End of Life Care Strategy

Fourth Annual Report

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

Dame Cicely Saunders
Founder of the Modern Hospice Movement

October 2012

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Foreword

The NHS is currently undergoing transformational change. This includes a complete revision of the Department of Health itself, the emergence of the NHS Commissioning Board and the development of a new Improvement Body.

Over the past few years end of life care has itself been in the process of transformational change. That change has been driven by innumerable partnerships, working to a common agenda set out in the End of Life Care Strategy published in 2008. This report shows how far we have come in just four years. As we handle the process of transition from the old structures to the new, it is salutary to revisit the strategy's big ideas and to see how they have been turned from paper to reality.

To tackle the taboo on discussing death, the Strategy proposed *"A national coalition to raise the profile of end of life care and to change attitudes to death and dying in society".* The National Council for Palliative Care has set up the Dying Matters coalition. From a standing start in 2009 it now has more that 20,000 members. This year's Awareness Week has been evaluated as reaching more than 170,000 people through events and activities run by Dying Matters members, while the Dying Matters website received record numbers of visitors, with almost 100,000 page views - an increase of 230% on last year's awareness week.

"Care plans, including the person's preferences, wishes and views on resuscitation, should be available to all who have a legitimate reason to access them … Holding the plan electronically will facilitate this…" Electronic Palliative Care Coordination Systems (EPaCCS for short, or locally named like London's Coordinate My Care) are now either in place or in development across the country. More to the point, outcomes data show that they are making a major contribution to enabling people to be cared for and to die in their place of choice.

"Following appropriate modification and piloting, regular surveys of bereaved relatives will be commissioned by the Department of Health ...". We have just had the results of the first national VOICES survey. This gives us the first systematic account of how people actually experience care in the last three months of life, whether they are in hospital, in a care home, a hospice or at home, or whether their care involves a combination of different settings. This sort of information is vitally important to local providers and commissioners – not just to show them how they compare, but to help them to track improvement.

"...The Department of Health will commission the development of an End of Life Care Intelligence Network." The National End of Life Care Intelligence Network took off in 2010. Its members – data owners and users from the statutory and voluntary sectors – have enabled South West Public Health Observatory to bring together different datasets which have transformed end of life care intelligence from something relying almost entirely on mortality data, into a wide range of themed

reports and locality profiles. *What We Know Now…* demonstrates the range of intelligence available now that simply did not exist in 2008.

These are just some of the most notable achievements. This report goes into more detail, including examples of how different areas are using the national tools and intelligence and innovating locally.

But we haven’t finished.

The challenge now is to make sure that we take all of this progress into the new organisations. We have demonstrated that end of life care can bring together health, social care and the voluntary sector, to the benefit of those approaching the end of life, their carers and families. This is truly an area of work which unites rather than divides.

We have benefited hugely from our committed champions across the organisations and across the sectors. Inevitably, in such a major reorganisation, some of them will move away. Some will be able to promote this work from new positions – for my part, I shall be as committed in my new role at Imperial as I was in my old one at Marie Curie. We have sadly to relinquish Professor Sir Mike Richards, who has provided such outstanding leadership as National Clinical Director for End of Life Care, to new responsibilities but I know that he will not miss any chance to improve this area of care too. And we are delighted that Dr Martin McShane will be the new champion for end of life care in the NHS Commissioning Board.

The End of Life Care Strategy says “How we care for the dying is an indicator of how we care for all sick and vulnerable people. It is a measure of society as a whole and it is a litmus test for health and social care services”. This is as true today as it was in 2008.

This report is a chance to celebrate the progress we have made, and to take stock for the challenge ahead.

Sir Tom Hughes-Hallett
Chairman, End of Life Care Strategy Implementation Advisory Board

Executive Summary

Dear Secretary of State

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

Last year I was able to report a growing recognition of the importance of end of life care, against a backdrop of preparation for the full implementation of the NHS reforms. This year the reforms have moved to centre stage but end of life care has continued to be a priority, as was evidenced by the number and range of case studies offered for inclusion in this report. We have seen important developments in embedding many of the key elements set out in the Strategy.

We are also able to point to tangible progress in improving end of life care. Deaths in usual place of residence (DiUPR) – the main marker of progress for the Strategy as well as the first Key Performance Indicator for our Quality, Innovation, Productivity and Prevention (QIPP) workstream - are continuing their steady rise, accompanied by a drop in deaths in hospital. I can report that, nationally, 42.4% of people are now dying at home or in a care home. While this does not necessarily capture individual patient choice it is nonetheless a good proxy. I am especially encouraged to note that progress is visible in all of the old Strategic Health Authority regions, regardless of their baseline. London, which had the lowest starting point, has made progress comparable to the South West, which started highest.

Dying Matters continues to make major strides towards engaging the public and tackling the taboo of discussing death and dying. Its membership now stands at more than 20,000. This year’s Awareness Week in May was marked by a vast amount of local activity, suggesting that Dying Matters’ members are taking ownership of the agenda in their area. Over that week there were also more than 400 pieces in the print media, including mainstream national papers. This is in marked contrast to the picture when the National Council for Palliative Care accepted the challenge to set up the Coalition in 2009.

Find Your 1%, which aims to engage GPs in identifying the individuals on their lists who might be in their last year of life, so that they can undertake end of life care planning with them, has reached its midpoint target of 1,000 GPs signed up by August 2012.

We are also starting to see excellent results from Electronic Palliative Care Coordination Systems (EPaCCS). These record people’s actual choice for their place of care; and where they are best established they are already showing significant reductions in hospital deaths and as many as 80% of people dying in their preferred place. EPaCCS are now spreading rapidly across the country, supported by the National End of Life Care Programme (NEoLCP), an Information Standard and work on interoperability. The more they become the norm the more we can rely on the DiUPR data as a close match for actual choice.

We also have the results from the first ever national VOICES survey of bereaved relatives. These provide a mine of fascinating information on the quality of care delivered in the last three months of life. Not surprisingly, hospice care is the most highly rated, followed by care at home. However, care in care homes is only narrowly behind. Care provided to people dying in hospitals was rated much more poorly. This is an area which needs to be given very high priority, as hospitals are likely to remain the most common place of death, even with a shift to community-based care.

VOICES still has much to tell us in the freetext responses, which are currently being anonymised to make the material useable for research. While many comments highlighted poor experience this was often in order to contrast it with better care in a different setting or from different staff. The single longest contribution, which ran to 51 pages, was about excellent care.

VOICES is being run now for its second year. At present we can analyse the data to PCT cluster level, which already shows wide variations. The cumulative data from successive surveys will allow us to look in more detail at different localities as well as to start tracking progress in the different care settings. It is also the source of an Indicator in Domain 4 of the NHS Outcomes Framework, ensuring that it will be a priority for the NHS.

Picking up the challenge illustrated by the VOICES findings, the NEoLCP's Transform programme for the acute sector started working with 25 Trusts. Because of intense interest another 40 hospitals will be attending shared learning events this autumn. Transform is based on the Route to Success for the acute sector. The programme is centred on five key enablers – Electronic Palliative Care Coordination Systems, Advance Care Planning, the AMBER Care Bundle, the rapid discharge home pathway, and the Liverpool Care Pathway.

The National End of Life Care Intelligence Network has added significantly to the information available and useful to both commissioners and providers. Its locality profiles now include information about social care and can be viewed at local authority level. A summary of *What We Know Now* brings together key information which was not available before the Network started its work. From its new home in Public Health England it will continue to provide the information commissioners and providers need to carry out their roles. For example, it will continue to host the End of Life Care Quality Assessment (ELCQuA) tool for benchmarking and tracking progress, revised to align it to the new NICE Quality Standard for end of life care for adults. All of this is readily available on the Network's website.

In April responsibility for the End of Life Care Strategy will move from the Department of Health to the NHS Commissioning Board where it will be the responsibility of the Board's Medical Directorate. The work will form part of Domain 2 – Long Term Conditions. This makes a good match. Much of the work which is now bearing fruit for end of life care – EPaCCS, and integrated care, for example – will be of interest in improving care for conditions such as dementia, helping to deliver on the Prime Minister's Dementia Challenge. End of life care will also have relevance to the other Domains, whether they focus on urgent care or on patient experience. The second VOICES survey will add richness and depth to our understanding of how people experience end of life care.

As Strategic Health Authorities and Primary Care Trusts wind down, so Clinical Commissioning Groups (CCGs) are beginning to pick up their role in commissioning and promoting these services. The NEoLCP has been working with a network of about a hundred CCGs to ensure not only that they know about the wealth of resource already available to them on end of life care, but that we listen to them and tailor support to their needs. The NEoLCP has also been supporting a network of about 360 end of life care facilitators, who are based in all parts of the service, and has established a new group of more than a hundred social care champions. These people will help to ensure that end of life care is embedded in new plans in the future health and social care landscape.

Ministers have made a commitment to evaluate progress on end of life care to determine whether it is possible to introduce a right to choose to die at home. Over the next year the focus will continue to be on supporting people to be cared for and to die in their place of choice, providing community-based services to enable this to happen. Integration of services is key to this and will be a theme for the new Improvement Body, which will enable us to continue to work with our range of partners in the statutory, voluntary and private sectors. At the same time the Transform programme will continue to support improvement in end of life care in hospitals.

We shall also see progress on Palliative Care Funding, as the eight pilots start to generate the data needed to take forward the work started by the independent Palliative Care Funding Review.

The progress we have seen to date is the summation of a great deal of work by a wide range of individuals including those in the Strategic Health Authorities and Primary Care Trusts, as well as the National End of Life Care Programme. I should like to take this opportunity to offer them my personal thanks.

