to measure progress and will be conducting further research at the end of the year to review its key performance targets.

Working together with members across all sectors Dying Matters has successfully shown the benefit of using a coalition approach in order to change public attitudes and behaviours to improve end of life care.

Dying Matters website: www.dyingmatters.org

The National End of Life Care Intelligence Network (NEoLCIN)

The National End of Life Care Intelligence Network (NEoLCIN) has made major progress in its key role of turning existing data into useable intelligence to help both commissioners and providers of end of life care.

In the twelve months to June 2011, it has developed a range of resources, including publishing nine reports, completing local end of life care profiles and developing tools to aid both commissioners and providers. The end of life care profiles allow current commissioners and the emerging commissioning organisations to benchmark performance against neighbouring or similar local health economies. This work draws on one of the network's earliest successes, the report on regional variations in how and where we die.

Some of its other tools have fed into the review of palliative care funding.

In keeping with the national Strategy's emphasis on co-ordinated services, the NEoLCIN has commissioned studies exploring how social care can work with healthcare partners to improve end of life care services and efficiency. Much of the network's output, particularly the reports on dementia and variations in place of death, has proved of wider interest – being covered by national television and newspapers as well as the specialist press.

NEoLCIN will continue to provide the data and analysis which will shape the National End of Life Care Programme's work. To ensure even closer co-ordination, management of the network is now sited within the programme.

The network will also provide an increasingly valuable resource to commissioners, policymakers, providers and researchers.

End of Life Care Profiles

This set of interactive web tools is available on the website and gives easy access to valuable data on end of life for each local authority area in England.

The profiles display information on the number and proportion of deaths in each area, by cause and place of death. They also show the age and gender of those who died. Users can compare local data with regional and national averages, helping the government, commissioners and providers to identify areas of need – and to plan and deliver effective health and social care services.

The profiles, which have been developed by the South West Public Health Observatory, are presented using the InstantAtlas mapping tool. This displays the indicators in map, chart and table format. A user guide is available on the website. For more information visit http://www.endoflifecare-intelligence.org.uk/profiles.aspx

Reports

The network has analysed a variety of information sources and so far produced nine reports
http://www.endoflifecare-intelligence.org.uk/resources/publications/default.aspx#neolcin

As an example of how the Network uses and presents data, *Deaths from Alzheimer's disease, dementia and senility in England* uses ONS data to show the absolute numbers of deaths - breaking them down by age, sex and location - and whether any of these conditions was the underlying or contributory cause. The data on contributory cause recording highlights how important it is to search the entire mortality record to get a clearer picture of the numbers of deaths in which Alzheimer's, dementia and senility are implicated, as people dying of these conditions have specific end of life care needs. This document will therefore be an invaluable resource to policy makers, commissioners and providers of care, patients, their relatives and carers and the non-statutory bodies who support them. An accompanying spreadsheet provides data by primary care trust.

Other resources include:

National Survey of Patient Activity Data for Specialist Palliative Care Services –

This report of data collected by the National Council for Palliative Care is the 15th since they initiated the original collection in 1995/6 and it is the first to report on activities since the rollout of additional investment associated with the End of Life Care Strategy in England, for the year 2009/10.

Deaths Registered as Occurring 'Elsewhere' – this uses Office for National Statistics (ONS) mortality data to examine deaths that are registered as occurring 'elsewhere' and how they vary by age and sex.

External Causes of Death – this examines variations in death from 'external' causes (including injuries, falls, self-harm, assault and poisoning) by age, cause and sex.

Predicting Death: Estimating the proportion of deaths that are 'unexpected' –this compares estimates, which can vary according to data source, and highlights the importance of predicting death to end of life care service commissioners.

Deaths in Older Adults in England – this provides data that highlight the importance of understanding the differing needs of older adults at the end of life.

Variations in Place of Death in England – this highlights key analysis of the End of Life Care Profiles indicator sets and additional data, breaking down place and cause of death by age and sex.

Deaths from Neurodegenerative Diseases in England, 2002 to 2008 and
Deaths from renal diseases in England 2002-2008 – these analyse the ONS mortality data to give insight into differences in numbers, rates and place of death from selected neurodegenerative diseases and from renal disease, respectively.

End of Life Care Patient Decision Aid for people with Advanced Kidney Disease

The aim of this project is to produce a patient decision aid (PDA) for people with advanced kidney disease (AKD) to support end of life care planning and inform the advance care planning process. The PDA is intended for:

- Patients with AKD receiving conservative management;
- Patients who choose to stop dialysis;
- Dialysis patients with significant morbidity and poor prognosis;

Materials are being developed and tested to cover the following areas:

- Supportive and palliative care for patients with AKD;
- Advance care plans and advance decisions;
- Legal and financial issues eg benefits and making a will;
- Cardiopulmonary resuscitation;
- Organ and tissue donation.

The PDA will be available to patients as a web-based tool on the NHS Direct website and as a DVD with a supporting leaflet.

Focus groups comprising healthcare professionals, users and bereaved carers are informing the development of the materials.

The PDA is intended to improve patient experience and satisfaction by improving patient knowledge of end of life care options compared with more routine interventions and promote the acceptability of the use of a patient decision aid as a way of informing end of life care decisions.

The PDA will also promote patient choice by increasing the completion of an advance care plan which will lead to an increase in patients achieving their preferred place of care.

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Website and Research

The NEoLCIN website has already become a key research tool and is used regularly by organisations seeking information that supports commissioning and service development.

It focuses on sharing the relevant data and analysis about end of life care for adults in England with the professionals who make decisions about policy and services. It includes data analysis, guides to key data sources, profiling tools, publications, advice and direct links to other useful resources, such as the ONS mortality data and the NHS Information Centre's Health Poverty Index.

Modelling tools

These three new resources support service providers and commissioners to:

- identify the end of life care needs of their local population;
- improve early recognition that people are approaching the end of life;
- reduce the number of deaths in hospital;
- understand the trajectories of different illnesses;
- identify the impact on their workforce.

The Yorkshire and the Humber Commissioner Financial Model - Developed by NHS Yorkshire and The Humber, this uses ONS and Secondary Use Services data to look at how many people who died in acute hospitals could reasonably have ended their days in an alternative care setting. It also calculates the cost implications for a local population.

The Cohort Model - Developed by the Whole Systems Partnership, this simulates the likely key end of life care needs over time for a typical population of 100,000. It focuses on the implications of early recognition and reduced hospital admissions and considers the patterns for a key range of disease trajectories.

Skills for Health Functional Analysis - Developed by Skills for Health, functional analysis identifies the community workforce skills required to ensure that an individual in their last year of life receives quality care. It supports service managers and commissioners to identify appropriate workforce structures and the required competences. It is especially helpful when used with the associated Cohort Model.

2009/10 Minimum Data Set for Specialist Palliative Care Services

This resource provides valuable information on hospice and specialist palliative care services and activity across England, Wales & Northern Ireland. It is the only national collection of data in relation to specialist palliative care activity. The National Council for Palliative Care (NCPC) has been collecting and reporting on the MDS for fifteen years and the Intelligence Network supported them with this most recent document. It will help inform local service development, management and audit as well as supporting commissioning and development of national policy. This year's dataset has also informed the Palliative Care Funding Review.

Despite the fact that, historically, specialist palliative care has tended to be more readily accessible for people with cancer, the latest data show that some people with other conditions are beginning to get better access to those services. For example, this year's research contains a chapter on access by people with Motor Neurone Disease. However there is still a long way to go to achieve equality of access for all people, whatever their diagnosis.

Aggregated data has been collected up to this point but the Intelligence Network is currently working with the NCPC towards collecting data for individuals and episodes of care. When linked with the other datasets this will allow additional analysis, further improving its potential to improve service quality and efficiency.
http://www.endoflifecare-intelligence.org.uk/resources/publications/default.aspx

NCPC workforce survey 2010

Workforce development is one of the key aspects to the End of Life Care Strategy. The specialist palliative care workforce has a vital role to play both in providing care for people with complex needs and also in educating their non-specialist colleagues.
NCPC, with the NHS Information Centre and the Centre for Workforce Intelligence, has carried out a number of surveys of the specialist palliative care workforce in hospitals and the voluntary sector over the last few years, collecting data about numbers, gender, age and banding (for nurses). This helps commissioners and providers to identify gaps or surpluses in local areas and to plan the role the specialist workforce might take, in wider workforce development. The data are also very relevant for recruitment and succession planning. The Intelligence Network supported the 2010 survey, the results of which are due to be published in summer 2011.

The Nuffield Trust (NT) report: Social care and hospital use at the end of life

The Nuffield Trust compared costs across three primary care trusts by using data that link patient records anonymously and provide key information on the use of health care and social care by people in the last months of life.

It found that on average 30 per cent used some form of local authority-funded social care in the 12 months before their death and that uptake was higher in older age groups. Use of local authority-funded social care increased gradually in the last year of life, whereas NHS-funded inpatient hospital care increased sharply - particularly in the final two months. The research found some evidence across all age groups that higher social care costs at the end of life tend to be associated with lower inpatient hospital costs.

While a direct causal link cannot be confirmed, it does suggest that any reductions in the availability of local authority-funded social care might increase demand for hospital services. This has potentially important implications for local service planning.

ELCQuA

The NEoLCIN in collaboration with NHS South West and NHS North West have developed an online, self-assessment resource which will enable commissioners and providers to monitor progress against a set of core specifications, based on the Department of Health's Quality Markers and measures for end of life care, published in 2009 to support local implementation of the national End of Life Care Strategy.

The End of Life Care Quality Assessment Tool (ELCQuA)

In June 2009 the Department of Health published Quality Markers and Measures for End of Life Care. NHS North West and South West then developed self-assessment tools for the range of organisations who might use the Quality Markers. Other areas then expressed an interest in utilising this work in their own locations. They were keen to enable richer comparisons area by area, and against a national benchmark, by adopting the tool across the country.

So in 2010 the National End of Life Care Intelligence Network (NEoLCIN), with SHA End of Life Care Leads and other partners, undertook to produce a Quality Markers self-assessment tool to be made available across the country. This would help organisations to define and track progress across their own action plans. It aimed to promote consistent good practice, service improvement and the delivery of high quality end of life care. The work included:

- Synthesis of the North West and South West objectives;
- Inclusion of an over-arching, user-focused 'objective' for each chapter with the relevant individual Quality Markers beneath;
- Simplification of the existing Quality Markers across different types of organisation and removing any duplication;
- Development of two new objectives relating to equality and patient feedback;
- An increased focus on patient outcomes in the definitions and suggested evidence;
- Identification of suggested performance indicators relating to each Quality Marker;
- Linkage to Care Quality Commission (CQC) registration requirements and end of life care Key Performance Indicators (KPIs);
- Refinement of the organisational structure to reflect the changes and likely changes in the NHS structure over the next 18 months and to ensure all organisations have all relevant Quality Markers identified against them.

The resulting ELCQuA tool is a web-based system with password access and the following features:

- Quality Markers are listed against each organisation for self-assessment;
- There are options to complete a full or summary self-assessment;

- The top ten Quality Markers are highlighted for high level reports;
- Relevant documents and supporting evidence can be uploaded and shared;
- Assessments are given a red/amber/green rating, for measuring improvement and benchmarking;
- Numerical as well as qualitative evidence can be captured;
- Links to Key Performance Indicators and Care Quality Commission regulation requirements are highlighted;
- There is a comprehensive suite of user support resources including a Q&A document, quick start guide, slide pack, technical guidance, helpline and online support and feedback system.

The tool will be updated according to any future versions of the Department of Health Quality Markers, and to reflect the forthcoming NICE Quality Standard for end of life care.

ELCQuA was launched in June 2011 and the tool is available at www.elcqua.nhs.uk

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Electronic Palliative Care Coordination Systems (End of life care locality registers)

The end of life care locality register pilots have developed a range of local solutions to electronic sharing of key information about individuals' end of life care plans and preferences, so that they can be supported to realise their choices for care.

The pilots developed and tested a core content data set, which is now going through the formal Information Standards Board approval processes. If approved, this data set will be mandated for use in the NHS, with a requirement that suppliers of systems supporting end of life care coordination incorporate it into their systems.

VOICES (Views Of Informal Carers – Evaluation of Services)

The Department of Health commissioned the University of Southampton to revise and test out a new version of the VOICES (Views Of Informal Carers – Evaluation of Services), and how this could be used as part of a national survey of bereaved relatives This pilot is now complete. The final report has been published and can be found on the Department's website at http://www.dh.gov.uk/health/2011/07/end-of-life-survey/.

We are now in a position to commission the first national survey. The Office for National Statistics will be undertaking the national survey and analysis, using the questionnaire developed through the pilot.

As it can be difficult to obtain the views of a complete sample of people nearing the end of life, particularly as some may be too ill, or they may deteriorate very rapidly and unexpectedly, the VOICES questionnaire uses the views of relatives as a proxy for the deceased's experience. This will provide detailed insight into the quality of end of life care experienced across the country and will be able to show differences by geography, and by diagnosis as well as by care setting.