It has been a privilege to lead work on end of life care. I am delighted to be able to hand it on to Martin McShane in such good shape.

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

Chapter 1: Meeting the challenges of end of life care

End of Life Care and the NHS Commissioning Board

Responsibility for end of life care, and for the End of Life Care Strategy, is to move from the Department of Health to the NHS Commissioning Board from April 2013. As it is an overarching topic, the work will necessarily span the three Domains of the NHS Outcomes Framework that are the responsibility of the Board's Medical Directorate. However, its 'home' Domain will be Long Term Conditions. This should ensure continuity and build on the progress made since the Strategy was launched in 2008.

Clinical Commissioning Groups – North Hants CCG

North Hants CCG has developed and implemented an end of life care pathway for all patients thought to be in the last 12 months of life. This has been a collaborative effort between the CCG, Hampshire Hospitals Foundation Trust, St Michael's Hospice, Southern Health and Adult Social Services. The development of six integrated care teams covering the area has been key to the pathway. Two of the teams have a social worker directly involved as a pilot. The 'Find the1%' campaign has been used to identify end of life patients and this has been linked to the long term conditions work through the use of the Adjusted Clinical Groups (ACG) GP-based risk stratification tool. The local Electronic Palliative Care Coordination System/ End of Life Care Locality Register is about to go live which will be vital for communication between the agencies involved in the care of these patients. The CCG has also developed a 'Gold card' scheme which identifies these end of life care patients to health and social care professionals as well as helping patients access appropriate care.

Charlotte Hutchings, EoLC Lead, North Hampshire CCG

The Mandate, NHS Outcomes Framework and Commissioning Outcomes Framework

The NHS Commissioning Board will work to a mandate set by the Department of Health. The draft Mandate went out to consultation in July, with a deadline for responses of 26 September. The final mandate will be published in the autumn to come into force in April 2013.

The draft mandate sets objectives for improving outcomes and reducing inequalities in each of the five Domains of the NHS Outcomes Framework. Domain 4 of the Framework focuses on ensuring that people have a positive experience of care and includes an Indicator based on the VOICES survey. This uses the views of bereaved relatives to assess the quality of care provided to dying people and their families across the range of care settings and conditions, as well as by geography.

The NHS Commissioning Board Authority is developing a Commissioning Outcomes Framework which will translate the outcomes in the NHS Outcomes Framework into measures which make sense at clinical commissioning group population level. This will have its first iteration in 2013/14. The NHS Commissioning Board will decide priorities for future development in discussion with partner organisations, including how to reflect indicators for the NHS Outcomes Framework in future iterations of the Commissioning Outcomes Framework.

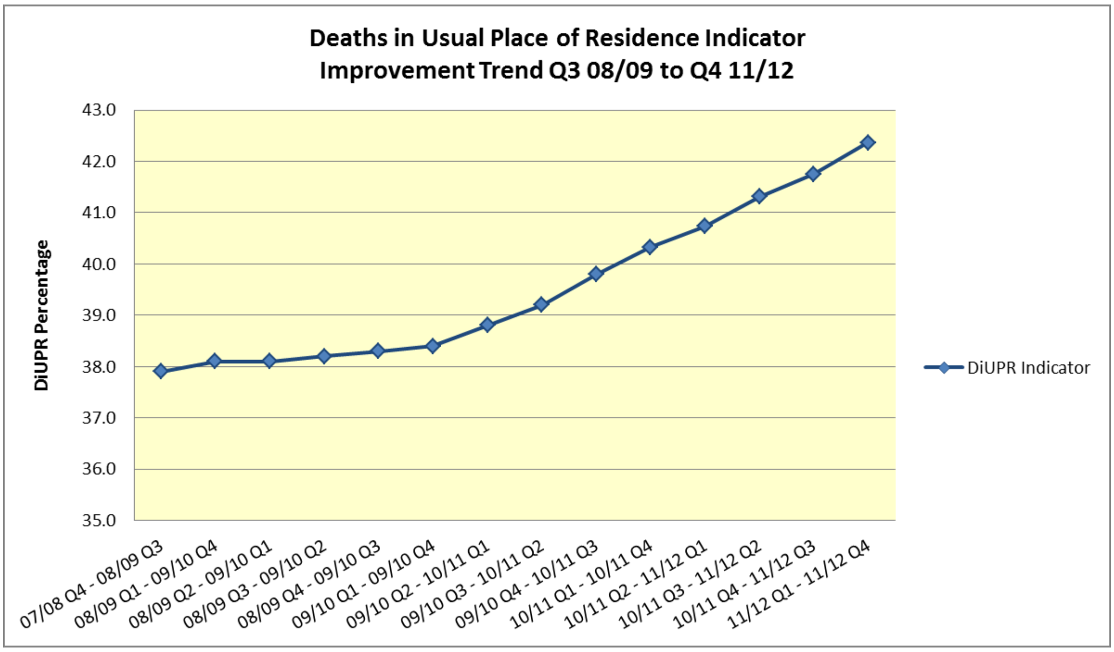
The National End of Life Care Programme

Since 2008 implementation of the Strategy has been supported by the National End of Life Care Programme (NEoLCP). The NEoLCP’s collaborative working with a wide range of partners in the statutory, voluntary and private sectors has been a critical factor in developing and maintaining engagement in this area, and in driving the encouraging progress towards the Strategy’s objectives. An external evaluation highlighted the NEoLCP as a ‘trusted hub’ and a driving force for change.

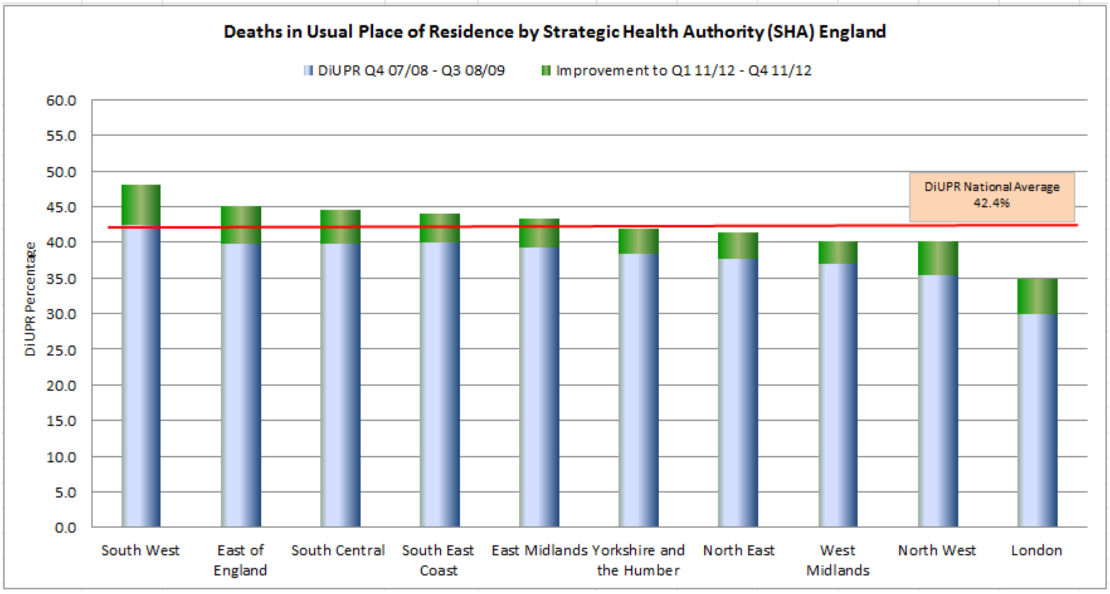
The health and care system requires nothing less than transformational change to ensure continued provision of high quality, affordable services, free to users at the time and point of need. Given this context – no significant growth in resources and major system change – there needs to be an integrated, systematic approach to large scale change. Improvement services are a critical component in the mix and a new Improvement Body (nIB) is being established to support this. The nIB will be formed from elements of some current improvement bodies, and this includes the NEoLCP.

Quality, Innovation, Productivity and Prevention (QIPP)