A key element of the pilot was to revise the existing VOICES questionnaire. The new version, VOICES-SF (Short Form), has been reduced to 58 questions. It has been designed to find out as much as possible about people's experiences and reflect the focus of the End of Life Care Strategy, whilst also keeping the questions to a minimum to encourage high response rates.

The pilot provided a wealth of information about perceived levels of care in the two PCT areas involved in the pilot, showing clear variations depending on setting, and cause of death, as well as between PCTs. It also provided important insights into the approach to be adopted for the national survey. The pilot demonstrated the clear advantage in employing an opt-out approach to the survey, and clarified the numbers of responses required to enable effective comparisons to be made.

The national survey will be the data source for the new national indicator for end of life care for Domain 4 of the NHS Outcomes Framework. The indicator is currently going through the Department's development process.

Equality issues – Equality Impact Assessment (EqIA)

The End of Life Care Strategy recognises that inequalities often exist in the care that different groups of people receive at the end of life. These inequalities are most marked between cancer and non-cancer diagnoses, but also affect other groups such as older people, people with disabilities and people from different cultural and religious groups.

A comprehensive Equality Impact Assessment (EqIA) was published alongside the Strategy in 2008. This recognised the need to address a range of equality and diversity issues to ensure that quality end of life care was available to all.

Last year we published a report on the Department's website on how we are progressing against the action points in the EqIA. Since then a great deal of further work has been undertaken, which addresses many of the issues included in the EqIA. Chief amongst these are:

- a series of practical resource guides addressing different care settings, needs, beliefs and cultural backgrounds;
- a number of disease specific resource guides;
- a series of reports identifying variations in service provision by age, gender, cause and place of death, and geography;
- an on-line tool to help commissioners and providers monitor their progress;
- e-learning resources to help change attitudes and behaviours of health and social care workers.

The full progress report for 2011 is published alongside this annual report on the Department's website.

Investment of new money, and survey of spend on specialist palliative care

Monitoring investment

The End of Life Care Strategy was supported by new money in 2009/10 and 2010/11. Although these funds were not ring-fenced, the Strategy included a clear expectation that this investment should be properly monitored. Central collection of this data was confirmed by Sir David Nicholson in his evidence to the Public Accounts Committee in December 2008 and data on new expenditure in 2009/10 was published with the Strategy's Second Annual Report.

In 2010/11, implementation of the Strategy was supported by £198m. This was an increase on the £88 million provided in 2009/10. In both years, most of the new money went to PCT baselines.

Table 1 shows that in 2010/11 new spend on end of life care was in line with the £198 million allocation.

Category	**Spend**	**Notes**
New Investment in 2009/10 rolled over	£79.5m	Comprising £74.4m PCT spend and £5.1m SHA spend
New Investment in 2010/11 (below)	£77.4m	Comprising £67.9m PCT Spend and £9.6m SHA spend
Hospice capital enhancement projects	£40m	
DH and National EOLC Prog Spend	£7.9m	
Total	**£204.8m**	

Table 1: Total new spend on End of Life Care in 2010/11 as a result of the End of Life Care Strategy

As of July 2011, we had received 141 returns from PCTs and nine returns from SHAs. The PCTs reported total new investment of £63.7 million in end of life care services in 2010/11. Based on this, and assuming that the remaining PCTs are not substantially different from those that reported, it is estimated the total new investment across all PCTs in 2010/11 was £67.9 million. The SHAs reported SHA level investment of £8.6 million, with, using the same technique as for PCTs, an estimated investment of £9.6 million by all SHAs in 2010/11. The SHA new investment was in training.

Average PCT new investment in 2010/11 was £452,000, or just over £7.50 per person over 65. As shown in Figure 1 below, the highest proportions of new spend were on care homes (26%), voluntary hospices (14%), other services (12%), specialist palliative care teams (11%) and specialist palliative care resources (11%). These are also the services that most PCTs invested in, for example 52 PCTs reported new investment in care homes. 12 PCTs reported disinvestment in end of life care services, amounting to £1.6 million.

In comparison with the returns from 2009/10, there is a notable shift in the different areas where PCTs are investing. In 2010/11, support for voluntary hospices made up 14% of new investment (20% in 2009/10), care homes 25% (17% in 2009/10), and support, training and 'other' 32% (45% in 2009/10). Table 2 and Figure 1 summarise PCT and SHA returns by category.

The returns record new investment in 2010/11. We do not have information on whether the new investments in services made in 2009/10 continued to be made but we have assumed this to be the case unless PCTs reported this as part of their disinvestment.

	2010/11		**2009/10**	
NEW PCT INVESTMENT	**Total Investment**	**% of Investment**	**Total Investment**	**% of Investment**
Raising awareness	854,396	1.3%	1,019,321	1.3%
Development of locality register	909,000	1.4%	845,000	1.1%
Assessment for carers	163,000	0.2%	522,010	0.7%
Coordination, eg coordination centres, strategic cooperation	1,747,657	2.7%	1,176,304	1.5%
Rapid response/24 hour community services	6,608,100	10.1%	6,185,214	8.1%
Palliative care transport	3,000	0.0%	224,000	0.3%
Investment in ambulance services, eg staff, capital	225,000	0.3%	206,000	0.3%
Rapid discharge facilitation	1,751,800	2.7%	1,885,682	2.5%
Improving care environments	1,157,600	1.8%	811,000	1.1%
Specialist palliative care resources - hospitals	7,152,685	10.9%	7,584,580	9.9%
Specialist palliative care teams	7,109,286	10.9%	8,796,000	11.5%
Care homes	16,610,630	25.4%	12,701,322	16.7%
Other locations: supporting the homeless	0	0.0%	197,000	0.0%
Other locations: prisons	0	0.0%	83,000	0.1%

OTHER NEW PCT INVESTMENT

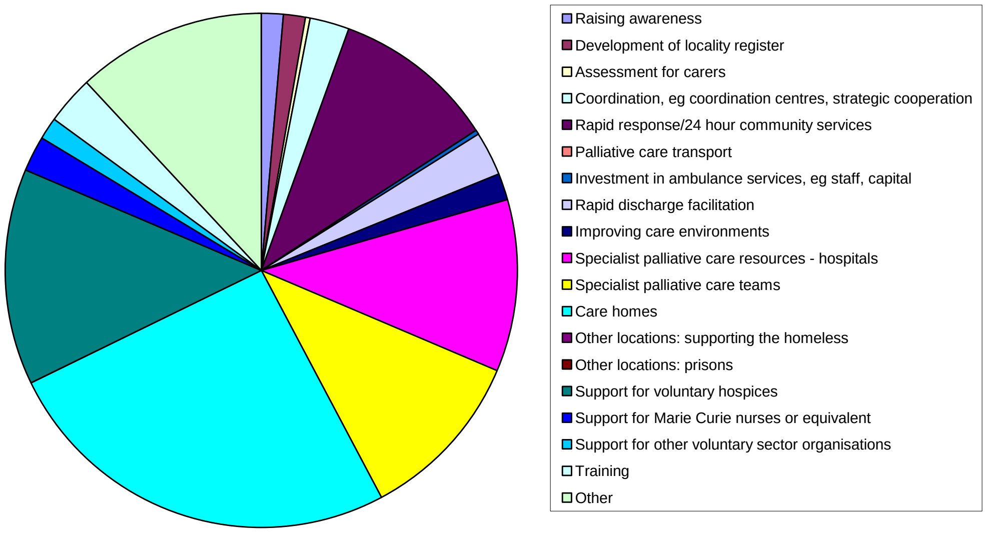
Support for voluntary hospices	9,019,891	13.8%	15,226,314	20.0%
Support for Marie Curie nurses or equivalent	1,425,291	2.2%	3,149,319	4.3%
Support for other voluntary sector organisations	838,500	1.3%	1,813,378	1.9%
Training	2,083,063	3.2%	2,118,417	3.9%
Other	7,734,645	11.8%	11,463,072	15.0%

PCT Disinvestment	-1,599,943	-2%	-1,580,000	-2%

SHA NEW INVESTMENT IN TRAINING	**Total Investment**	**% of SHA Investment**	**Total Investment**	**% of SHA Investment**
Care planning/assessment (eg NHS, social care, care homes)	3,090,000	35.7%	1,524,000	29.8%
Symptom management	166,000	1.9%	296,000	3.4%
Communication skills training	622,000	7.2%	1,166,000	13.5%
Social care staff	1,300,000	15.0%	730,000	8.4%
Other training	3,370,000	39.0%	1,313,000	15.2%
Backfill	100,000	1.2%	91,000	1.1%

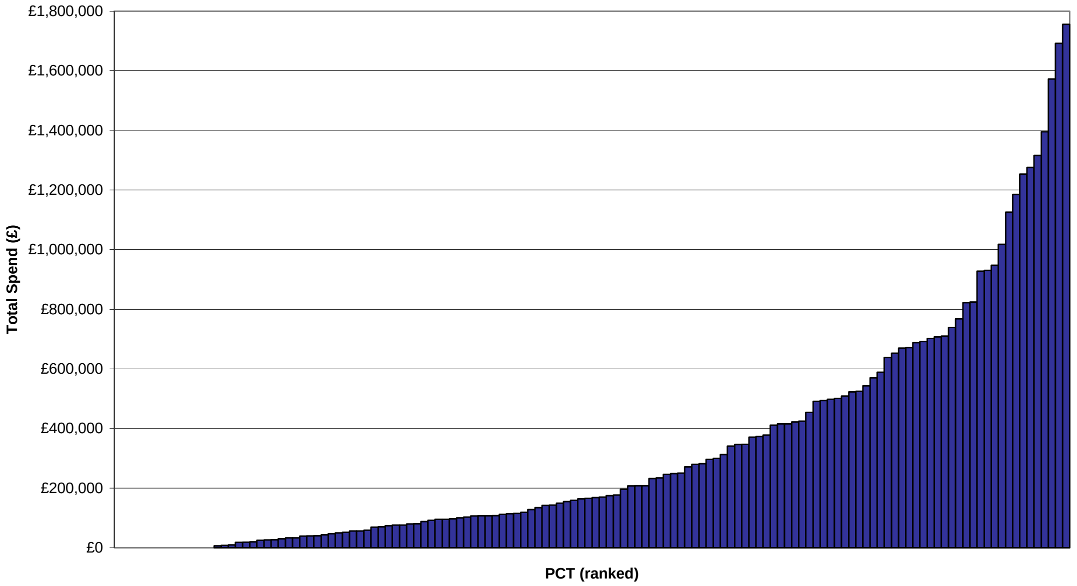
Table 2: Breakdown of new investment by PCTs and SHAs into End of Life Care. See Appendix C for a breakdown of costs under “Other”

Figure 1: PCT Spend by Category



There is considerable variation in the level of new investment between PCTs. 14 PCTs reported no new investment in end of life care services in 2010/11; in 2009/10 these 14 PCTs invested on average £394,000 (range: £55,000 - £1.02 million). 17 PCTs reported new investment of greater than £1 million, with the maximum reported investment being in East Riding of Yorkshire PCT, with £5.6 million. Even after excluding outliers, there remain large variations in investment levels. Figure 2 shows this variation in a bar chart, ranked by PCT new spend, with the top 5% of returns excluded[2].

Figure 2: Bar graph of Total New Spend by PCTs, excluding outliers



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[2] For reference, the top 5% of PCTs spent more than £1.8m in 2010/11. A table with all PCTs investment is in Appendix A.

This variation could be explained by a variety of factors; these are explored further in the report accompanying this Annual Report, which is published on the Department of Health's website. Information on new investment by individual PCTs is at Annex A.

Also included in the £198 million was £38.7 million, which was allocated under the Multi Professional Education and Training (MPET) budget. This was devolved to SHAs and PCTs and is included in their totals for 'training'. In addition, the Department of Health and the National End of Life Care Programme spent just under £7.9 million on national work and projects. The Department also provided a capital budget of £40 million for hospice enhancement projects (see Chapter 4).

Specialist Palliative Care

Through the returns from PCTs and SHAs on their new investment on end of life care services, we also received information on the total amount PCTs spent on specialist palliative care services in 2010/11. The coverage was the same as for end of life care services (141 returns from PCTs, nine from SHAs). Those that responded declared spend of £385.0 million. Assuming that PCTs that did not respond spent the average amount, we estimate that total spend on specialist palliative care in 2010/11 was £409.6 million across all PCTs.

In order to allow meaningful comparison with PCT spend from the 2006/07 survey it was necessary to exclude some areas of spend that PCTs declared in their return as covering related activities (like end of life care services and palliative care). This amounted to approximately £74.8 million and is not included in the figures above. Total spend on specialist palliative care services in 2006/07 was £245.0 million, so the £409.6 million in 2010/11 represents a 49% increase in spend in real terms over four years[3].

Average PCT spend in 2010/11 was £2.7 million, which equates to just under £8 per person or £840 per death. The largest portion of money was spent on adult voluntary hospices, which received £176 million or 46% of total spend. A breakdown of total spend is in Table 3 below[4]. Information on investment in specialist palliative care by individual PCTs is at Annex B.