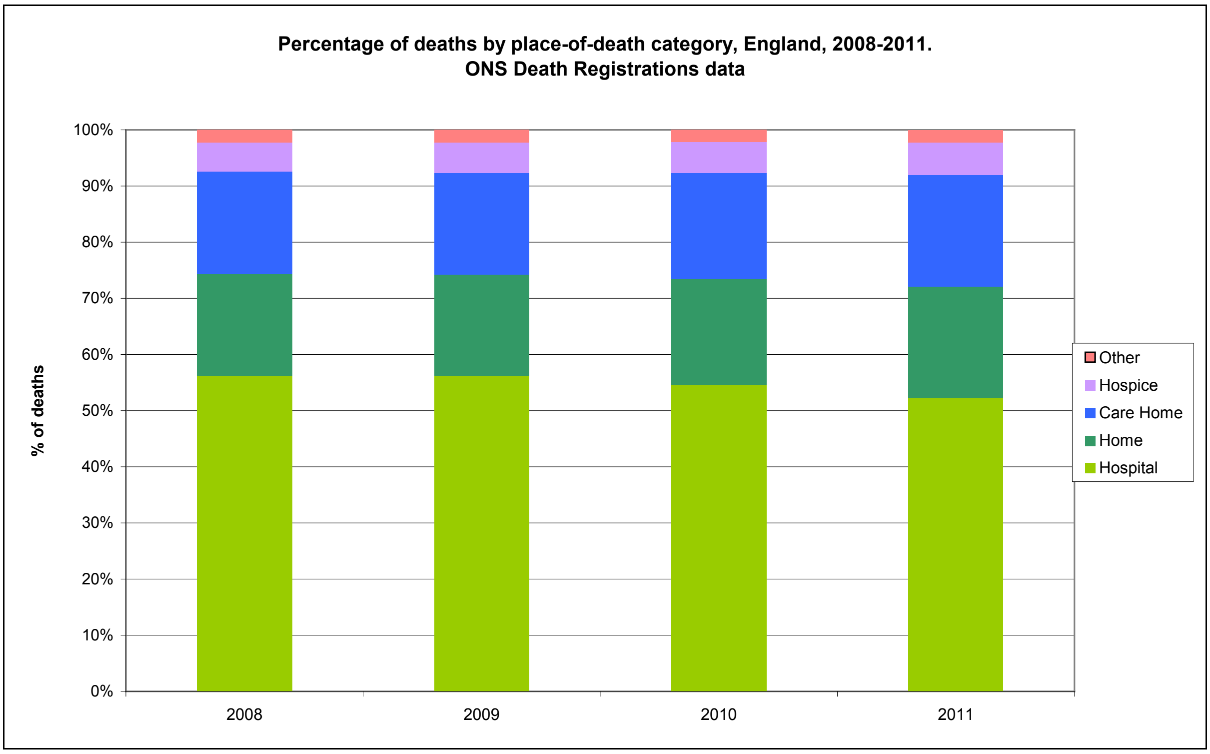
End of life care has benefited from its status as one of the Quality, Innovation, Productivity and Prevention (QIPP) national workstreams. This has adopted, as a key performance indicator (KPI), the measure we have been using for the End of Life Care Strategy itself: to improve the proportion of people who die in their usual place of residence, which combines people’s own homes and care homes. We are now able to track this on a quarterly basis using mortality data from the Office for National Statistics. These data show a steady improvement in this KPI at both national and old Strategic Health Authority levels.



It is especially encouraging to note that it is not just the areas which have historically performed well which have improved here. We are able to see similar improvements in the South West, which had the highest baseline, and in London which had the lowest. The continuing improvement in the South West also suggests that we have not yet reached the ceiling: there is still headroom for even the best performers to do better.



Previous reports have illustrated full calendar year data on place of death across the range of settings – hospital, care home, home, hospice and other. 2011 data show the increase in deaths at home to 21.8% and in care homes to 19.4%, while hospital deaths dropped to 51%.



We have been working to develop two additional KPIs to help drive and measure improvements in both quality and productivity. KPI2, "To reduce the number of hospital admissions of 8 days or more, which end in death. This is based on clinical need, quality of care and individuals' preferences" is currently being piloted in five areas to ensure that it is practical and that it does not introduce any perverse incentives. Work on developing a third KPI has focussed on emergency admissions in the final year of life. Analysis of the data suggests that this is a more complex area than expected. The current intention, being tested for validity by further analysis, is to develop a dashboard mapping emergency admission by condition so that local commissioners can target their attention where it is most needed.

The QIPP work for end of life care has concentrated on the early part of the pathway, identifying people who are approaching the end of life and planning their care, and on care coordination. Key initiatives involved – Dying Matters, Find Your 1%, Advance Care Planning, Electronic Palliative Care Coordination Systems (EPaCCS), the Transform programme for the acute sector, VOICES and Do Not Attempt Cardiopulmonary Resuscitation – are reported on throughout this document.

Palliative Care Funding

The Coalition agreement included a commitment to developing a per-patient funding system 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."*

The final report of the independent Palliative Care Funding Review in July 2011 set out a series of recommendations to create a fair and transparent funding system for palliative care. The Review found the current system "overly complicated, difficult to navigate and not joined-up enough, leading to a lack of fairness and transparency for commissioners, providers and patients. The system is focused on providers and not patients."

To take this work forward the Department has identified eight pilot sites, seven for adult and one for children's services, which between them bring together 93 separate organisations across the statutory and voluntary sectors. They will gather the data we need on a range of patient characteristics, such as problem severity, functional level and phase of illness, to understand the national picture for palliative care resource use and associated costs. These data will inform the development and refinement of a classification system categorising palliative patients according to level of need, and attach resource use/ costs to each of the levels of need in the classification system, which will support the tariff development.

The Social Care White Paper - *Caring for our future: reforming care and support*

End of life care spans both health and social care. QIPP highlights this connection: its emphasis on quality means providing good care where people want it, in the community, while the focus on productivity means avoiding unnecessary hospital stays. Both of these mean improving community-based services, including end of life care in care homes. This is reflected in the White Paper on social care, *Caring for our future: reforming care and support,* published by the Department of Health in July, which says:

> *"There has also been strong support for the [Palliative Care Funding] Review's recommendation that 'once a patient reaches the end of life stage, and is put on the end of life locality register, all health and social care should be funded by the state and be free at the point of delivery'. We think there is much merit in providing free health and social care in a fully integrated service at the end of life."*

The White Paper goes on to say that the Government will work with the Palliative Care Funding pilot sites to collect the vital data and information needed to assess this proposal, and its costs. A decision on including free social care at the end of life in the new funding system will be informed by the evaluation of the pilots, and an assessment of resource implications and overall affordability.

In recognition of the scale of the task in getting these issues right, the Government has doubled its investment in the pilot sites from £1.8 million to £3.6 million to ensure we have the information needed for implementation.

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

The Information Strategy
Dying Matters
The National End of Life Care Intelligence Network and Public Health England
Electronic Palliative Care Coordination Systems (EPaCCS) and the Information Standard
VOICES
Equality Issues and Equality Impact Assessment
Research

"It is good some of these questions are being asked."
"I am really passionate that lessons are learnt."
"I am writing this for all the people who are completely at the mercy of the system and have no-one to be an advocate for them."
"I found it cathartic to write it down".
"I am disgusted with X hospital and her treatment there. Ageism is rife".

First national VOICES survey of bereaved people, July 2012

The Information Strategy

In May the Department published its information strategy - *The power of information* – which sets a ten-year framework for transforming information for the NHS, public health and social care. The focus is on improving access to information and ensuring the support needed to use and understand it. It is about making sure that everyone benefits equally from information about care services. It also emphasises how health and care professionals can use connected information and new technology to join up and improve services, to inform the decisions they make and to help deliver safer, more integrated care.

There is a range of work going on in just these areas to implement the End of Life Care Strategy.

Dying Matters

The Dying Matters national coalition was set up in 2009, led by the National Council for Palliative Care, to tackle the taboo on discussing death, dying and bereavement. Since then it has, year on year, increased its membership, reach and impact.

Membership now stands at over 20,000, including charities, care homes, hospitals, hospices, funeral directors, legal and financial organisations and major employers.

Dying Matters Awareness Week, which ran this year from 14-20 May 2012, is for many members the focus of their activities. ComRes research for the Awareness Week found that more than three-quarters of the public agree that if we felt more comfortable talking about dying, death and bereavement it would be easier to have our end of life wishes met. This will be supported by the wealth of activity during the Week. Highlights included:

- Events and activities by Dying Matters members directly reached over 170,000 people, with investment from members amounting to £110,000 and with over 11,000 hours of volunteer time provided.

- Extensive media coverage for Dying Matters Awareness Week, with 400 separate pieces of media coverage, including articles in six national newspapers, including a powerful article in the Daily Telegraph by the Archbishop of York, Dr John Sentamu, and across health and social media. There was also substantial broadcast coverage, including on BBC Breakfast TV, BBC Radio 4, BBC Radio 5 and across regional media.

- The Dying Matters website www.dyingmatters.org received record numbers of visitors, with almost 100,000 page views (an increase of 230% on last year's awareness week) and significant increases in social media followers. Social networking enables dialogue and direct messaging from the public and all posts / tweets / comments are monitored providing feedback such as:

  "'My Grandmother sadly passed away last Friday. Prior to her passing I found your website and spent some time reading through all the information on it. I believe that this helped me to prepare for her death, and it certainly gave me the confidence to be with her, before, during and after she had departed. I now feel very differently about death and dying, and firmly believe that it truly does matter how, when and where we die and it should not be hidden away and feared"

- The range of free postcards and posters for the awareness week, focusing on the small actions that individuals, organisations and communities can take, proved to be a real hit with excellent feedback received. In all, over 200,000 Dying Matters promotional items were distributed in the run up to the awareness week.

- *Final Chapters*, the first ever creative writing competition on end of life, received a staggering 1,400 entries. Winning and highly commended entries, which were read out by actors Peter Eyre and Barbara Flynn, were announced at a highly successful event during the awareness week hosted and supported by BT and chaired by publisher and writer Carmen Callil.

Cheshire and Merseyside Community Engagement Initiative on Death, Dying and Loss

The 2008 End of Life Care Strategy called death “the last great taboo in our society”. The North West Clinical Pathway Group (2008) identified as one of its 11 key recommendations “A public campaign should be established to raise awareness about end of life care resulting in a more open conversation within society which also engages people’s views about death and dying”. This recommendation was mirrored in the evaluation of the Merseyside and Cheshire Cancer Network (MCCN) Dying Matters Week in 2010.

North West Multi-Professional Education and Training Levy (MPET) monies were identified by MCCN to engage the public at the local level and build on the work of the Dying Matters Coalition. The plan was to work with the local hospices or end of life care Locality Groups, with a named individual taking the lead in organising a number of community engagement events.

This approach had broad support across the network, as it did not focus on a single period of time, such as the national Dying Matters week, but would be continued over weeks and months and would work beyond health services. To support the hospice/locality lead(s) the following was planned and delivered.

Mary Mathieson, Director for Conversations for Life, held a workshop for all leads, explaining the concept of community engagement and how to go about identifying and engaging with up to 30 community leaders. She then held a one day event local to each area, with the hospice/locality lead and the community leaders, which was followed up with a further half day session with the same group entitled “moving to action”, helped the group to plan what they did over the following weeks and months.

There were funds to support the local action plans and there was support from a media company, secured and funded through the Network to work in a bespoke way with each local team. Each lead was asked to submit their community engagement plan, with a progress report, including how funding had been committed part way through and at the end of the year.

Since 2011, six areas have held community engagement events (Wirral, Southport, Aintree and Halton, Central and South Liverpool and Western Cheshire). These events have been well received. The various organisations have established community groups to discuss the topic of death, dying and loss in their own communities and follow up meetings have occurred in autumn 2011 and in 2012.

These groups are either linked to current groups, for example, LINKs (local involvement networks) in Halton or new Groups, The Bucket Group, in Central and South Liverpool, and Dying to Know Group, supported by Voluntary and Community Action Wirral, and Western Cheshire Sub Group – Living Well Dying Well. Other organisations across the network have become involved e.g. The Salvation Army, local sixth form colleges etc. and are supporting the local end of life care teams to drive this forward.

An evaluation of this initiative is being undertaken to analyse the changes as a consequence of this piece of work. The next stage is to look at the future sustainability of the groups and to link to the public health agenda.

Elaine Owen, End of Life Care Service Improvement Lead for Acute and Specialist Services. Elaine.Owen@mccn.nhs.uk

- The launch of the Small Actions, Big Difference photography exhibition featuring work by the photographer Nadia Bettega, showing the differences that can be made at the end of life. Following a highly successful launch and national media coverage, this is now touring the country and is available to Dying Matters members.

- The Awareness Week launched two new short films which are available to view at www.dyingmatters.org. *Last Laugh*, produced by Picturewise Productions with support from Dying Matters Bolton, St Anne's Hospice in Manchester and Bolton Hospice, features Alexei Sayle exploring the value of humour with terminally ill people, whilst *I didn't want that* examines what happens if you don't make your end of life wishes known.

- All Dying Matters materials have been produced in partnership with people with personal experience to ensure the language and tone resonates with the public.

- A new leaflet entitled *Time to Talk* focusing on opening up conversations with people with dementia (produced on request of GPs), was launched in Parliament by the Minister for Care Services, Paul Burstow MP, APPG Chair, Fabian Hamilton MP, National Clinical Director for Cancer and End of Life Care, Professor Sir Mike Richards, and Dying Matters Chairman, Professor Mayur Lakhani.

- Dying Matters' 30 minute film *Dying to Know* was accepted to be screened at the Cannes Film Festival – there was so much interest the film was screened twice with people sitting on the floor due to limited seating. There has been significant international interest from people considering bulk orders and screening the film on TV as well as replicating the Dying Matters model in various countries.

- The GP training project continues to go from strength to strength with evaluations continuing to show significant improvements in the confidence of GPs to initiate and undertake end of life care conversations with patients. The training DVD has been particularly successful with work already beginning on the second in the series focusing on patients with dementia. Positive comments have been considerable. One especially striking story comes from a GP who appeared in the DVD:

  "The scenario I used was from a real patient called Ronald James Smith. He died suddenly at home today with his PPC/DNAR on the coffee table and wife next to him. I told his wife about us making this film based on the conversations we had had. She was very moved (and so was I actually) that

he may have a lasting legacy. Can my part of the DVD be dedicated to the memory of Ronald James Smith (1929-2012)? What we did and said worked well for him."

Dr Nightingale then wrote: "Mrs. Smith has given some money to me and I would like to buy 13 copies of the DVD for all the GP practices in our consortium to have a copy."

- The *train the facilitator* programme got underway in September 2012 supported by the National End of Life Care Programme (NEoLCP) and will allow those who have undertaken the training to be trained in facilitation to cascade the training further in their own localities.

The National End of Life Care Intelligence Network (NEoLCIN)

The NEoLCIN was set up to address the lack of routine data, information and intelligence on end of life care. It aims to improve the collection and analysis of nationally available information, providing significant insight into end of life care in order to drive improvements in the quality and productivity of services.

Over the last year, the NEoLCIN has produced a range of reports covering specific conditions and topics such as equality. This report summarises the highlights.

The NEoLCIN's partners at Cicely Saunders International produced the report *Local Preferences and Place of Death in Regions within England 2010.* This compares people's preferences for place of death with actual place of death, as recorded by Office for National Statistics (ONS) mortality data.

The NEoLCIN's key partners at the South West Public Health Observatory produced a report on *Deprivation and Death: Variation in place and cause of death.* This report looks at patterns of death in England by socioeconomic deprivation. It examines the interaction between deprivation, sex and age group, and place and underlying cause of death and improves our understanding of deprivation as a key factor influencing end of life care, and adds to the evidence base for those making decisions about the provision and commissioning of care and aiming to reduce inequalities.

The report on *Deaths from Liver Disease* hit the attention of the media when it was published in March. This report presents the latest data on place of death for those with liver disease and shows how this varies with sex, age, region and socioeconomic deprivation. It included some important public health messages:

- Liver disease causes approximately 2% of all deaths but the number of people who die from liver disease in England is rising;
- 90% of people who die from liver disease are under 70 years with more than 1 in 10 deaths of people in their 40s. More men than women die from the disease;
- Alcohol-related liver disease accounts for 37% of all liver disease deaths which is more prevalent in more deprived areas.

The work of NEoLCIN is led by a group of stakeholders, bringing together the various holders of information, analysts, national charities, researchers and key users of this intelligence in order to benefit from their wide experiences and expertise. The *What we know now that we didn't know a year ago* report published in May highlights the range of intelligence that we have gained over the last year through the work of the network and its partners. It pulls together key findings from studies and surveys to provide an insight into the pattern of death and dying in England which can be used as a lever for change.

The NEoLCIN website houses a series of locality profiles which commissioners and providers can use to inform their service planning and to compare themselves with their peers. In summer 2012 the profiles were updated with new profiles for each PCT in England which can be viewed as a table chart or map using InstantAtlas interactive mapping tool or downloaded as a PDF for each PCT in England. A second set of profiles has also been produced for Local Authorities which for the first time include a set of social care indicators. The profiles present over 40 indicators relating to end of life care and allow easy comparison of a locality's position to England and the current SHA. The mapping tool also enables comparison of one local authority or PCT with another.

Eight sites across England were selected as early adopters for the end of life care modelling tools. This suite of three modelling tools the Cohort model, the Yorkshire & Humber Co-Design Model and the Workforce Functional Analysis model and are designed to support end of life care commissioning and planning through analytical modelling to provide better understanding of local need for services and an indication of workforce and cost implications. The early adopters have been involved in testing the tools, applying local data and statistics to the models, learning about the tools and their implementation and then putting them into action. Case studies from the early adopters are available on the website. The tools and work books have now been updated and are all available on the website with a comprehensive range of support resources available for organisations interested in using these approaches to better understand their needs and to project the impact of change.

From the autumn NEoLCIN will have access to new linked data sets of ONS mortality data and hospital activity which will give more up to date information and will allow it to better track delivery of the End of Life Care Strategy.

For the future, from April 2013 the NEoLCIN will come under the umbrella of Public Health England to ensure that it continues to build on the solid foundations it has established.

Electronic Palliative Care Coordination Systems (EPaCCS)

EPaCCS is the term now in use for the locality registers for end of life care described in the End of Life Care Strategy. EPaCCS' main purpose is to facilitate coordination of care for individuals approaching the end of life. Chapter 4 of this report provides more detail. They are not primarily data capture systems but a valuable spin-off benefit is their ability to track progress locally. The more EPaCCS systems are adopted, the more useful these data will be for comparisons between localities and against national data.

The NEoLCP and the Department developed a national information standard to underpin EPaCCS (End of Life Care Co-ordination: core content[1]), which has been approved by the Information Standards Board for Health and Social Care. The standard was published on 20th March 2012 and specifies a core record content to support end of life care coordination systems, which facilitates the consistent recording of information by health and social care agencies. Reporting functions in the systems, where integrated, allows them to see, for example, how many people expressed a preference for a place of care, how many achieved it, and, where there was a difference, why that was the case.

Established EPaCCS are beginning to show these outcomes. While sample sizes are still small, some sites report achieving Preferred Place of Death for 70% to 80% of those on a register. Deaths in hospital have more than halved for others.

VOICES

This year we have carried out the first ever national VOICES survey of bereaved people to establish a systematic record of the quality of care experienced by people in their final three months of life. This followed a successful pilot carried out in 2010/11 in two PCT areas, Isle of Wight and East Berkshire. The Office for National Statistics (ONS) carried out the survey and undertook the analysis. As well as the quantitative data from the surveys we received a wealth of freetext responses. Those are currently being anonymised so that they too can be used for research into this topic, and are the source of the quotations used at the heads of the Chapters throughout this report.

The questionnaire was sent out to 48,766 people who had registered a death 4 to 11 months earlier. A total of 22,292 people responded, giving a response rate of 45.7% which is considered excellent for a survey of this type.

Overall quality of care in the last three months of life was rated as outstanding or excellent by 43% of respondents, good by 33%, fair by 14% and poor by 10%. There was significant variation according to the setting for care at death. Where the death occurred in a hospice, 59% rated care "outstanding/excellent", home 54%, care home 51% and hospital 33%. Cancer patients and people aged under 65 were most likely to receive outstanding/excellent care.