PCT SPEND	**Total Spend (£)**	**%**
Adult Voluntary Hospices	176,163,751	45.8%
NHS Hospices/SPC Units	68,332,321	17.7%
NHS Managed Services	98,754,623	25.6%
Voluntary Managed Services	17,168,069	4.5%
SPC services provided in hospital settings not otherwise accounted	11,585,468	3.0%
Other SPC services	13,044,905	3.4%

Table 3: Breakdown of spend on specialist palliative care by PCTs in 2010/11.

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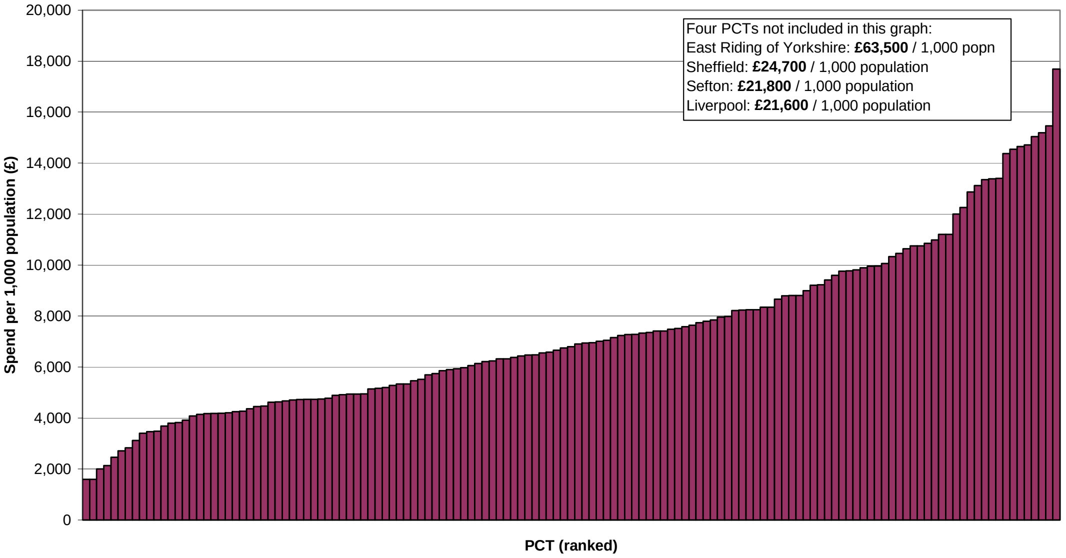
[3] The 2006/07 estimate (£245m) is inflated to 2010/11 prices (£274.2m) using the CPI inflator figures on the Office for National Statistics website.

[4] Some PCTs provided estimated spend on children's voluntary hospices, amounting to £2.7m. Spend on children's specialist palliative care services was not explicitly asked for, so this estimate will be an underestimate of true spend in this area. This estimate is included in the £74.8m estimate of "Other Declared Spend".

As with end of life care investment there is considerable variation in PCT spend on specialist palliative care. Figure 3 graphs PCT spending per 1,000 population on specialist palliative care, ranked in order of spend[5].

Figure 3: Bar graph of Spend per 1,000 population on specialist palliative care by PCTs, excluding outliers



Four PCTs not included in this graph:
East Riding of Yorkshire: **£63,500** / 1,000 popn
Sheffield: **£24,700** / 1,000 population
Sefton: **£21,800** / 1,000 population
Liverpool: **£21,600** / 1,000 population

The graph shows that the majority (60%) of PCTs spent between £1 million and £3 million on specialist palliative care in 2010/11. At either extreme, Darlington PCT reported spend of £201,000 while East Riding of Yorkshire PCT spent over £21.4 million on specialist palliative care in 2010/11. This implies that the highest spending PCT spent over 100 times more than the lowest spending PCT. Even after excluding the top and bottom 10% of PCTs, there is still considerable variation, where the 90th percentile PCT spends 5.6 times more than the 10th percentile PCT.

As with new investment in end of life care, this variation could be explained by a variety of factors. These are explored further in the report accompanying this Annual Report, published on the Department of Health's website. This report also includes a further breakdown of all the data received for both new investment in end of life care and spend on specialist palliative care in 2010/11.

Route to Success

The NEOLCP has expanded its practical Route to Success series building on the well-received resources for care homes and acute care. The new resources include a particular focus on some groups who have traditionally been under-served in end of life care. These are:

- *The route to success in end of life care – achieving quality for people with learning disabilities,* developed in collaboration with a number of organisations including Enfold and GOLD (Growing Older with a Learning Disability);

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[5] Since the five highest spending PCTs spend on average five times more than the national average, this tends to distort graphs of PCT spend. For this reason, we have excluded the top 5% of PCTs from Figure 3.

- *End of life care – achieving quality in hostels and for homeless people: a route to success*;
- *The route to success in end of life care – achieving quality in domiciliary care,* developed in collaboration with United Kingdom Home Care;
- *The route to success in end of life care – achieving quality for occupational therapists,* developed in collaboration with the College of Occupational Therapists;
- *The route to success in end of life care – achieving quality in prisons and for prisoners*;
- *Route to success: the key contribution of nursing to end of life care;*
- *Route to success: achieving quality environments for care at end of life,* developed with the Kings Fund.

Further Routes to Success are nearing completion. Resources for ambulances and for social care are planned for the winter.

Partnership working between a hospice and a male prison containing life prisoners.

Within the catchment of Dorothy House Hospice Care there is a male populated prison, which houses solely life prisoners. It has an increasing ageing, static population of 186 prisoners. As a hospice we have worked closely with the healthcare staff at the prison to ensure specialist palliative care is available to those patients that require this service.

We have been actively involved with this joint working for about a year, receiving six referrals and numerous calls to give advice to healthcare staff and GPs covering the prison clinics. During this period of time the prisoners have had the opportunity to discuss advance care planning and end of life care needs. This has resulted in a more streamlined approach within the prison service when looking at end of life care generally, and specific issues such as DNAR and anticipatory prescribing. During this time a prisoner was admitted to the hospice for terminal care and this enabled the restoration of personal family relationships. Prior to this admission, work was carried out with the prisoner looking at viable choices for his end of life care. Most importantly he was given the opportunity to discuss his wishes on a regular basis.

Since the death bereavement work has also been carried out by hospice staff with a group of prisoners that have needed such support.

This partnership has led to more specialist palliative care being delivered in a community that has historically been hard to reach. The partnership has required changes in working practice - for example, ways in which medication is prescribed and delivered, discussions around family and carer support and, and ways in which we empower the patients have all needed to be adapted for this environment. The philosophy underpinning specialist palliative care does not lend itself well to the world of a life prisoner, which has proved challenging. The key to the success of this piece of work has been the partnership working with the hospice and the healthcare staff at the prison.

Contact: Wayne.de_leeuw@dorothyhouse-hospice.org.uk

Extra Care Housing

In 2009 the NEoLCP, working with Housing 21 and Skills for Care, produced a resource document, *Is it that time already?,* and a resource pack for staff working in extra care housing. The University of York was commissioned to evaluate these materials. They concluded that the pack has been a useful resource for staff and residences in the extra care setting but an on-going proactive dissemination was required to ensure further usage of this resource.

NHS Choices

A comprehensive and useful guide about end of life care is available on the NHS Choices website. First published in October 2010, the guide covers a range of topics under the headings *What is end of life care?, Planning ahead* and *Your wellbeing.* It also has useful links to a number of organisations and publications that can provide further information and assistance to patients, carers and families.

Research

The Department of Health has continued to support end of life care research projects. A full list of the projects funded by the Department is at Annex D.

Chapter 3: Improving outcomes for people approaching the end of life: identification and care planning

Identification and care planning are the two stages on the end of life care pathway chosen for the QIPP focus, since they are the foundations for good care.

The *Find your 1%* campaign

Approximately 500,000 people die every year in England. This amounts to about 1% of the population. Of this group up to 70% would prefer to die at home and yet only 39% of patients currently die in their usual place of residence. This mobilisation campaign therefore encourages GPs to sign up to the 1% campaign, actively committing to identifying the 1% of people on their list who might be in their last year of life, to work with those individuals to plan their care, and to encourage colleagues to do the same.

AMBER

Assessment – **M**anagement – **B**est Practice – **E**ngagement for patients and carers – for patients whose **R**ecovery is uncertain

AMBER was originally developed by Guy's and St Thomas's. Their work is part of the Modernisation Initiative End of Life Care programme across Lambeth and Southwark. It contributes to the QIPP workstream, by providing a specific focus for identification and care planning for and with patients and families in an acute hospital setting.

The early, encouraging findings from using the AMBER care bundle were published in the NEoLCP's *The Route To Success in acute hospitals*. Building on Guy's and St Thomas's work, the East Midlands SHA initiated its own pilot in collaboration with the NEoLCP.

The pilot aimed to assess whether the East Midlands hospitals could replicate these promising findings in other acute hospital settings in order to accelerate learning for wider application – testing local ideas for national application.

The results were encouraging. There was a consistent view that the care bundle was simple to implement. Substantial numbers of medical admissions met the screening criteria. It promoted thought and dialogue about end of life care. More patients were being discharged to community settings, consistent with the findings from Guy's and St Thomas's, though data collection issues mean that it was not possible to assess the impact on achieving preferred place of care.

The pilot's report concludes that it is possible to implement AMBER without significant additional resources but the settings need to be receptive. Some staff had training and development needs, in particular communication skills for holding difficult conversations with patients and families.

Discussion with pilot teams has highlighted ways to replicate what worked which have been translated into recommendations to support wider take-up. A synthesis of the learning has resulted in the development of a resource to support this.

Locally owned prognostic indicator tools for cardiac failure, chronic obstructive pulmonary disease and dementia

The national End of Life Care Strategy sets a challenge to identify non-cancer patients who may be in the last year of life, to improve communication between primary and secondary care teams about these patients and by doing so, increase the numbers included on Gold Standards Framework (GSF) Registers in GP practices. A snapshot of GSF Registers in Torbay in 2009 revealed only 16% of patients having non-cancer diagnoses.

Building on existing links with cardiac, respiratory and dementia teams, small working groups were set up to develop locally owned prognostic indicator tools for these diseases. Each group included a lead Consultant, disease specific nurse specialist, palliative care team members, community matron, acute hospital ward nurse and occupational therapist or physiotherapist. Each group developed its own prognostic indicator tool based on nationally available tools, available research evidence and clinical experience. They also agreed on other measures to improve the care of these patient groups such as inclusion of additional information in clinic and discharge letters to GPs. The groups continue to meet on a three monthly basis to monitor progress and develop further initiatives such as multi-disciplinary communication sheets to record discussions of end of life preferences with patients.

In addition to the intended benefits stated above, production of the tools has generated other improvements in the care of non-cancer patients by bringing together health professionals and raising the profile of end of life care in non-cancer. Local production and ownership of the tools, with identifiable local lead clinicians, has improved their credibility and use. Since their production, the tools have been used at numerous education sessions and workshops for primary and secondary care staff. They have also been used in another project in Torbay aiming to improve the care of patients in the last year of life residing in Nursing Homes through education of care home staff on the principles of good end of life care.

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jo.sykes@nhs.net

The Dying Matters Coalition GP Project

In 2010 Dying Matters ran a GP pilot project to examine how best to support GPs when discussing dying and death. The pilot had three objectives: to raise the profile of the Dying Matters Coalition; to support GPs in their consultations with patients when the subjects of death, dying and bereavement arise; and to test the usefulness of communication materials from the GP and patient perspective.

GPs were invited to participate in a training workshop which included an interactive session on communication skills in conversations about death, dying and bereavement. At the workshops, GPs were given a preview of the communication materials and asked for their feedback on the leaflets, posters and postcards about end of life designed for patients and carers.

The pilot was independently evaluated and the results clearly show that GPs' confidence in initiating end of life care conversations increased significantly after the workshop. Pre-pilot, 60% of GPs assessed themselves as not confident when initiating conversation about dying, but post-pilot, confidence rose to 86%. 90% of the participating GPs also rated themselves as 'confident' or 'very confident' in continuing the conversation once it was underway. 80% of GPs found the supporting leaflets very helpful. Nine out of ten patients wanted to continue the conversation even if the GP was feeling confident or not. Conversations between GP and patients resulted in actions which support a good death, including putting patients on the end of life care register.

A second phase of the project is now being run in Devon, Somerset, Blackpool and South Central. This second phase is building on the work already done and will be supported by national learning packs for GPs.

Care homes

The NEoLCP's Care Home work stream continues to gain momentum. The last year has seen the development and publication of a tool kit of resources which have been produced in collaboration with Anchor Care Homes and the National End of Life Care Intelligence Network. The tool kit includes a quality assessment tool comprising a baseline questionnaire and an extraction analysis tool.

Further, the Six Steps to Success programme developed by the North West End of Life Care Home Coordinators and produced by the NEoLCP is designed to enhance and support organisational change and develop staff working in care homes, ensuring that all residents receive high quality end of life care. The tools are underpinned by the NEoLCP resource *Route to Success guide- achieving quality in care homes* and the wider Route to Success series, for example, those covering nursing, occupational therapy and learning difficulties.

Plans for the coming year are to increase awareness and uptake of this tool through a series of workshops. The North West team is planning to roll out the six-step programme to 800 care homes in Cumbria and Lancashire.