There was also significant variation in the reporting of which staff treated the person with dignity and respect. This was highest for staff in hospices (87% "all of the time" for hospice doctors and 80% for hospice nurses); followed by district/community

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[1] End of Life Care Co-ordination: core content. http://www.endoflifecareforadults.nhs.uk/strategy/strategy/coordination-of-care/end-of-life-care-information-standard

nurses (79%); GPs (72%); care home staff (61%); hospital doctors (57%) and hospital nurses (48%).

The size of the sample determines how detailed the analysis can be. Geographically, they can be examined down to PCT cluster level. By condition, the analysis has split responses between cancer, CVD and other but we have been able to look at additional detail where the numbers have permitted. For example, around one fifth of patients had dementia or senility mentioned on their death certificate. This means that we can say that respondents for patients where dementia was mentioned were more likely to rate the overall quality of care as outstanding or excellent (46%) compared with those without (42%). This is especially interesting when compared to the overall rating for care in care homes, since more than half of deaths in care homes had dementia mentioned (56%).

ONS will be running the second VOICES survey along the same lines as the first one. We shall be able to combine the two sets of data to look at the results for smaller areas, which should allow for analysis to CCG level. VOICES is also the basis for an Indicator in Domain 4 of the NHS Outcomes Framework. This will focus on improving the experience of care for people at the end of their lives and will be based on the overarching question in the survey on quality of care in the last three months, supplemented by the summary questions for care in the different settings:

Overarching question:

- *Overall, and taking all services into account, how would you rate his care in the last three months of life?*

The supplementary questions cover:

- *Overall perception of the care s/he got [at home] from the GP in the last three months of his life*
- *Overall perception of the care that s/he got from the staff in the hospice*
- *Overall perception of the care that s/he got from the care home in the last three months of his life*
- *Overall perception of the care that s/he got from the staff in the hospital on that [last] admission (responding for both doctors and nurses)*

The findings at PCT cluster level show significant variations which are already prompting local services to ask what lies behind their results so far.

National Bereavement Survey, 2011

Table 29: Summary table of benchmark ratings for PCT Clusters across 11 key questions

NORTH EAST	A1	A2	A3	A4	A5	A6	A7	A8	A9	A10	A11
Durham and Darlington	🟥	🟨	🟩	🟨	🟩	🟩	🟩	🟨	🟨	🟩	🟨
North of Tyne	🟩	🟩	🟩	🟩	🟩	🟩	🟨	🟥	🟩	🟩	🟩
South of Tyne and Wear	🟨	🟨	🟨	🟩	🟩	🟨	🟨	🟥	🟨	🟨	🟨
Tees	🟨	🟩	🟨	🟨	🟨	🟩	🟥	🟩	🟨	🟩	🟨
NORTH WEST											
Cheshire, Warrington and Wirral	🟩	🟩	🟨	🟨	🟩	🟨	🟩	🟥	🟩	🟩	🟨
Cumbria	🟩	🟨	🟨	🟨	🟨	🟩	🟨	🟨	🟨	🟨	🟩
Greater Manchester	🟨	🟥	🟨	🟨	🟨	🟩	🟨	🟨	🟨	🟨	🟨
Merseyside	🟨	🟨	🟨	🟩	🟨	🟩	🟨	🟨	🟨	🟨	🟥
Pan-Lancashire	🟨	🟥	🟥	🟥	🟥	🟨	🟨	🟨	🟨	🟨	🟨
YORKSHIRE & THE HUMBER											
Bradford and Airedale	🟨	🟨	🟨	🟨	🟨	🟨	🟥	🟨	🟥	🟥	🟨
Humber	🟨	🟨	🟨	🟨	🟨	🟥	🟨	🟨	🟥	🟨	🟥
Leeds	🟨	🟨	🟨	🟨	🟩	🟨	🟥	🟥	🟨	🟨	🟨
North Yorkshire & York	🟩	🟨	🟩	🟨	🟨	🟨	🟨	🟨	🟩	🟩	🟨
South Yorkshire	🟨	🟥	🟥	🟨	🟨	🟨	🟥	🟨	🟨	🟨	🟨
West Yorkshire	🟨	🟩	🟨	🟨	🟨	🟨	🟨	🟥	🟨	🟨	🟨
EAST MIDLANDS											
Derbyshire	🟨	🟨	🟩	🟨	🟨	🟨	🟨	🟨	🟥	🟨	🟨
Leicestershire	🟨	🟨	🟥	🟥	🟨	🟨	🟨	🟨	🟨	🟨	🟨
Lincolnshire	🟥	🟨	🟥	🟥	🟥	🟥	🟨	🟨	🟥	🟥	🟨
Milton Keynes and Northamptonshire	🟨	🟨	🟥	🟨	🟨	🟨	🟨	🟩	🟨	🟨	🟨
Nottingham	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟩	🟨	🟨	🟨
WEST MIDLANDS											
Arden	🟩	🟨	🟨	🟨	🟨	🟨	🟨	🟥	🟨	🟨	🟨
Birmingham	🟨	🟥	🟨	🟨	🟨	🟨	🟨	🟩	🟥	🟥	🟨
Black Country	🟥	🟨	🟨	🟥	🟥	🟥	🟥	🟨	🟨	🟥	🟨
Staffordshire	🟨	🟨	🟨	🟨	🟨	🟨	🟩	🟨	🟨	🟩	🟨
West Mercia	🟩	🟩	🟨	🟩	🟨	🟩	🟨	🟥	🟨	🟨	🟨
EAST OF ENGLAND											
Bedfordshire and Luton	🟥	🟨	🟥	🟨	🟥	🟥	🟥	🟨	🟨	🟨	🟩
Cambridgeshire and Peterborough	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟩	🟩	🟩	🟩
Hertfordshire	🟥	🟨	🟥	🟥	🟥	🟥	🟥	🟨	🟨	🟥	🟨
Norfolk, Great Yarmouth and Waveney	🟨	🟨	🟩	🟨	🟨	🟨	🟨	🟩	🟩	🟨	🟨
North Essex	🟨	🟥	🟥	🟨	🟨	🟨	🟨	🟨	🟨	🟥	🟥
South Essex	🟥	🟥	🟨	🟥	🟥	🟥	🟨	🟩	🟨	🟨	🟥
Suffolk	🟨	🟨	🟩	🟨	🟩	🟨	🟩	🟩	🟨	🟨	🟩
LONDON											
Inner North East London	⬜	⬜	⬜	⬜	⬜	⬜	⬜	⬜	⬜	⬜	⬜
North Central London	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟥	🟨	🟥
North West London	🟥	🟥	🟨	🟥	🟥	🟨	🟥	🟥	🟥	🟥	🟥
Outer North East London	🟥	🟥	🟨	🟥	🟥	🟥	🟥	🟨	🟥	🟥	🟥
South East London	🟥	🟥	🟥	🟥	🟥	🟥	🟨	🟨	🟥	🟥	🟥
South West London	🟨	🟨	🟨	🟨	🟥	🟨	🟨	🟨	🟨	🟥	🟥
SOUTH EAST COAST											
Kent and Medway	🟨	🟨	🟨	🟥	🟨	🟨	🟨	🟨	🟨	🟨	🟨
Surrey	🟨	🟨	🟥	🟨	🟨	🟨	🟥	🟥	🟨	🟨	🟨
Sussex	🟨	🟩	🟨	🟨	🟨	🟨	🟨	🟨	🟩	🟨	🟨
SOUTH CENTRAL											
Berkshire	🟥	🟥	🟨	🟨	🟨	🟥	🟨	🟨	🟥	🟨	🟥
Buckinghamshire and Oxfordshire	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟩	🟨	🟩
Southampton, Hants, Isle of Wight & Portsmouth	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨	🟨
SOUTH WEST											
Bath & North East Somerset and Wiltshire	🟨	🟨	🟨	🟩	🟨	🟨	🟩	🟩	🟨	🟩	🟩
Bournemouth and Poole and Dorset	🟩	🟩	🟩	🟩	🟩	🟩	🟨	🟨	🟨	🟨	🟩
Bristol, North Somerset & South Gloucestershire	🟩	🟨	🟨	🟩	🟨	🟩	🟩	🟨	🟨	🟨	🟩
Devon, Torbay and Plymouth	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟨	🟩	🟩	🟨
Swindon and Gloucestershire	🟨	🟨	🟨	🟨	🟨	🟥	🟩	🟥	🟨	🟨	🟨
Somerset	🟩	🟩	🟩	🟩	🟩	🟨	🟩	🟩	🟩	🟨	🟩
Cornwall and Isles of Scilly	🟨	🟩	🟩	🟩	🟩	🟨	🟩	🟨	🟩	🟩	🟨

A1. Overall quality of care across all services by PCT Clusters
A2. Co-ordination of care while patient was at home
A3. Co-ordination of care: hospital with GP/community services
A4. Dignity & Respect shown by doctors all of the time last 2 days
A5. Dignity & Respect shown by nurses all of the time last 2 days
A6. Pain management in the last two days
A7. Patient involved in decisions re: care as much as wanted
A8. Patient expressed preference where would like to die
A9. Respondent considered patient died in the right place
A10. Support for carers while patient at home
A11. Support for carers able to discuss worries with GP

The freetext adds greatly to the richness of the quantitative data. A high proportion of responses included substantial additional comments. These were spread across both positives and negatives: where someone highlighted poor care, it was frequently in contrast to good care received in another setting or from other staff. The longest single response, which included copies of letters and press cuttings, ran to 51 pages and was about an excellent experience of care.