Disease specific initiatives

The End of Life Care Strategy recognised that the biggest single inequality in this area of care is between those with cancer and non-cancer diagnoses. While we are anxious to continue to improve the care provided to people with cancer there is more work needed to provide high quality care for people with other conditions, such as organ failure or dementia, or who have multiple conditions. The NEoLCP has already worked with a range of partners to produce Routes to Success for specific conditions. This year it has focussed especially on dementia and neurological conditions.

- *Care towards the end of life for people with dementia: an online resource guide* links to a wide range of useful resources and case studies illustrating the delivery of high quality end of life care that meets the special requirements of people with dementia and their families. The online resource emphasises the importance of partnership working between professionals who work in dementia and their counterparts in palliative or end of life care.

  The guide links the particular characteristics and needs of people affected by dementia with the six step end of life care pathway – including assessment, advance care planning, co-ordination of care and recognition and management of symptoms. The nature of dementia means that responding to the individual needs of people with the condition as they near the end of life can be challenging.

- *Difficult conversations: making it easier to talk to people with dementia in end of life* care has been produced in collaboration with NCPC. This resource booklet was launched on 1 July. The NEoLCP and NCPC aim to get it into all memory clinics across England.

- A resource document, *End of life care in long term neurological conditions: a framework for implementation* was produced by the NEoLCP in partnership with the Neurological Alliance and the National Council for Palliative Care. It highlights other challenges to be overcome if services are to be improved. These include:

  - The long duration of many neurological diseases;
  - The risk of sudden death;
  - The lack of a predictable course – making planning difficult;
  - The complex, multidisciplinary care required;
  - The range of specialist treatments available;
  - Rapidly advancing diseases may need palliative care early in their course;
  - Many people die with - but not from - their neurological condition.

  The document has been widely disseminated and is planned to be the foundation of developing possible European guidance.

NHS Devon - Using the Map of Medicine in End of Life Care

The Map of Medicine provides a visualisation of the ideal, evidence-based patient journey for common and important conditions - a sat nav overview that can be shared across all care settings. The Map is a web-based tool that can help drive clinical consensus to improve quality and safety in any healthcare organisation.

NHS Devon, with primary and secondary care clinicians, has been using the Map of Medicine to develop local care pathways and protocols across a range of conditions, including for end of life care.

End of life pathway:

- Localised across Devon;
- Links to the Gold Standards Framework;
- All agencies can add patient/carer information;

- NICE standards embedded;
- Education tools hyper linked;
- Map of Medicine Local Care pilot;
- Five End of Life Care pathways:
    - assessment & care planning;
    - management of psychological symptoms;
    - palliative care services;
    - management of physical symptoms;
    - care in the last days of life.

Localising the End of Life Care pathway:

- Included all stakeholders – palliative care consultant, hospices, community matron, social care, GPs, commissioner, consultant in elderly care, specialist nurse, public health, PPI, AHP;
- International pathway as starting point;
- Add/amend as appropriate;
- Links to local patient information contact numbers joint formulary etc.

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Cancer Survivorship

Sixty per cent of patients diagnosed with cancer will live for five years or more, yet they will not all be cured of their malignancy. Consequently, the Department of Health's Cancer Programme, as part of the National Cancer Survivor Initiative (NCSI), includes a workstream on *Active and Advanced Disease*. This is chaired by Dr Adam Glaser, Clinical Director of the NCSI, and is a collaboration with the NEoLCP, service users, professionals and Macmillan Cancer Support. It is addressing issues faced by those who are diagnosed with advanced cancer, experience progression or recurrence of their malignancy. Issues under investigation include the "language of palliative care", identification of events that would enable timely access to appropriate palliative and end of life care support, and cancer MDT working to facilitate optimal care and support.

Advance Care Planning (ACP)

The National End of Life Care Programme in collaboration with health and social care professionals, with the National Council for Palliative Care and Dying Matters, and led by Professor Jane Seymour of Nottingham University, has updated its resource document for health and social care staff on advance care planning. The report, *Capacity, care planning and advance care planning in life limiting illness,* includes information on the differences between care planning and advance care planning, an expanded glossary and core competences. It also highlights issues around informed consent and capacity.

The NEoLCP also commissioned an economic study of the possible impact of ACP which was undertaken by the Institute for Health Service Management. The findings show that the value to the individual and their family is immense while the cost is variable depending on the needs and family support required.

East of England, Advanced Communication Skills Programme

The Advanced Communication Skills Programme was completed in March 2011 with 400 Group A staff (specialist staff who work in palliative and end of life care areas) attending the three day training course.

This project started in 2009 with the aim of delivering end of life care (EoLC) communication skills training to health and social care staff following on from the End of Life Care Strategy.

This training package was facilitated by Mount Vernon, Anglia and Essex Cancer Networks, delivering the national *Connected* Advanced Communication Skills (ACST) course to non-cancer end of life conditions participants. The cancer course was adapted to meet the evidence and knowledge based needs of participants not working in cancer or palliative care. For example, information about the communication needs and strategies for end of life cancer conditions such as COPD, Heart Failure, Dementia and End Stage Renal Disease was included in the programme.

Roleplay of common scenarios was particularly popular on the course and covered areas such as breaking bad news, collusion, family dynamics, transition from palliative to end of life care, advance care planning, anger, hopelessness and denial.

What participants said:
“I found the End of Life ACST to be one of the best I have attended in 30 years of nursing.”
“I get a lot more personal satisfaction since attending the course and feel more confident that patients do not expect me to solve their problems; often they just need someone to talk to.”
And, from a doctor, “Now I spend more time concentrating on the reasons why they don’t want medical treatment rather than the medical implications.”

Contact: Vanessa Convey, Palliative and End of Life Care Education & Training Programme Manager, East of England Multi-Professional Deanery, vanessa.convey@eoe.nhs.uk

Preferred Priorities for Care (PPC)

The Preferred Priorities for Care (PPC) document continues to be implemented across many care settings and has been supported by a small core team. There has been a substantial demand for support with implementation which has led to the team attending and presenting at more than 35 conferences and workshops.

PPC is being adopted as core business in some areas. Within Essex Social Care, for example, the document now forms part of their assessment process, while it is included in some of the Dying Matters Coalition literature.

An information leaflet and poster has been designed and is available for organisations to use. An accessible version of the PPC is currently being designed for individuals who have a learning disability diagnosis.

Chapter 4: Improving outcomes for people approaching the end of life: coordination and delivery

Coordination and integration of care is a running theme through the entire end of life care agenda, reflected in QIPP and in the findings from the Palliative Care Funding Review.

Electronic Palliative Care Coordination Systems (Locality end of life care registers)

Eight pilot sites across England have been part of a pilot programme to develop and test End of life care locality registers as a way to share key information about people's end of life care needs and wishes, in order to deliver improvements in care. The pilot programme formally ended in March 2011 although the pilot sites are continuing to work on development and implementation.

Ipsos MORI were commissioned to undertake an independent evaluation of the pilot programme. An interim report was published in February 2011, providing a useful resource to help inform and support wider take-up, particularly in relation to how significant challenges were overcome, and the key processes that needed to be worked through.

The final report was published on 29 June 2011. This expands on the key learning already identified in the interim report, and also contains detailed case studies for each pilot. This provides important insights into factors that influence locality register development, including such key issues as choice of IT systems.

Actual outcome data are still limited but early findings are encouraging. They suggest that the use of a register supports the delivery of care in line with individual preferences, supporting more people to die in the place of their choice.

To support ongoing implementation of the registers, a core content data set for end of life care coordination, which was tested through the pilots programme, is now going through the formal Information Standards Board approval processes. If approved, this data set will be mandated for use in the NHS, with a requirement that suppliers of systems supporting end of life care coordination incorporate it into their systems.

Feedback from the pilots has suggested that the term "locality end of life care registers" does not accurately reflect what the registers are intended to do. The new, descriptive generic name for the registers is Electronic Palliative Care Coordination Systems (EPCCS). Locally, people have devised their own titles: for example, London's scheme is called *Coordinate My Care*.

Quality Markers and Measures for end of life care

Chapter 2 sets out the detail of the ELCQuA project, which enables electronic benchmarking and monitoring of progress against the Quality Markers published in 2009.

Improving Bereavement Services in Leeds Teaching Hospitals Trust (LTHT)

Around 3,000 people die in LTHT hospitals every year and so the issues that relate to care and support of bereaved relatives and next of kin are fundamental for the organisation.

One of the specialist palliative care nurses was seconded for one day a week for a three month period to carry out a bereavement services review across the trust, identifying any deficiencies in meeting Department of Health recommendations. The review included the nurse ‘walking’ through the journey that the bereaved family would make following a death within the hospital, including viewing the body, collecting the death certificate etc.

The findings and recommendations from the review, including photographs of current facilities, were taken to the Trust Senior Management Team.

As a result of the review and recommendations, the following changes have been achieved across the trust:

- A bereaved carers’ user group has been established and the group now provides input and feedback on service developments;
- Based on feedback from the carers’ group, the trust’s bereavement booklet is now provided earlier, when the death certificate is collected;
- Minor works have been carried out (using small amounts of charitable funding) to improve the environment for bereaved families. These include improvements to the bereavement suite to add an additional counselling room, a dedicated waiting room for families who are coming to the mortuary and new signage to direct relatives to the mortuary;
- A multidisciplinary bereavement working group has been formed;
- Primary responsibility for bereavement service has been allocated to a clinical staff member;
- A new bereavement policy is now in final stages of development;
- All patient movement porters are receiving training from mortuary staff in how to lay out the deceased as they are responsible for carrying this out for those people who die overnight and at weekends;
- The specialist palliative care team are attending staff nurse and HCA study days to highlight issues around care after death and care of the bereaved.

Contact: Karen Henry, Palliative Care Team Leader, Leeds Teaching Hospitals NHS Trust
Karen-J.Henry@leedsth.nhs.uk

Some of the comments on the Quality Markers consultation noted that they did not cover bereavement care or spiritual support, despite their being a part of the End of Life Care Strategy. They were omitted because more work needed to be done. That work has now been carried out, based on independent literature reviews and with the help of expert working groups. However, given NICE’s consultation on developing an end of life care

Secretary of State decided to pass the drafts to NICE to contribute to their project. In the meantime, since people were asking for these Markers to help develop practice, they have been published in their draft form on the NEoLCP's website.

Implementation of the Gold Standards Framework for Care Homes – Hartlepool

This project was commissioned from April 2009 to improve equity of care at the end of life for residents within residential and nursing home residents within Hartlepool.

The programme has three aims:

- to improve the quality of care provided for all residents from admission to the home;
- to improve the collaboration with GPs, primary care teams and specialists; and
- to reduce hospital admission in the final stage of life, enabling more to die with dignity in their care/nursing home if that is their wish.

Evidence from previous audits indicated a need for a specialist Macmillan nurse to work closely with the community matrons for care homes. This post was approved and funded by Macmillan Cancer Support.

In April 2009 11/22 care and nursing homes within the Hartlepool area commenced the project, with a further seven joining in September 2010. These homes have worked closely with the Macmillan Nurse for Care Homes and have actively changed their practice for providing end of life care:

- All the care homes have developed a palliative care register and coding system to identify residents with palliative care needs including cancer, and non-cancer conditions such as COPD, Heart Failure, Frail Elderly and Dementia;
- Development of closer working relationships with local GP practices, District Nursing Service and Community Matrons and Macmillan Services;
- All six nursing homes have been allocated syringe drivers and key worker training has been completed;
- All members of staff are encouraged to attend a minimum of one day palliative care course, and care managers/qualified nurses have accessed Teesside University Course facilitated by the community Macmillan nurse for care homes;
- The implementation and training for Preferred Priorities of Care and Advance Care Planning is ongoing;
- The nursing homes and residential homes have implemented the Integrated Care Pathway for the Dying Patient.

Contact:
Sue Burke Macmillan Nurse for Care Homes Hartlepool, sue.burke@nhs.net or 07740512069.

Social care (Phase 1 of the Social Care Framework)

The resource*, Supporting people to live and die well: a framework for social care at the end of life* was published by the NEoLCP in July 2010. It maps out how social care commissioners and providers, together with those involved in training and education, can boost social care's role in end of life care for individuals and their families.

As part of the dissemination, nine regional road show were held across the country with more than 900 people attending.

As an outcome from the social care framework eight pilot sites were supported. These have concluded and are in the evaluation stage. Initial reports have highlighted very good engagement with social care at many levels, although more work remains to be done as to best ways to engage. Examples of the models in use include Essex, with a strategy based on the social care framework - the first to do so; St Thomas's where they are using a successful champion model; and the West Essex hybrid model which is producing very good data.

All have reported that their pilot outcome has transferability and that they are discussing sustainability with their partners. Each will be featured on the NEoLCP website and an event is planned for September to share and disseminate outcomes and evaluation. There has also been much interest from areas that have not had a test site wanting to know the outcomes from the pilots to see what they may be able to model in their areas.

Liverpool Care Pathway Implementation Support Model for Care Homes

This project was set up to support Liverpool Care Pathway (LCP) implementation within a specific care home group. The main aim of the project was to enable care home staff to understand fully the key principles and processes related to LCP use. This involved building the capacity of the workforce to ensure appropriate use of the LCP in supporting residents in their last hours and days of life and their families. The model developed provides a sustainable structure for ongoing LCP use.