The full report on the findings, published in July, is available at http://www.dh.gov.uk/health/2012/07/voices/

Equality Issues

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. Whilst these inequalities have been most marked between cancer and non-cancer diagnoses, other groups, such as older people, people with disabilities and people from different cultural and religious groups, often face issues of inequality.

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 concerns and set out a series of action points.

Every year we publish alongside the Strategy's Annual Report a progress report against the action points set out in the 2008 EqIA. These progress reports should be read as a continuing narrative of developments and progress made since 2008. The reports show that much has been achieved but also show that there is more still to be done.

Key progress since the 2011 Annual Report includes:

- The NEoLCP has produced *Planning your future care: a guide* in six languages: Arabic, Punjabi, Urdu, Polish, Bengali, Chinese;
- The NEoLCP has produced *The route to success in end of life care - achieving quality for lesbian, gay, bisexual and transgender people;*
- The National End of Life Care Intelligence Network has produced local PCT and LA profiles, which include over 40 indicators relating to population, deaths, place of death and cause of death and provide vital data for commissioners of services; and,
- The National Institute for Health and Clinical Excellence (NICE) Quality Standard for end of life care for adults stresses the importance of ensuring that treatment and care, and the information given about it, should be

culturally appropriate and accessible to people with additional needs such as physical, cognitive, sensory or learning disabilities.

The full progress report for 2012 is published alongside this Annual Report on the Department's website.

St Nicholas Hospice Care – The Stephen Project - Improving End of Life Care for homeless people in a rural county and beyond.

Introduction: This Burdett Trust funded initiative explored the local and national provision of end of life care for the homeless. On average a homeless person dies 30 years before someone who has a home; the death arises from social situations rather than the most common life shortening diseases. 6.9% of the local population are statutorily homeless (and rising) but there is no indication that 6.9% of hospice care supports homeless people. St Mungo's and Marie Curie Cancer Care have considered urban homelessness; we sought to explore the impact of rural homelessness.

Method: We consulted and continue to work with homelessness services and their clients, including those in conurbations, faith based, the Big Issue, night shelters, residential units and young people supported housing units, building bridges with clinicians involved in the care of homeless people with mental health and addiction problems, and those with learning disabilities.

Project findings: One of the significant causes of persistent homelessness is often unaddressed grief arising from multiple traumatic losses and deaths.

Why, where and how homeless people die was a revelation. We supported an organization who knew their client would only accept death on a park bench; the skill lies in adapting the principles of a good death to his preferred place of death. The national initiative to promote 'admission avoidance' at point of dying is unachievable for someone who is or chooses to be homeless; a challenge to clinicians and commissioners of services!

Social care staff within homeless services are extraordinarily eager to learn more about bereavement and end of life care in order to support their clients. Our work has resulted in local services being linked into our education sessions and thereby promoting our hospice as 'open' to care and support on homeless peoples terms whenever possible.

Recommendations: Albeit findings to date are anecdotal and not statistically determined, nevertheless ideas are tangible. In offering bereavement support to vulnerable young people outwith 'traditional hospice care' homelessness and self-destructive behaviours might be reduced. Hospice has a role to 'work with' other agencies to meet grief and 'death' issues in a new way.

The challenge is to deconstruct the current diagnosis/illness led hospice-care model, to compassionate, community, health promotion addressing the social experience of death in its various forms.

Hospices have always filled ‘gaps’. This project has highlighted how contemporary models of end of life care need revision in order to support homeless people and the agencies which strive to support them. It is further work for hospices nationally to provide services equitably, to identify marginalized groups and ‘hidden’ need.

Jane Carpenter, Senior Registered Nurse,
Jackie Saunders, Clinical Services Director
St Nicholas Hospice Care, Suffolk

Housing

The NEoLCP has a history of partnership working to take forward end of life care in a range of settings. Most recently they have worked with the Housing Learning and Improvement Network (Housing LIN) to produce a resource pack for extra care housing staff.

End of life care in extra care housing: a learning resource pack provides practical information and advice for managers and support staff working in extra care housing schemes. It covers a range of issues relating to the care of residents with a life-limiting or progressive condition. The topics range from initial conversations and care planning through to the things staff might be expected to do after a death. As well as case studies and ‘top tips’, the pack includes template local directories of key contacts.

Research

One of the functions of the National End of Life Care Intelligence Network is to provide easy access to the latest data, research, analysis and statistics. Its website acts as a gateway for access to good quality research. Its primary function, to improve the collection and analysis of information related to the quality, volume and costs of care provided by the NHS, social services and the third sector, to adults approaching the end of life, itself is a valuable support to those undertaking research in this area.

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

Find Your 1%
AMBER Care Bundle
Advance Care Planning
Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)
Choice
The Prime Minister's Dementia Challenge
Cancer survivorship
Social care

"Services are lacking in this area and if I could have one wish, it would be to improve the 'continued care in the home' service".
"Respite care to live-in is very difficult to obtain. With the best will in the world, no-one can be expected to care for someone 24/7 without a break".
"He didn't like going to the hospital and wanted to get back to his flat as soon as possible".
"The residential care home provided wonderful care. My father .. was looked after with dignity and love. (The staff) managed to help him enhance his life with interests and activities".
"The fast track provision of equipment, bed and air mattress happened within hours to allow Mum to die in her preferred place of care".
"She may have died in hospital and this was not what she wanted. Some people might not have the fight in them to get them home. Health and safety can be over the top. I just hope no-one else in this situation goes through this kind of stress".

First national VOICES survey of bereaved people, July 2012

The End of Life Care Strategy highlighted the challenges of identifying people who are approaching the end of life. Unless this can be done it is not possible to plan with and for these people, to explore their choices and options and to help make them a reality. This can involve a range of staff in both the NHS and social care.

Hill View Surgery – Gold Standards Framework (GSF)

Hill View Surgery is a small GP practice of around 3000 patients and 1.5 FTE GPs and is part of the Newark and Sherwood CCG in Nottinghamshire. The surgery team are committed to improving end of life care services for their patients and have put in place a number of initiatives to ensure that communication about a patient who is near the end of life is shared across the whole team involved in their care.

They hold GSF meetings every three months which include all the GP practice staff, District Nurses, Macmillan Nurses and any other staff needing to be involved. They have a check list to help them update records and identify patients' needs as well as looking at needs of the carers who are not necessarily resident with the patient.

When someone has passed away the team look at how they managed the care and reflect on any improvements that could be made for the future. Bereavement counselling is also something that is offered and if someone has a complaint around the care either before or after the death then they are invited in to discuss the issues, although sometimes it is just a reaction to the death and an inability to cope rather than a failure in the system.

Regular handover meetings are also held with the full team to enable smooth transition of care during staff changeovers. One of the GPs has recently undertaken a Diploma in Palliative Care to address a shortfall in knowledge on anticipatory medicines and syringe driver medications within the practice. All staff including administration and reception staff are aware of Liverpool Care Pathway and how to manage conversations around the associated care and outcomes.

Only one death has not occurred in the patient's preferred place since adopting GSF and this was mainly due to it occurring during an out of hours episode with the family panicking as the end stage was developing very quickly. The practice is also undertaking work to help their dementia patients make decisions on their wishes and preferences whilst they are still capable and also ensure that the family is aware of the decisions and wishes expressed. The practice is currently using SystmOne and Summary Care Records but will start to use the end of life care template recently received.

The surgery team are very proud of their achievements and the end of life care they are able to give to their patients and carers.

Mandy Brown – Surgery Manager

Find Your 1%

The 'Find your 1%' mobilisation campaign, led by the National End of Life Care Programme (NEoLCP), has been actively engaging with clinicians in collaboration with Dying Matters, Doctors.Net.UK, the Royal College of General Practitioners and other key partners to encourage clinicians to commit 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.

The campaign has seen over 2900 clinicians sign up so far and a post campaign survey conducted with 600 GPs who engaged with the campaign showed the following improvements –

	End of March 2011	End of March 2012
Number of GPs with an EOLC register	221	333
Number of patients on an EOLC register (excluding outliers)	4,242	7,723
Patients with primary diagnoses other than cancer on EOLC register (Excluding outliers)	959	2,534
Number of patients with Advance Care Planning	1,652	3,531
Number of GPs across their practices said to have increased EOLC activity		1,905

Overall among GPs who have interacted with the Find your 1% campaign:

- Two in five have increased the number of patients listed on their end of life care (EoLC) register;
- Although cancer patients remain the largest group on EoLC registers, the number of patients with other primary diagnoses has increased (up from 29% in 2011 to 39% at the end of March 2012);
- The percentage of patients achieving preferred place of care or preferred place of death has increased, as have the number of patients with advance care plans;
- 19% of those interviewed indicated that their practice had at least one patient on an EoLC register in March 2012 where there had been none in March 2012;
- 20% had increased the number of patients on their pre-existing EoLC register.

Campaign activity is now focusing on supporting and facilitating local calls to actions with active participation already underway in London, South Central, South of England and the North West.

For more information see http://www.dyingmatters.org/gp

NHS Midlands & East – East of England End of Life Care GP Practice Education Programme

To meet the requirements of the Strategic Vision '*Towards the Best Together* (2008)' requires a step change in the ability of staff to deliver palliative and end of life care.

About 70% of people in the East of England express a wish to die in a place of their choice. The East of England End of Life Care GP Practice Education Programme aims to facilitate this by enabling GP practice staff (clinical and non clinical staff) to have more confidence and skills through end of life education and resources. The project will run over two years (ending in 2014) and is facilitated by the Mount Vernon, Anglia and Essex Cancer Networks.