Key personnel, identified as Key Champions, were chosen from within individual care homes to drive the change forward. An intense level of support was provided by palliative care lecturers (Project Leads) with previous clinical experience for an initial six month period and subsequent ongoing contact for the lifespan of the project. The Key Champions met monthly to reflect on established practices within the care home and for peer support on management of change and progress. In addition, the Key Champions worked individually using a reflective workbook and diary. Site visits were made by the Project Leads, giving the opportunity for the Key Champion and care home manager to discuss progress and obtain feedback against model core objectives.

The model included direct LCP training for all levels of staff in the care homes and required a minimum of 80% attendance for LCP implementation to be commenced. A Facilitators Guide: Introduction Training pack (LCP V12) has been developed and left within the 66 care homes involved in the project to promote continuing LCP training as part of a sustainable approach.

Pre and post evaluation of this project suggests a substantial and positive impact on the following areas of clinical practice: knowledge; attitude; behaviour; documentation; advocacy; confidence; autonomy; and preferred priorities for care within the care homes involved.
Contact: Janet Howard / Sharon Phillips, Lecturers / Project Leads. Marie Curie Palliative Care Institute, Liverpool. Tel: 0151 801 1443
email: janet.howard@liv.ac.uk and sharon.phillips@mariecurie.org.uk

Carers Strategy

As mentioned in the second report, the Coalition Government made an early decision to update the national carer's strategy. *Recognised, valued and supported: next steps for the Carers Strategy* was published in November 2010. It identified four priority areas for the next four years, all of which are as relevant to those caring for people coming to the end of their lives as to other carers. These are:

- Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages;
- Enabling those with caring responsibilities to fulfil their educational and employment potential;
- Personalised support for carers and those they support, enabling them to have a family and community life;
- Supporting carers to remain mentally and physically well.

The Department of Health is providing additional resources during 2011/12 for GP training to increase GP awareness and understanding of carers' need for support at different times in their caring role. It has also made available an additional £400 million over the period 2011/12 to 2014/15 in NHS baselines to support carers of all ages take a break from their caring responsibilities.

Independent evaluations of the Department's Carers Strategy 25 demonstrator sites will be published by the end of 2011. A number of the sites have had a particular focus on end of life care.

Clinically Enhanced Discharge Project

Historically in County Durham and Darlington, over reliance on local hospitals has created pressures on acute beds often due to unnecessary admissions and long lengths of stay. To provide better patient outcomes and more effective use of resources, the Clinically Enhanced Discharge Project within County Durham and Darlington Foundation Trust aims to ensure that patients are cared for in the most appropriate setting.

This will be achieved by having a dedicated in-reach service into hospitals to identify patients who could be discharged earlier with robust packages of care that meet their medical and support needs. One of the key elements of the project will be a 24 hour/ 7 day coordination centre which will provide a single point of access and will be responsible for assessing patient need, referring patients onto the relevant service area, and coordinating their package of care.

Contact: kaymcalinden@nhs.net

Hospice Capital Grants

The outcome of the application process for the £40 million capital grant scheme was announced on 2 April 2010, with 123 projects from 116 organisations being supported.

Originally it was envisaged that the projects would be completed by March 2011. However, some extensions were agreed due to extenuating circumstances, including severe winter weather conditions. 121 of the 123 projects have now been completed and the other two will be imminently. Help the Hospices, who managed the scheme on behalf of the Department of Health, have compiled a report on the outcomes of the scheme.

Marie Curie Hospice, Newcastle - chapel, before development

Marie Curie Hospice, Newcastle - reflection room, after development

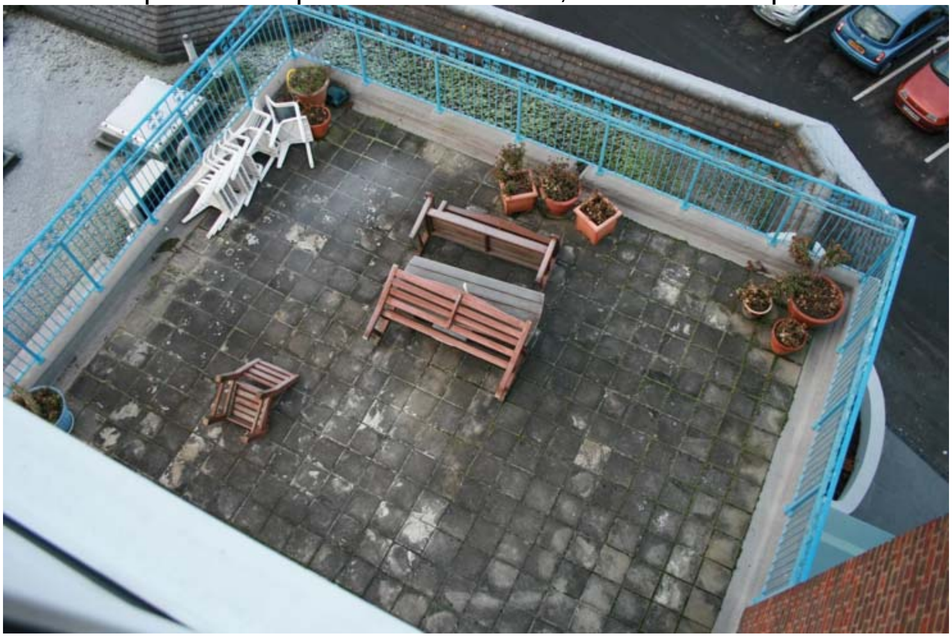
Ellenor Lions Hospice - Lounge, before development

Ellenor Lions Hospice - Lounge, after development

Butterwick Hospice - Exterior of the building, before development

Butterwick Hospice - Exterior of the building, after development

St Christopher's Hospice - Roof terrace, before development



St Christopher's Hospice - Roof terrace, after development

Chapter 5: Improving outcomes for people approaching the end of life: the last days of life and care after death

Liverpool Care Pathway (LCP)

The Liverpool Care Pathway (LCP) is a multi-professional, evidence-based framework for the delivery of care for patients in the last hours or days of life. It has been identified as best practice within the NICE Guidance for Supportive and Palliative Care (DH, 2004) and by the Department of Health (DH, 2006, 2008, 2009). The Strategy continues to support the LCP as the key tool for delivering and improving care at the very end of life. The pathway is subject to a continuing programme of revision and review and is also the subject of a regular audit.

National Care of the Dying Audit Hospitals (NCDAH) Programme

The National Care of the Dying Audit Hospitals (NCDAH), is a national audit of practice of care of the dying in the secondary care environment, undertaken by the Marie Curie Palliative Care Institute Liverpool (MCPCIL) in collaboration with the Royal College of Physicians (RCP), supported by the National End of Life Care Programme and Marie Curie Cancer Care (MCCC). The NCDAH is currently in its 3rd round, and is listed on the DH 'Quality Accounts' list for 2011 – 2012. The audit examines investment by the hospital trust in terms of provision, and delivery of care for patients in the last hours or days of life. The audit is comprised of two sections:

- an ***Organisational Audit***, linked to the DH Quality Markers and Measures for End of Life Care (DH, 2009) and the CQC essential requirements (2010). This has been extended for the 3rd round to enable participation from all acute hospital trusts; and.

- a ***Clinical Audit*** for those hospitals using the Liverpool Care Pathway for the Dying Patient (LCP). This element examines care delivery for patients in the last hours or days of life, and their family/carers as documented on the LCP.

The NCDAH allows hospitals to understand their own level of comparative audit in relation to others, and enables them to start the process of action planning for the future. Results from workshops (from both round 1 and round 2) held after dissemination of the results illustrated this opportunity to reflect on performance in comparison with that of others nationally is invaluable in promoting Continuous Quality Improvement (CQI) in care of the dying. The NCDAH report also promotes data driven Key Performance Indicators, to enable individual hospitals to translate salient elements of performance in the audit onto their local Trust Corporate Performance Dashboard.

Liverpool Care Pathway - CQUIN

A CQUIN for the Liverpool Care Pathway (LCP) was introduced into acute contracts within NHS South Central for 2009/10. This has led to an increase in the number of people dying on the pathway and in the education of staff on the LCP.

Portsmouth Hospitals have conducted a study to evaluate the quality of end of life care and the use of the LCP before and after the introduction of the MOPRS EOLCT (Medicine for Older Persons and Rehabilitation Service End of Life Care Team) which coincided with the 2009/10 CQUIN. This showed that involvement of the MOPRS EOLCT increased from 5% - 47%, with an associated improvement in a number of aspects of end of life care delivery:

- documentation of advance recognition of death improved from 71% - 94%;
- mean time on the LCP increased from 41 hours to 63 hours;
- documentation of communication with family members improved from 81% - 94%; and,
- prescription of appropriate PRN subcutaneous medication improved from 52% - 82%.

For more details contact Mark Roland, Respiratory Consultant at mark.roland@porthosp.nhs.uk.

Death Certification

The Coroners and Justice Act, which gained Royal Assent in November 2009, introduced provisions for reforming the process of death certification in England and Wales. The reforms will unify procedures for all deaths, whether the body is to be buried or cremated. Local Authorities in England (and Local Health Boards in Wales) will be required to have medical examiners who will scrutinise medical certificates of cause of death (MCCDs), patient records and circumstances of all deaths not investigated by a coroner, before the deaths are registered. The Act also includes provision for appointment to the statutory post of National Medical Examiner to provide professional leadership to medical examiners. Implementation of the reforms is scheduled to begin in April 2013.

Bereavement

A Bereavement Working Group was established to advise on the development of a work programme around bereavement. Chapter 4 set out the progress on developing Quality Markers for bereavement.

Care After Death (“last offices”)

The resource document, *Guidance for staff responsible for care after death (last offices)* emphasises that care extends well beyond physically preparing the body for transfer either to the mortuary or funeral director. This includes:

- Ensuring that the deceased and their family/carers have their privacy and dignity respected at all times;

- Honouring the spiritual and cultural wishes of the deceased person and their family/carers;
- Honouring people's wishes for organ and tissue donation;
- Ensuring the health and safety of everyone who comes into contact with the body;
- Ensuring that if the death is being referred to the coroner no action is taken which might impede establishing the cause of death;
- Ensuring correct certification procedures have been followed.

Care after death can be made less stressful by discussions while the patient is still alive around issues such as organ donation and cultural attitudes towards death.

The work was initiated by the National Palliative Care Nurse Consultants Group and undertaken in partnership with the National End of Life Care Programme (NEoLCP). It has been endorsed by the Royal College of Nursing and the Royal College of Pathologists. All organisations identified as being involved in the pathways of care of the deceased have contributed to the development of the resource document.

This resource has been reinforced by two new learning sessions on care after death available through e-ELCA (End of Life Care for All). This additional resource, developed by the NEoLCP in association with e-Learning for Healthcare and the Association for Palliative Medicine, is available free to many health and social care staff. In addition, 6 sessions on bereavement have also been developed.

When a Person Dies

An important strand of work identified by the Bereavement Working Group was the revision of *When a Patient Dies*, the 2005 DH guidance to support the development of bereavement services in the NHS. The group recognised the need to provide an up to date resource, reflecting developments in policy, practice and the legal context, including the End of Life Care Strategy and the shift towards provision of care in the community.

The Bereavement Services Association (BSA) have led on the work to revise this resource, with support from the NEoLCP and others, and have consulted extensively with a range of stakeholder groups.

The document will be published in the autumn 2011.

'Tell Us Once'

In an attempt to make the process of reporting a death less stressful and repetitive, Tell Us Once, a cross-government initiative led by the Department for Work and Pensions (DWP), is being rolled out to enable people to report a death to several Government departments and agencies in a single contact.

Tell Us Once is currently offered in 42 local authorities across England, Scotland and Wales, and can be accessed face-to-face at a local authority office or via a dedicated freephone number. The DWP have announced that the service will be rolled out nationally between June and December this year, with 90% of local authorities on board.

From May 2011 the new Bereavement Service recently launched by the DWP will be incorporated into the scheme, meaning that enquirers can opt in for an eligibility check to find out which benefits they may be entitled to, for example Bereavement Benefit and Social Fund Funeral Payments, and make claims over the phone.

Chapter 6: Improving outcomes for people approaching the end of life: commissioning and levers for change

Commissioning in the new NHS

The NHS and Social Care Bill has now moved to the Lords in Parliament. The timetable for developing new commissioning arrangements will depend on the progress of the Bill.

In June the National Council for Palliative Care launched *Commissioning End of Life Care: Act + Early or A & E: initial actions for new commissioners"*. This was developed with a range of voluntary sector partners and the National End of Life Care Programme. This resource has been well received and prompted much interest and discussion.

NHS South Central – End of Life Care sustainability

As the Coalition Government's NHS reforms took shape, NHS South Central saw a need to reconsider how best to ensure the improvements in end of life care (EoLC) were maintained under the new structures. So far, improvements in EoLC in the SHA have been supported by their clear management structure: South Central has an EoLC lead at the SHA and EoLC leads in each PCT. For the future EoLC will need to be embedded within what will be Health and Well Being Boards and emerging commissioners.