During this time all GP practices (including Out of Hours services) across the East of England will be invited to identify and discuss their end of life care training requirements with objectives to:

- provide facilitation to enable staff to improve their skills, behaviours and knowledge with respect to caring for people who require palliative and end of life care;
- improve communication between GP practices, care homes and other end of life care providers;
- decrease the numbers of people/residents being admitted inappropriately from their homes/care homes to the acute hospital services;
- increase the accuracy and quality of the GPs' end of life register.

With the support of experienced facilitators, practice staff will have opportunity to discuss and review their current end of life care provision. This will help identify gaps in care and systems, highlight skills required and negotiate/access appropriate education and learning opportunities. Training will be varied and flexible to meet the needs of clinicians and practice staff and will contribute towards continuous professional development evidence of learning.

The GP facilitator will then endeavour to support the Practice in embedding their enhanced skills and confidence to deliver an optimal service, through advanced communication, enhanced knowledge and excellence in clinical skills, for the benefit of all patients affected by end of life care issues.

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

AMBER Care Bundle

The AMBER Care Bundle was developed at Guy's and St Thomas' Hospital to support teams in identifying and responding to someone's end of life care needs when their recovery is uncertain. It is designed to enable treatment to occur alongside palliative care.

The tool incorporates and is supported by a package of interventions which includes staff training and development required to embed the tool in daily ward and operational practice.

The AMBER acronym stands for:

- Assessment
- Management
- Best practice
- Engagement of individuals and carers
- For people whose Recovery is uncertain

Emerging evidence suggests that using the AMBER care bundle improves decision-making. It also has a positive impact on multi-professional team communication and working and increases nurses' confidence about when to approach medical colleagues to discuss treatment plans. In addition people are treated with greater dignity and respect and there is greater clarity around preferences and how they can be achieved.

Guy's and St Thomas' Foundation Trust

Guy's and St Thomas' Foundation Trust (GSTT) has been implementing the AMBER care bundle in around half of its wards since last August.

During this time over 600 patients have been identified as being at risk of dying in the next one to two months or facing an uncertain recovery and have gone through the AMBER process. Of patients cared for using the AMBER care bundle in 2011, 55% were discharged home to die while the rest stayed in hospital, often because they chose to rather than because they were too ill to transfer. Latest available figures suggest 70% of those who died achieved their preferred place of death.

While the majority of those dying in hospital died within a fortnight of being placed on AMBER, most of those who returned home died within 100 days.

A possible indication of the wider effect of the AMBER care bundle is a reduction in the overall hospital death rate. This may be linked to increased numbers of patients being fast-tracked home to allow them to die there if this is their wish.

Teamwork has improved on the wards that use the care bundle.

There are plans to roll the tool out to most of the hospital's remaining wards. It is also planned to increase its use at neighbouring King's College Hospital as well as piloting it in surrounding community areas.

The AMBER care bundle has been identified as a key enabler in the Transform Programme for acute hospitals. The team at Guy's & St Thomas' is working with trusts across the country to support implementation.

More information on the AMBER Care Bundle can be found on the GSTT website.
../../dhuserdfs/nw020/TIng/Data/notes99D109/www.guysandstthomas.nhs.uk/services/ambercare/amber-carebundle.aspx

Advance Care Planning (ACP)

Advance care planning is a voluntary process of discussion and review with the aim of helping someone who has the capacity to indicate what their preferences and wishes are for future care.

If the individual wishes, they can record choices about their care and treatment and an advance decision to refuse a treatment in specific circumstances. These choices can then be referred to by those responsible for care and treatment if, as the illness progresses, the individual loses capacity to make decisions for themselves.

Advance care planning involves a series of conversations in which a person's wishes are explored, identified and then recorded. Policies should be agreed locally about where care planning documentation should be kept, including any formalised outcomes. There should also be systems in place to enable health and social care professionals – including out of hours providers and ambulance services - involved with the individual to share information.

Advance Care Planning and the Information Sharing Process in Knowsley

Advance care planning (ACP) in Knowsley uses the Preferred Place for Care (PPC), a patient-held document. To be effective the information contained in the PPC needs to be shared with all the staff who are involved in the patient's care. A Notification document was developed to ensure that this process takes place as efficiently as possible. Patients are made aware of the importance of the Notification Form to support the PPC document to help them to achieve their wishes and preferences for the care at the end of their lives.

A project was set up to take this forward, with three aims:

- to support staff to start the conversation about end of life choices with patients and record these in the PPC document;
- to set up a system that would share the information contained in the PPC with relevant professionals, to ensure choices were respected; and,
- to use the information anonymously to audit the reasons why some patients do not die in their place of choice.

Letters were sent to every GP Practice informing them of the project and what to do with the information supplied on the Notification Form. GP Out Of Hours (OOHs) and North West Ambulance Service (NWAS) agreed to input onto their IT systems and use the information. Two open days were held for acute and community staff; a total of 88 staff attended.

More than 200 staff across all sectors attended intensive training sessions on 'starting the conversation', the PPC document and the Notification Form, a further 34 attending communication skills training. Information from the Notification Forms was anonymously collected onto a database, as well as being shared with appropriate urgent care services and primary health care teams identified on the form, e.g. GP's, District Nurses, Community Matrons, Specialist Nursing Teams, Community Macmillan Nurses, hospice and social care, including OOHs and NWAS. It enables staff to plan ahead; if they are aware of patients' preferences they can put systems in place to support them to achieve their wishes.

This has continued to snowball, with more staff continuing to recognize the value and importance of ACP. 400 have been completed and the success rate is amazing to see, with 87.1% of people achieving their PPC.

Another huge achievement is the number of patients now involved in ACP who had life limiting conditions other than cancer. 73% of all the notifications received are non-cancer, although traditionally these patients do not always receive the same consideration in achieving their preferences for end of life care as people with cancer do.

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There is now a range of useful ACP support tools available to both health and social care professionals, including:

- *Holistic common assessment of supportive and palliative care needs for adults requiring end of life care*
- *Capacity, care planning and advance care planning in life-limiting illness: a guide for health and social care staff*
- *Planning for your future care*
- Preferred priorities for care documentation
- *The differences between general care planning and decisions made in advance*
- *Concise Guidance to Good Practice: Advance Care Planning* (RCP, 2009).
- *Thinking and planning ahead: learning from others*
- e-ELCA End of Life Care for All e-learning, which includes modules on ACP
- *It All ADSE Up* (Ask, Document, Sharing, Evaluating plan) was launched at the conference *In the End Care Counts* on 16 October 2012.

Blackpool Teaching Hospitals Foundation Trust

In recent months Blackpool Teaching Hospitals Foundation Trust, one of the participants in the Transform programme, has been running special half-day training sessions for its staff on communications as part of its plan to introduce advance care planning (ACP) for all patients approaching the end of life.

The trust's end of life care team found that one of the main stumbling blocks to ACP was staff's apprehension about entering into what they saw as difficult conversations.

As a result the trust identified funding to train a cohort of six facilitators who are now starting a rolling programme of three-hour sessions on communications skills which will be made available to all staff within the organisation. So far 30 staff a month are going through the training but it is hoped shortly to expand the number of facilitators and therefore double the numbers receiving the training each month.

The initiative is part of a wider end of life care strategy across the entire health economy aimed at ensuring that people are cared for and die where they wish. The next stage of this process will be the gradual introduction of the Preferred Place for Care within selected wards as well as making use of the AMBER care bundle.

The current policy began in 2009 when the trust carried out an audit of deaths within its hospitals. It found that of 60 deaths, 45 had been expected where the patient expressed a wish to return home but for one reason or another had been unable to.

A number of changes have been made to improve the rapid discharge pathway, including making use of a private ambulance that can be ready within a couple of hours, taking a more flexible approach to equipment and ensuring that prescriptions are available within half an hour.

The hospitals are now discharging around 20 patients per month within 24 hours and one or two a week within four hours. The numbers appear to be growing.

The end of life care team is also working closely with other parts of primary and secondary care as well as local hospices to ensure that all aspects of care are co-ordinated and that, for instance, people aren't admitted to hospital unnecessarily in the first place.

Although it is difficult to find hard measures of progress in such a complex field, the response of patients and families to the new policy has been very positive. In one example, a patient who was being discharged home said her dying wish was to see the sea one last time. "So the ambulance took her home but on the way they pulled up at the promenade and the lady was able to sit looking at the sea for 30 minutes before going home."

DNACPR

SHAs have worked hard to develop Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) policies which can be used consistently across their areas.

Deciding right

Deciding right is England's first integrated policy on making care decisions in advance and covers three key national frameworks: the 2005 Mental Capacity Act; the 2007 BMA/RC/RCN joint statement on cardiopulmonary resuscitation decisions; and the 2011 NHS guidance on advance care planning. Its key components are

C hoice and capacity The right of individuals to choose their care preferences, either now should they lose capacity in the future, or have the right choices made on their behalf if they do not have capacity
A greement The right choice comes from shared decision making which is a partnership between two experts, the individual and the professional
R ight documents Having the same documents in every care setting ensures that decisions are centred on the individual, not the organisation
E ducation The right for patients and professionals to have the resources to understand and use *Deciding right*.

Developed by a team led by Dr Claud Regnard for NHS North East and championed by the end of life Clinical Innovation Team, *Deciding right* includes provision for shared, region-wide documents so that a patient's decision, once made, is respected wherever they receive care, and the process of evolving decision-making (including changing one's mind) is respected. Documents include:

- a Regional Advance Decision to Refuse Treatment (ADRT)

- a Regional Do Not Attempt CPR order (DNACPR)
- a Regional Emergency Health Care Plan

These and other resources are available on www.theclinicalnetwork.org (click on *Deciding right* signpost at the foot of the homepage).