During 2010 real progress has been made in this. There is an EoLC lead designated in each Local Authority, EoLC included in many Joint Strategic Needs Assessments, EoLC leads in many Practice Based Commissioning Consortia and emerging commissioning consortia, while EoLC leads are just being determined within care homes. These leads are all involved in their local PCT EoLC groups which will become EoLC hubs of organisational memory of improvements in EoLC independent of the changing NHS structures around them.

Contact: Lucy Sutton, Associate Director of End of life Care
lucy.sutton@southcentral.nhs.uk

Workforce

The focus since the last report has been very much around consolidation and development at regional levels. The three foundation projects to develop core principles and competences, communication skills and elearning (e-ELCA) have been completed and much of the content is being used to inform further development such as blended learning and the application within specialist areas such as learning disabilities and mental health. The case studies within this section are only a sample of the work being undertaken. We have delivered on all the areas highlighted in the last annual report.

East of England - End of Life Care (EoLC) training for final year GP trainees

An end of life care (EoLC) GP trainee project in the East of England is building on the success of a GP trainee pilot project in Norfolk. Eighteen GP Schemes in the East of England (EoE) will provide EoLC training for GP trainees in their 3rd (final) year of training.

Over recent years there has been increasing recognition, including in the End of Life Care Strategy, that all doctors should have experience in Palliative Care as part of their training programme. In 2010 a pilot scheme was initiated, led by Dr Nicola Holtom (Palliative Care Consultant), providing GP trainees with a two day course looking at various aspects of palliative care. These included

- Management of nausea and vomiting;
- Bowel obstruction;
- Neuropathic and nociceptive pain;
- Palliative care emergencies;
- Ethical issues;
- Bereavement;
- Use of syringe drivers; and
- Management of final stages.

The trainees were then asked to return to their own practices to look after terminally ill people, write up their experiences in a portfolio, returning six weeks later for a day's meeting to discuss aspects of palliative care with other trainee colleagues and experienced palliative care consultants.

This pilot has proved successful with all trainees feeling the course met their expectations, with a demonstrable increase in their confidence and knowledge. They would recommend the course to future trainees.

Due to the success of this project another EoLC training project will get underway later his year. This training will be targeted at GPs (principals, salaried and out of hours) with aims to improve communications between care homes, GP practices and EoLC services and provide GP practices with EoLC skills they require.

Both these projects are being managed by a GP Steering Group and will be evaluated to provide the evidence needed to sustain these training packages in the future.

Contact: Vanessa Convey, Palliative and End of Life Care Education & Training Programme Manager, East of England Multi-Professional Deanery, vanessa.convey@eoe.nhs.uk

e-Learning

In May, we launched a further 23 sessions covering spirituality, bereavement and social care as well as adding to an integrating learning module which now includes care after death (last offices), Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) and continuing care. The Review and Editorial Board is set up and the process for the formal content review by the Association for Palliative Medicine is currently being worked up. Access issues remain challenging as both social care organisations and health organisations are not necessarily signed up to the agreed access methods. We have reviewed this and identified simplified access for social care through the National Minimum Data Set for Social Care (NMDS-SC) and people who have an ‘NHS’ email address will also have access irrespective of whether their Trust is signed up to the National Learning Management System (NLMS). Currently there is an average of 2,000 NHS users accessing the content each month and within social care approximately 1,500 users have registered on e-ELCA, but with 25,000 employers registered on NMDS there is potential to reach 800,000 social care employees. The activity levels and registrations are very poor considering the total number of workers we want to target. Reasons given are poor access to technology, better communication needed about e-learning, but overall the lack of commitment at senior management level, given this is not mandatory training, has been identified as the biggest issue.

The NEoLCP is also working with BUPA on a project to develop blended learning which will inform the updating of learning pathways as they would apply to care homes. This work will report in March 2012. Further learning pathways in other areas to supplement those already in place for secondary and primary care are already planned.

Communications skills

Twelve pilot sites were established in 2009 to review the needs and provision of communication skills training for the health and social care workforce. This project completed in September and a final report *Talking about End of Life Care: right conversations, right people, right time* was published in January 2011.

The pilot sites used whole systems approaches, matched to their local need. Building on the findings from training needs analysis, the pilot sites benchmarked existing training provision against national competences and then used a needs-based approach to develop new training plans. Service users and other partners also contributed to the project which was evaluated by the Institute of Healthcare Management. The project not only had an impact on training plans and delivery for the local pilot sites, but there was a wider regional interest and involvement and national learning. The final report highlights the spectrum of communication skills training provision, key delivery components and requirements for training. The project also identified important factors that contribute to spread and sustainability of communication skills training.

Consolidation and application of core principles and competences

Skills for Health and Skills for Care have continued to work in partnership with the NEoLCP to improve the workforce development structures and to increase awareness of this area of care within social care and to help employers to access training resources. Achievements this year have included;

- Development of Qualifications and Credit Framework units and supporting material about end of life care;
- Joint work through the social care end of life care framework road shows to support local employers and trainers to work together;

- Action learning research on end of life care for people with learning disabilities, mental health problems or sensory impairments;
- Review and further development of the common core principles to reflect developing practice due to be available in October.

Additional funding for workforce projects

In the autumn of 2010, SHAs were invited to bid for additional funding provided by the NEoLCP for workforce related projects. In total just under £1 million was allocated to the seven SHAs that applied. The projects ranged from enabling more staff to access training including those in care homes, blended learning development, clinical and mentoring tools, improving local infrastructures to enable wider e-learning access as well as “train the trainers” programmes. These projects are due to provide an interim report in the summer and a final report by March 2012, including evaluation.

MPET (Multi Professional Education and Training) continues to be an issue, with feedback that funds for end of life education and training are sometimes not made available due to other local pressures. It would appear that there is a range of processes across the SHAs.

A Collaborative Approach to Driving Improvements in End of Life Care through Workforce Development in the West Midlands

The West Midlands Workforce Programme *'End of life Care is Everyone's Business'* has been a focus for a developing partnership working between health, care, education and the voluntary and independent sectors. The collaboration started in 2009 with regional workshops looking at Core Competences. The regional launch of e-ELCA in February 2010 provided a forum for everyone to identify workforce priorities that would make a real difference to people appraoching the end of life. These were refined through further workshops and with stakeholders from all sectors.

The comprehensive programme runs in five themes with 33 work streams in all:
- **Education and Training for staff**: includes tailored programmes for targeted groups including domiciliary workers; care home workers; and doctors in Specialty Training
- **Education Programmes** developed include a Master’s module for pharmacists working in care home settings; a programme for consultants with a special interest; inter-professional learning sets for doctors, social workers and nurses;
- **Technology Enabled Solutions** includes roll out of e-ELCA in hospitals, care homes and community;
- **Identification, Care Planning and Advance Care Planning** includes work developing education resources for end of life triggers, care planning and Advance Care Planning for people with dementia, respiratory conditions and heart failure.
- **Strategic Planning and Partnership working** will continue to be at the forefront with work on integrated workforce planning.

The impact of the programme is being evaluated by GHK Consulting Ltd, looking at outputs but also outcomes of the work undertaken.

We expect the evaluation to show a difference in the numbers of people dying in preferred place of care; the confidence of workers dealing with people at the end of life; and the experience people and their families can expect at this important time.

The programme shows increased collaboration between health and care professionals and other organisations working with people approaching the end of life. Staff from over 100 organisations including hospice educators, educationalists, training professionals, health and care workers, carers and people with life limiting conditions have all actively taken part. The work is beginning to show real benefits which can be shared across the West Midlands and beyond.

For further information on any of the projects or to join our Community of Practice contact nicole.woodyatt@westmidlands.nhs.uk

The next twelve months

We will continue to review the work undertaken to date to ensure that it is up to date and can support the changes brought about by Liberating the NHS (2010) and various strategic frameworks as they are developed. We will also need to be mindful of the outcomes of *Liberating the NHS: Developing the Healthcare Workforce – A consultation on proposals* (December 2010) and a response from the NHS Future Forum, which was available in June. We must ensure that the future Health Education England (HEE), commissioners of services and education as well as service providers are aware of the tools we have developed to assist them to plan and secure the workforce they require. We need to be able to ensure that end of life care workforce development maintains a high profile by providing a strong evidence base of workforce developments that we know can deliver change whilst meeting the QIPP agenda. By working closely with the SHA End of Life Care Workforce Leads we need to ensure that the work undertaken with and through the SHAs is sustainable and not lost when organisational change happens, for example by establishing links with the suggested Local NHS Education and Training Boards (LETBs) once their full remit is known.

East Midlands: Workforce Modelling tool

During 2010 and the early part of 2011 a wide range of East Midlands health and social care practitioners and service planners have supported the development of a workforce modelling tool that supports functional analysis of a patient care pathway at the end of life.

The methodology for competence-based workforce design and associated education is based on the direct relationship between functions (what needs to be done), the context in which it is done (e.g. high risk, or very predictable) and the skill level required to provide a quality service.

The Functional Analysis approach takes the end of life pathway and identifies what skills are required to ensure the individual in their last year of life receives quality care. These are articulated using nationally recognised and model statements of function or competence and indicative skill level for the functions related to the stage on the pathway and the care context.

The website provides workbooks for each of five end of life care trajectories (cancer; frailty; organ failure; other terminal condition; and unexpected death) and narrative which articulate the needs of individuals in their last year of life.

The quality of the care these individuals can expect is defined in terms of skills needed, level of skill and amount of time for this skill.

Using Skills for Health's Health Functional Map this methodology can be used to describe workforce needs in a whole range of scenarios. The full suite can be accessed at www.skillsforhealth.org.uk.

Further information about how functional analysis might work for you can be gained from Pippa Hodgson, (pippahodgson147@gmail.com) and/or, Skills for Health (sam.gallaher@skillsforhealth.org.uk), or by visiting the website http://www.endoflifecare-intelligence.org.uk/end_of_life_care_models/skills_for_health.aspx

NICE Quality Standard

The Department of Health has commissioned NICE to produce a series of Quality Standards. These are a set of specific, concise statements that act as markers of high-quality, cost-effective patient care, covering the treatment and prevention of different diseases and conditions.

Derived from the best available evidence, such as NICE guidance, and other evidence sources accredited by NHS Evidence, they are developed independently by NICE, in collaboration with the NHS and social care professions, their partners and service users, and address three dimensions of quality: clinical effectiveness, patient safety and patient experience.

NICE is currently working on a Quality Standard for end of life care. The consultation ran from 24 June to 22 July and the final standard is due for publication in November. The Quality Standard will then form the basis for commissioning guidance and for clinical audit.

Personal health budgets

Personal health budgets are currently being piloted across England. The Department has announced in *The Government Response to the NHS Future Forum Report* that it will extend the roll out of personal health budgets more widely, subject to the results of the independent evaluation from the pilot programme, due in October 2012.

As part of the pilot programme people are choosing to meet their health needs in ways that are personal and appropriate to them, for example gym membership instead of physiotherapy to increase mobility or reflexology to help with pain relief. Others are using their budgets to arrange traditional services in a way that is more flexible and fits with their and their families' needs as a whole. For example, Brian was able to spend his last few months at home with his family, where he wanted to be, because his daughter could arrange for carers to come when she was at work. Hear their full story and others at: www.personalhealthbudgets.dh.gov.uk/About/Stories/

Payment by Results

The Palliative Care Funding Review has been able to build on the work which had previously been undertaken to develop Health Resource Groups and currencies for in-patient specialist palliative care. Their starting point for the challenging area of community-based services was the work on Transforming Community services, and the East Midlands work on currencies and costings for end of life care in the community. Further work to explore the development of tariffs in this area will flow from the review's report and recommendations.

Annex A: Results of the Department of Health’s monitoring of new investment in end of life care, 2010/11

NORTH EAST		**£2,537,000**
5ND	County Durham	£1,253,000
5J9	Darlington	£107,000
5KF	Gateshead	£196,000
5D9	Hartlepool	£40,000
5KM	Middlesbrough	£70,000
5D7	Newcastle	£69,000
5D8	North Tyneside	£208,000
TAC	Northumberland	£74,000
5QR	Redcar and Cleveland	£33,000
5KG	South Tyneside	£135,000
5E1	Stockton-on-Tees Teaching	£296,000
5KL	Sunderland Teaching	£56,000
NORTH WEST		**£9,270,974**
5HG	Ashton, Leigh and Wigan	£271,000
5CC	Blackburn with Darwen	£6,000
5HP	Blackpool	£39,323
5HQ	Bolton	£52,000
5JX	Bury	£170,000
5NP	Central and Eastern Cheshire	£164,085
5NG	Central Lancashire	£425,000
5NE	Cumbria Teaching	£234,000
5NH	East Lancashire Teaching	£702,000
5NM	Halton and St Helens	£346,366
5NQ	Heywood, Middleton and Rochdale	£232,000
5J4	Knowsley	£159,000
5NL	Liverpool	£491,000
5NT	Manchester	£10,000
5NF	North Lancashire Teaching	£669,900
5J5	Oldham	£107,000
5F5	Salford	£177,000
5NJ	Sefton	£142,000
5F7	Stockport	£0
5LH	Tameside and Glossop	£76,300
5NR	Trafford	£95,000
5J2	Warrington	£39,000
5NN	Western Cheshire	£0
5NK	Wirral	£930,000
YORKSHIRE AND HUMBER		**£11,897,400**
5JE	Barnsley	£149,400
5NY	Bradford and Airedale Teaching	£114,000
5J6	Calderdale	£0
5N5	Doncaster	£100,000
5NW	East Riding of Yorkshire	£5,641,000
5NX	Hull Teaching	£347,000
5N2	Kirklees	£416,000
5N1	Leeds	£928,000
TAN	North East Lincolnshire	£824,000
5EF	North Lincolnshire	£454,000
5NV	North Yorkshire and York	£589,000
5H8	Rotherham	£948,000
5N4	Sheffield	£688,000
5N3	Wakefield District	£509,000
EAST MIDLANDS		**£1,926,637**
5ET	Bassetlaw	£19,200
5N7	Derby City	£97,000
5N6	Derbyshire County	£43,186
5PC	Leicester City	£0
5PA	Leicestershire County and Rutland	£0
5N9	Lincolnshire Teaching	£707,000
5PD	Northamptonshire Teaching	£692,000
5EM	Nottingham City	£92,251
5N8	Nottinghamshire County Teaching	£30,000
WEST MIDLANDS		**£9,777,607**
5PG	Birmingham East and North	£1,860,000
5MD	Coventry Teaching	£638,000
5PE	Dudley	£87,607
5MX	Heart of Birmingham Teaching	£494,000
5CN	Herefordshire	£8,000
5PH	North Staffordshire	£76,000
5PF	Sandwell	£282,000
5M2	Shropshire County	£0
TAM	Solihull	£59,000
5M1	South Birmingham	£300,000
5PK	South Staffordshire	£378,000
5PJ	Stoke on Trent	£1,185,000
5MK	Telford and Wrekin	£25,000
5M3	Walsall Teaching	£710,000
5PM	Warwickshire	£208,000
5MV	Wolverhampton City	£0
5PL	Worcestershire	£1,276,000

EAST OF ENGLAND		**£1,723,000**
5P2	Bedfordshire	N/A
5PP	Cambridgeshire	N/A
5PR	Great Yarmouth and Waveney	£128,000
5GC	Luton	N/A
5PX	Mid Essex	£1,316,000
5PQ	Norfolk	N/A
5PW	North East Essex	£246,000
5PN	Peterborough	N/A
5P1	South East Essex	N/A
5PY	South West Essex	£33,000
5PT	Suffolk	N/A
5PV	West Essex	N/A
5P3 5P4	West Hertfordshire AND East and North Hertf	N/A
LONDON		**£8,096,394**
5C2	Barking and Dagenham	£768,000
5A9	Barnet	£411,246
TAK	Bexley	£95,000
5K5	Brent Teaching	£18,000
5A7	Bromley	£207,000
5K7	Camden	£0
5C3	City and Hackney Teaching	£108,000
5K9	Croydon	£312,500
5HX	Ealing	£143,000
5C1	Enfield	£50,000
5A8	Greenwich Teaching	£371,000
5H1	Hammersmith and Fulham	£26,000
5C9	Haringey Teaching	£249,000
5K6	Harrow	£0
5A4	Havering	£1,018,000
5AT	Hillingdon	£543,000
5HY	Hounslow	£80,251
5K8	Islington	£0
5LA	Kensington and Chelsea	£154,800
5A5	Kingston	£19,597
5LD	Lambeth	£27,000
5LF	Lewisham	£175,000
5C5	Newham	£739,000
5NA	Redbridge	£498,000
5M6	Richmond and Twickenham	£373,000
5LE	Southwark	£80,000
5M7	Sutton and Merton	£0
5C4	Tower Hamlets	£416,000
5NC	Waltham Forest	£822,000
5LG	Wandsworth	£112,000
5LC	Westminster	£280,000
SOUTH EAST COAST		**£1,100,289**
5LQ	Brighton and Hove City	£47,000
5P7 5P8	East Sussex Downs and Weald AND Hastings	£106,865
5QA	Eastern and Coastal Kent	£103,000
5L3	Medway	£56,000
5P5	Surrey	£250,424
5P9	West Kent	£115,000
5P6	West Sussex	£422,000
SOUTH CENTRAL		**£5,279,100**
5QG	Berkshire East	£523,000
5QF	Berkshire West	£119,000
5QD	Buckinghamshire	£2,768,000
5QC	Hampshire	£501,000
5QT	Isle of Wight National Health Service	£166,100
5CQ	Milton Keynes	£0
5QE	Oxfordshire	£168,000
5FE	Portsmouth City Teaching	£0
5L1	Southampton City	£0
SOUTH WEST		**£20,833,200**
5FL	Bath and North East Somerset	£653,000
5QN	Bournemouth and Poole Teaching	£1,395,000
5QJ	Bristol	£1,692,000
5QP	Cornwall and Isles of Scilly	£2,320,000
5QQ	Devon	£2,724,000
5QM	Dorset	£1,572,500
5QH	Gloucestershire	£2,324,485
5M8	North Somerset	£570,000
5F1	Plymouth Teaching	£1,126,000
5QL	Somerset	£1,909,000
5A3	South Gloucestershire	£671,215
5K3	Swindon	£525,000
TAL	Torbay	£341,000
5QK	Wiltshire	£1,756,000

Note: PCTs with "N/A" have not provided a return, so their reported new investment is not known. SHA totals include SHA investment.

Annex B: Results of the Department of Health’s monitoring of expenditure on specialist palliative care, 2010/11

Code	PCT Name	SPC Spend	Other Declared Spend	Total Declared Spend (inc. SPC)
ENGLAND (141 PCTs)		**£385,049,137**	**£72,085,240**	**£457,134,377**
NORTH EAST		**£19,153,000**	**£217,000**	**£19,370,000**
5ND	County Durham	£3,621,000	£22,000	£3,643,000
5J9	Darlington	£201,000	£3,000	£204,000
5KF	Gateshead	£1,156,000	£0	£1,156,000
5D9	Hartlepool	£1,218,000	£33,000	£1,251,000
5KM	Middlesbrough	£888,000	£53,000	£941,000
5D7	Newcastle	£2,346,000	£0	£2,346,000
5D8	North Tyneside	£1,737,000	£0	£1,737,000
TAC	Northumberland	£1,845,000	£0	£1,845,000
5QR	Redcar and Cleveland	£858,000	£47,000	£905,000
5KG	South Tyneside	£1,145,000	£0	£1,145,000
5E1	Stockton-on-Tees Teaching	£1,229,000	£59,000	£1,288,000
5KL	Sunderland Teaching	£2,909,000	£0	£2,909,000
NORTH WEST		**£53,658,032**	**£5,677,354**	**£59,335,386**
5HG	Ashton, Leigh and Wigan	£1,338,851	£928,299	£2,267,150
5CC	Blackburn with Darwen	£1,149,000	£136,000	£1,285,000
5HP	Blackpool	£1,177,627	£87,012	£1,264,639
5HQ	Bolton	£1,224,304	£0	£1,224,304
5JX	Bury	£1,183,000	£0	£1,183,000
5NP	Central and Eastern Cheshire	£2,346,044	£48,000	£2,394,044
5NG	Central Lancashire	£1,793,004	£200,000	£1,993,004
5NE	Cumbria Teaching	£2,642,000	£0	£2,642,000
5NH	East Lancashire Teaching	£2,988,000	£357,000	£3,345,000
5NM	Halton and St Helens	£2,728,688	£0	£2,728,688
5NQ	Heywood, Middleton and Rochdale	£1,420,000	£0	£1,420,000
5J4	Knowsley	£1,247,000	£47,000	£1,294,000
5NL	Liverpool	£9,580,000	£2,203,000	£11,783,000
5NT	Manchester	£1,846,888	£0	£1,846,888
5NF	North Lancashire Teaching	£2,551,000	£98,000	£2,649,000
5J5	Oldham	£1,637,800	£81,000	£1,718,800
5F5	Salford	£1,319,000	£120,000	£1,439,000
5NJ	Sefton	£5,948,369	£305,343	£6,253,712
5F7	Stockport	£1,323,976	£0	£1,323,976
5LH	Tameside and Glossop	£1,178,400	£39,100	£1,217,500
5NR	Trafford	£1,584,000	£0	£1,584,000
5J2	Warrington	£1,467,000	£911,000	£2,378,000
5NN	Western Cheshire	£973,081	£116,600	£1,089,681
5NK	Wirral	£3,011,000	£0	£3,011,000
YORKSHIRE AND HUMBER		**£78,587,459**	**£12,015,256**	**£90,602,715**

Code	PCT Name	SPC Spend	Other Declared Spend	Total Declared Spend (inc. SPC)
5JE	Barnsley	£3,403,922	£0	£3,403,922
5NY	Bradford and Airedale Teaching	£8,965,000	£0	£8,965,000
5J6	Calderdale	£743,000	£64,000	£807,000
5N5	Doncaster	£2,110,000	£141,256	£2,251,256
5NW	East Riding of Yorkshire	£21,392,000	£4,821,000	£26,213,000
5NX	Hull Teaching	£1,115,000	£516,000	£1,631,000
5N2	Kirklees	£3,659,000	£2,256,000	£5,915,000
5N1	Leeds	£10,330,000	£1,139,000	£11,469,000
TAN	North East Lincolnshire	£1,001,000	£0	£1,001,000
5EF	North Lincolnshire	£838,000	£0	£838,000
5NV	North Yorkshire and York	£5,498,000	£229,000	£5,727,000
5H8	Rotherham	£2,554,537	£2,300,000	£4,854,537
5N4	Sheffield	£13,494,000	£119,000	£13,613,000
5N3	Wakefield District	£3,484,000	£430,000	£3,914,000
EAST MIDLANDS		**£42,592,722**	**£14,580,714**	**£57,173,436**
5ET	Bassetlaw	£1,095,122	£151,607	£1,246,729
5N7	Derby City	£1,659,000	£370,000	£2,029,000
5N6	Derbyshire County	£2,962,291	£1,263,000	£4,225,291
5PC	Leicester City	£4,381,000	£4,930,000	£9,311,000
5PA	Leicestershire County and Rutland	£10,375,000	£7,311,000	£17,686,000
5N9	Lincolnshire Teaching	£6,973,500	£153,000	£7,126,500
5PD	Northamptonshire Teaching	£7,419,000	£0	£7,419,000
5EM	Nottingham City	£2,649,131	£0	£2,649,131
5N8	Nottinghamshire County Teaching	£5,078,678	£402,107	£5,480,785
WEST MIDLANDS		**£39,324,534**	**£4,802,217**	**£44,126,751**
5PG	Birmingham East and North	£5,241,000	£1,715,000	£6,956,000
5MD	Coventry Teaching	£3,753,100	£98,270	£3,851,370
5PE	Dudley	£753,869	£186,626	£940,495
5MX	Heart of Birmingham Teaching	£1,179,000	£0	£1,179,000
5CN	Herefordshire	£2,624,000	£520,000	£3,144,000
5PH	North Staffordshire	£1,167,000	£132,000	£1,299,000
5PF	Sandwell	£1,740,000	£210,000	£1,950,000
5M2	Shropshire County	£2,030,000	£133,000	£2,163,000
TAM	Solihull	£1,438,000	£0	£1,438,000
5M1	South Birmingham	£2,403,000	£0	£2,403,000
5PK	South Staffordshire	£3,785,000	£320,000	£4,105,000
5PJ	Stoke on Trent	£2,413,000	£0	£2,413,000
5MK	Telford and Wrekin	£1,095,000	£0	£1,095,000
5M3	Walsall Teaching	£1,212,000	£1,367,000	£2,579,000
5PM	Warwickshire	£2,643,565	£81,321	£2,724,886
5MV	Wolverhampton City	£2,565,000	£0	£2,565,000
5PL	Worcestershire	£3,282,000	£39,000	£3,321,000
EAST OF ENGLAND		**£10,109,236**	**£14,523,761**	**£24,632,997**
5P2	Bedfordshire	N/A	N/A	N/A
5PP	Cambridgeshire	N/A	N/A	N/A
5PR	Great Yarmouth and Waveney	£895,000	£25,000	£920,000
5GC	Luton	N/A	N/A	N/A
5PX	Mid Essex	£4,952,000	£12,324,000	£17,276,000
5PQ	Norfolk	N/A	N/A	N/A
5PW	North East Essex	£1,775,000	£1,857,000	£3,632,000
5PN	Peterborough	N/A	N/A	N/A

Code	PCT Name	SPC Spend	Other Declared Spend	Total Declared Spend (inc. SPC)
5P1	South East Essex	N/A	N/A	N/A
5PY	South West Essex	£2,487,236	£317,761	£2,804,997
5PT	Suffolk	N/A	N/A	N/A
5PV	West Essex	N/A	N/A	N/A
5P3 5P4	West Hertfordshire AND East and North Hertfordshire	N/A	N/A	N/A
LONDON		**£52,364,919**	**£7,291,242**	**£59,656,161**
5C2	Barking and Dagenham	£1,449,000	£238,000	£1,687,000
5A9	Barnet	£2,656,000	£0	£2,656,000
TAK	Bexley	£937,000	£56,000	£993,000
5K5	Brent Teaching	£2,213,164	£0	£2,213,164
5A7	Bromley	£2,352,000	£72,000	£2,424,000
5K7	Camden	£2,835,114	£2,075,682	£4,910,796
5C3	City and Hackney Teaching	£1,307,000	£697,000	£2,004,000
5K9	Croydon	£2,259,000	£0	£2,259,000
5HX	Ealing	£2,608,000	£0	£2,608,000
5C1	Enfield	£622,967	£18,000	£640,967
5A8	Greenwich Teaching	£1,636,000	£1,126,000	£2,762,000
5H1	Hammersmith and Fulham	£1,099,000	£0	£1,099,000
5C9	Haringey Teaching	£1,165,000	£0	£1,165,000
5K6	Harrow	£645,000	£0	£645,000
5A4	Havering	£1,715,000	£284,000	£1,999,000
5AT	Hillingdon	£1,246,000	£0	£1,246,000
5HY	Hounslow	£2,315,745	£101,560	£2,417,305
5K8	Islington	£1,766,640	£18,000	£1,784,640
5LA	Kensington and Chelsea	£1,599,956	£0	£1,599,956
5A5	Kingston	£577,633	£0	£577,633
5LD	Lambeth	£1,187,000	£487,000	£1,674,000
5LF	Lewisham	£1,308,000	£0	£1,308,000
5C5	Newham	£2,567,000	£0	£2,567,000
5NA	Redbridge	£1,783,000	£274,000	£2,057,000
5M6	Richmond and Twickenham	£301,000	£0	£301,000
5LE	Southwark	£1,872,000	£29,000	£1,901,000
5M7	Sutton and Merton	£2,954,000	£399,000	£3,353,000
5C4	Tower Hamlets	£3,414,700	£115,000	£3,529,700
5NC	Waltham Forest	£357,000	£1,280,000	£1,637,000
5LG	Wandsworth	£1,222,000	£0	£1,222,000
5LC	Westminster	£2,394,000	£21,000	£2,415,000
SOUTH EAST COAST		**£23,240,202**	**£945,402**	**£24,185,604**
5LQ	Brighton and Hove City	£2,680,000	£0	£2,680,000
5P7 5P8	East Sussex Downs and Weald AND Hastings and Rother	£2,704,398	£692,765	£3,397,163
5QA	Eastern and Coastal Kent	£3,578,000	£0	£3,578,000
5L3	Medway	£1,205,088	£212,637	£1,417,725
5P5	Surrey	£6,268,716	£0	£6,268,716
5P9	West Kent	£3,019,000	£0	£3,019,000
5P6	West Sussex	£3,785,000	£40,000	£3,825,000
SOUTH CENTRAL		**£28,892,907**	**£1,720,292**	**£30,613,199**
5QG	Berkshire East	£2,547,231	£0	£2,547,231
5QF	Berkshire West	£3,398,000	£0	£3,398,000
5QD	Buckinghamshire	£2,644,000	£0	£2,644,000
5QC	Hampshire	£10,296,528	£917,492	£11,214,020

Code	PCT Name	SPC Spend	Other Declared Spend	Total Declared Spend (inc. SPC)
5QT	Isle of Wight National Health Service	£2,063,541	£0	£2,063,541
5CQ	Milton Keynes	£1,139,000	£411,000	£1,550,000
5QE	Oxfordshire	£1,923,607	£17,800	£1,941,407
5FE	Portsmouth City Teaching	£2,280,000	£0	£2,280,000
5L1	Southampton City	£2,601,000	£374,000	£2,975,000
SOUTH WEST		**£37,126,126**	**£10,312,002**	**£47,438,128**
5FL	Bath and North East Somerset	£675,000	£0	£675,000
5QN	Bournemouth and Poole Teaching	£1,418,000	£610,000	£2,028,000
5QJ	Bristol	£3,446,000	£474,000	£3,920,000
5QP	Cornwall and Isles of Scilly	£2,623,000	£4,972,000	£7,595,000
5QQ	Devon	£3,690,000	£0	£3,690,000
5QM	Dorset	£4,803,000	£0	£4,803,000
5QH	Gloucestershire	£9,107,886	£224,787	£9,332,673
5M8	North Somerset	£711,000	£0	£711,000
5F1	Plymouth Teaching	£2,257,000	£3,029,000	£5,286,000
5QL	Somerset	£1,824,000	£0	£1,824,000
5A3	South Gloucestershire	£710,240	£459,215	£1,169,455
5K3	Swindon	£2,029,000	£543,000	£2,572,000
TAL	Torbay	£1,794,000	£0	£1,794,000
5QK	Wiltshire	£2,038,000	£0	£2,038,000

Note: PCTs with "N/A" have not provided a return, so their reported spend is not known.

Breakdown of End of Life Care Investment classified as “Other”

PCT	Total spend classified as "Other"	Detail	Cost
Barking and Dagenham	£238,000	Palliative Care Network	£238,000
Bath and North East Somerset	£458,000	Gold Standards Framework	£25,000
		CHC Nurse supporting fast track / terminally ill patients	£43,000
		CHC fast track / terminally ill patients	£250,000
		EoLC Project Management	£40,000
		Nursing Support to GP's on EoLC planning and register	£10,000
		Community Nursing	£90,000
Berkshire East	£167,000	Intermediate EOL Care Packages	£150,000
		GPSI	£17,000
Birmingham East and North	£37,000	Specialist Pharmacists	£37,000
Blackpool	£23,013	Macmillan GP (funded by Macmillan and GP employed by PCT)	£23,013
Brighton and Hove City	£7,000	End of Life Information resource (carers)	£7,000
Cornwall and Isles of Scilly	£61,000	GSF training in Care Homes and Community Hospitals	£61,000
Derbyshire County	£36,000	GP EOL Facilitator Sessions (training and engagement)	£36,000
Devon	£1,125,000	Hospital services incl drugs	£1,125,000
Dorset	£10,000	GP EOLC Clinical Lead	£10,000
Great Yarmouth and Waveney	£64,000	End Of Life GP Facilitator	£25,000
		Marie Curie Delivering Choice Team	£39,000
Halton and St Helens	£346,366	24/7 advice (Willowbrook)	£65,335
		End of Life Facilitator Post (Halton Haven)	£77,000
		HBC End of Life	£204,031
Havering	£284,000	Pallitative Care network	£284,000
Heart of Birmingham Teaching	£284,000	NHS investment for End of Life provision	£284,000
Herefordshire	£130,000	Community support for people wishing to die at home (Children)	£111,000
		Palliative district nursing	£19,000
Hillingdon	£300,000	Four Palliative beds Care in community hospital	£300,000
Isle of Wight National Health Service	£50,266	Psychologist	£50,266
Lewisham	£86,000	GSF Facilitator for GPs/LES/Improvement Officer hospital care	£86,000
Lincolnshire Teaching	£110,000	Palliative Care Consultant recruitment	£110,000
Mid Essex	£300,000	Cancer Drugs (estimated palliative care element)	£300,000
Newham	£115,000	Community Equipment	£50,000
		Psychologist	£65,000
North Lancashire Teaching	£35,000	Going for Gold Development Programme	£12,000
		Macmillan GP	£23,000
North Yorkshire and York	£26,000	Patient Care Pathway Audit	£26,000
Oldham	£26,000	Citizen Advice Bureau	£26,000
Oxfordshire	£16,000	Community Equipment for EoLC	£15,000
		Patient held records	£1,000
Redbridge	£274,000	Pallitative Care network	£274,000
Richmond and Twickenham	£45,000	LCP in the community and GP Clinical lead	£45,000
Sandwell	£264,000	Consultant in Palliative Medicine	£145,000
		Community Palliative care teams	£80,000
		Welfare Benefits Worker	£0
		Volunteer Co-ordinator	£4,000
		Complimentary Therapy	£0
		Supportive Care including transport, raising awareness, advocacy, bereavement support groups etc	£0
		Medical Secretary to support Consultant's post	£10,000
		Strategic Partner to do Feasibility Study	£25,000
		Personal Health Budgets	£0
Sheffield	£366,000	Home care packages to allow patients to die at home	£366,000
Somerset	£1,117,000	Respite Care Facilities	£70,000
		CHC Fast Track Activity increase	£981,000
		CHC Staffing requirements to support Fast Track activity increases	£66,000
South Birmingham	£20,000	Bereavement Support	£20,000
South Staffordshire	£31,000	East palliative care basic care service (palliative care support team community project)	£31,000
Tameside and Glossop	£29,000	GP Facilitator	£29,000
Torbay	£50,000	funding for substantive End of Life Lead Commissioner	£50,000
Wakefield District	£90,000	non recurrent investment(bereavement support,EOL Comms and COPD pilot)	£90,000
Walsall Teaching	£656,000	Development & commissioning of new Palliative Care centre	£656,000
Waltham Forest	£303,000	Palliative Care Network	£303,000
Warwickshire	£14,000	GP with special interest	£14,000
West Kent	£11,000	GP / Practice Based Commisisoning support	£11,000
West Sussex	£57,000	EOLC Facilitator	£57,000
Westminster	£31,000	Dementia Voice Nurse	£31,000
Wiltshire	£42,000	CHC Team Costs	£42,000

Note: Some costs rounded to the nearest £1,000

Annex C: Hospice Capital Grant Scheme for 2010/11

List of projects funded

Hospice	**SHA**	**Project**
Ashgate Hospice	East Midlands	In-patient unit/Refurbishment
Barnsley Hospice	Yorkshire and Humber	Day care unit/ Refurbishment
Beaumond 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
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
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
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
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
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

Annex D: List of current research projects funded by Department of Health

Reference	Project Title	Contracting Institution	Lead researcher	Start date	End date	Award total
i4i						
II-FS-0509-12006	Fully Flushable Sustainable Ostomy Pouch (SUSOSTOMY)	University of Leeds	Dr R Blackburn	01/03/2010	28/02/2011	£ 99,759.00
II-FS-0109-11081	Enabling Independence by Means of Upper Limb Kinetic Tremor Suppression	North Bristol NHS Trust	Dr R Jones	01/09/2009	30/11/2010	£ 97,275.00
HTD 541	A respiratory aid and portable artificial lung	Haemair Ltd	Bill Johns	01-Sep-09	31-Aug-12	£ 291,632.00
II-3B-0109-10043	GO2-digital (New Generation Oxygen Supplies with Digital Patient Interface)	Luxfer Gas Cylinders	Dr Warren Hepples	01-Sep-10	28-Feb-13	£ 344,345.00
Research for Patient Benefit						
PB-PG-0808-17311	Development, effectiveness and cost-effectiveness of a new respiratory and palliative care out-patient breathlessness support service	King's College Hospital NHS Foundation Trust	Professor John Moxham	01/03/2010	29/02/2012	£ 249,994.00
PB-PG-0107-12109	Implementation of an end of life care pathway in intensive therapy units based in an inner London teaching hospital: does it make a	King's College Hospital NHS Foundation Trust	Professor Irene Higginson	01/04/2008	30/09/2011	£ 260,843.00

	difference?					
PB-PG-0407-13349	Planning for end-of-life care in dialysis patients: attitudes and perceptions	East & North Hertfordshire NHS Trust	Mrs Maria Da Silva-Gane	01/10/2008	30/09/2011	£ 235,563.00
PB-PG-0808-16126	Evaluation of pilgrims hospices rapid response community end of life service in East Kent	East Kent Hospitals University NHS Foundation Trust	Dr Clare Butler	01/12/2009	30/04/2012	£ 227,186.00
PB-PG-0609-19059	Development and evaluation of an intervention to assist lay carers to provide physical care to family members with cancer at end-of-life	Manchester Teaching Primary Care Trust	Professor Karen Luker	06/04/2011	05/04/2013	£ 243,865.00
PB-PG-0909-20188	What do carers of patients with cancer & advanced progressive illness find burdensome during the final year of life; how might this be alleviated by the adoption of an alert system	Halton and St Helens Primary Care Trust	Professor Barbara Jack	01/04/2011	31/05/2013	£ 198,880.00
Programme Grants for Applied Research						
RP-PG-0606-1005	Changing practice in dementia care in the community: developing and testing evidence-based interventions, from timely diagnosis to	Central and North West London NHS Foundation Trust	Professor Steve Iliffe	01/08/2007	31/07/2012	£ 1,999,583.00

	end of life.					
RP-PG-0407-10147	Medical crises in older people	Nottingham University Hospitals NHS Trust	Professor John Gladman	01/08/2008	31/07/2013	£ 1,997,368.00
RP-DG-0709-10162	C-CHANGE: Delivering quality and cost-effective care across the range of complexity for those with advanced conditions in the last year of life	King's College Hospital NHS Foundation Trust	Dr Fliss Murtagh	01/10/2010	30/09/2011	£ 99,052.00

Policy Research Programme

053/0008	Defining the palliative care needs of people with severe Parkinsonian disorders	KCL	Professor Nigel Leigh	01/12/2006	31/12/2010	£ 228,675.00