Deciding right so far

Deciding right is being widely disseminated to all health and social care organisations in the north east and has been adopted by all NHS trusts. Most trusts have already started implementing the initiative and some have already made the switch to the new regional DNACPR form. *Deciding right* is included in the palliative care register information pack that has gone to all GPs. The North East Ambulance service has been part of the development process and by April 2013 they will only accept the new regional forms.

Elizabeth Kendrick, GPwSI Older people and Chair End of Life Clinical Innovation Team NHS North East
Claud Regnard, consultant in palliative care medicine, St. Oswald's Hospice, Newcastle upon Tyne

In response to continuing demand for clarification in this extremely sensitive area the NEoLCP has supported Professor Rob George, clinical end of life care lead for London and a palliative care specialist, to develop a web-based resource for DNACPR. This was published on 27 September.

Leeds Health and Social Care implementation of regional DNACPR form

The health and social care economy in Leeds began implementation of the newly developed regional DNACPR form in August 2011 as part of the wider project to implement across the whole of the Yorkshire and Humber region.

The project was supported by the NHS Yorkshire and Humber Strategic Health Authority, the overall aim being to establish a common DNACPR form that would facilitate the documentation and communication of DNACPR decisions across all care settings on transfer between them.

As the biggest city within the Yorkshire and Humber region with a population close to 800,000 and housing two of the largest teaching hospitals in Europe, Leeds were aware of the challenge ahead to implement the form.

A local, high level Leeds DNACPR Task & Finish Group was established to plan and oversee the introduction, implementation and embedding of the form. The Leeds health and social care economy, which crucially ensured senior representation from the acute, community, mental health and commissioning trusts, the two hospices, adult social care and Yorkshire Ambulance Service, worked collaboratively. Citywide collaborative working has been key to the success of implementation.

The group developed and adhered to a communication and education plan and as a result, implementation has been relatively smooth with some excellent examples of the impact in practice, not least a Senior Sister within A&E at one of the acute hospitals reporting increasing numbers of patients arriving in A&E with the form.

Post implementation audits have broadly demonstrated increasing improvement in the completion on the forms but underlined the need for ongoing education and training particularly for medical staff and specifically around communication skills. Finally, a READ code has been agreed with SystmOne for the DNACPR form which, as the form is recognised by all involved, has improved communication between healthcare professionals across organisations regarding a patients' DNACPR status. There may not have been a similar impact before the existence of a 'universally' accepted form. The form has also been added to the Electronic Palliative Care Coordination System (EPaCCS) which is currently being rolled out in Leeds which will further improve electronic communication across organisations.

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Choice

The initiatives described in this report will enable people to formulate and communicate their choices for care at the end of life. In May the Department of Health published *Liberating the NHS: No decision about me, without me - Further consultation on proposals to secure shared decision-making.* This reiterated the Department's commitment to introducing a right to choose to die at home, including a care home, when services are well enough developed to allow that to be a realistic offer. The document also reiterated the plans to run an evaluation of progress in 2013 to determine how soon this might be deliverable.

Dementia – the Prime Minister's Dementia Challenge

While the principles set out in the End of Life Care Strategy apply to all adults approaching the end of life, the detail of how and what care is provided will vary depending on someone's condition. We have reported in previous years on the work done focussed on kidney care, which itself has provided a model for heart failure.

With an ageing population dementia is a particular and growing challenge for end of life care. In March the Prime Minister launched his Dementia Challenge, which includes end of life care. The NEoLCP is one of the key stakeholders which is now engaging with these issues.

Merseyside & Cheshire Palliative & End of Life Care Network (MCPEoLCN) - Dementia Roadshows

MCPEoLCN scoped the needs of people diagnosed with dementia in relation to support for planning for their future care. There was very little activity from health professionals in offering an opportunity to people with dementia with mental capacity to plan for their future care. The planning process mainly occurred when the person had lost mental capacity.

In dementia, this needs to take place early, while someone has sufficient mental capacity and where decisions and preferences can be recorded consistent with the principles set out in the Mental Capacity Act. GPs are crucial for people with dementia, both for obtaining a diagnosis and accessing ongoing support and care.

Three roadshows across the network were delivered in April and May 2012. The roadshows covered five localities. They were delivered to 150 health professionals, 91 of whom were GPs. They aimed to increase awareness of the role of health professionals (especially GPs) to support people diagnosed with dementia who still have capacity to plan for their future care. This would include offering an advance care planning discussion.

It was also important to increase the health professionals' knowledge in identifying end of life in dementia patients and potentially reducing burdensome interventions.

Speakers included a community geriatrician active in the ACP process in care homes, two Consultants in Palliative Medicine, Alzheimers Society, End of Life Care (EoLC) Facilitators and a carer. The roadshow content included the use of the EoLC tools, identification of the end of life in dementia using prognostic indicators, evidence based research on what would be a burdensome intervention for a person with dementia and how to reduce avoidable hospital admissions. Ethical considerations were also discussed i.e. nutrition and hydration.

The EoLC Facilitators were crucial in giving the local overview of services and information especially around the EoLC tools. Delegates had a resource pack which included NEoLCP resources.

Evaluations consisted of a questionnaire pre and post event on knowledge, skills and confidence and the delegates will be followed up at three and six month intervals to capture outcomes from the roadshows and identify any further training needs.

Evaluations showed an overall increase in knowledge, skills and confidence of participants in having discussions and using the ACP process, identifying end of life in dementia patients, also reducing burdensome interventions and the use of the Liverpool Care Pathway. Feedback was extremely positive. As a result of the roadshows there is evidence ACP has taken place for a number of patients with dementia already and there have been enquiries looking for more dementia events.

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Improving the End of Life Care experience of People with Dementia

For the past two years the NHS South of England Central Clinical Leaders Network has focused on increasing awareness of the end of life care (EoLC) needs of people with dementia and their carers. The campaign has had a big impact – but there is still a long way to go.

The network decided to focus on dementia because we were well aware of gaps in the provision of palliative and EoLC as well as in support for patients with dementia and their carers. We also recognised that the number of people developing dementia was growing as was the cost of caring for them.

We set out two principal aims: to create a robust and clear dementia pathway and to ensure mass awareness and engagement so that EoLC for people with dementia can be improved.

Initially this involved seeing how many people with dementia were on EoLC locality registers. Numbers were very low so a robust campaign to raise general awareness about dementia began. Educational sessions took place in the community to help case managers improve their understanding of dementia as well as their ability to support patients and relatives.

Memory clinics were visited to link with colleagues working in mental health to promote the inclusion of patients with dementia on end of life registers. The EoLC practice educators also actively promoted identification of people nearing the end of life and end of life registers, both within GP surgeries and across nursing homes. To ensure dementia and EoLC are linked strategically EoLC groups routinely discuss dementia at EoLC meetings.

The results have been dramatic. Numbers of people with dementia and who are offered an advance care plan have increased and EoLC is now a recognised part of dementia services, something that will be further strengthened by EoLC's inclusion in the Prime Minister's Dementia Challenge.

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Cancer

Much of the basis for the End of Life Care Strategy came from work with cancer. The challenge has been to bring the quality of care for other conditions closer to the standard which has been available for cancer. However this does not mean that cancer can safely be ignored. Indeed, the improvements in cancer care mean that there are now increasing numbers of cancer survivors who present particular end of life care challenges. The Cancer Survivorship initiative includes a workstream on Active and Advanced Disease which is making the connections with end of life care.

Social Care

The NEoLCP's report *What we know now that we didn't know a year ago: New intelligence on end of life care in England* (National End of Life Care Intelligence Network (NEoLCIN) May 2012) includes the fact that 29% of people with an Electronic Palliative Care Co-ordination System record (EPaCCS) identified that they would prefer to die within the care home setting.

We know that in 2008-2010 16% of people living in care homes were admitted to hospital within their last week of life and died there (NEoLCIN 2012).

In order to meet the changes in demographics and ensure that the preferences and wishes of individuals are met at the end of life including preferred place of care and death, the NEoLCP has been supporting care homes at national, strategic and local levels. The *Route to success in end of life care: Achieving quality in care homes* was published in 2010. The guide follows the six steps of the pathway set out in the End of Life Care Strategy. Along with this guide, other resources were published including a quality assessment tool and a training package developed within the North West of England Six Steps to Success programme for care homes (http://www.endoflifecareforadults.nhs.uk/care-settings/carehomes/route-to-success-in-care-homes-package)

Following the development and publication of the Six Steps training programme the North West have employed facilitators to roll out and implement this within 800 plus care homes. The Six Steps is also being implemented by end of life care facilitators/educators within care homes nationally, including in Kent, Norfolk and Plymouth. St Luke's Hospice in Plymouth is implementing an adapted version of the programme which covers over 50% of their care homes as well as ten domiciliary care agencies.

The Six Steps to Success End of Life Care Home Programme

The Six Steps to Success End of Life Care Home Programme, developed in the North West, was launched nationally in January 2010.

The programme has now reached approximately 400 care homes across the North West. It has been delivered by end of life care facilitators and hospice staff to support care homes to put into practice the information from the *'Routes to Success in end of life care – achieving quality in care homes'* (NEoLCP 2010).

To support the delivery of the programme the three North West Networks (Greater Manchester and Cheshire Cancer Network, Cumbria and Lancashire End of Life Network and Cheshire and Merseyside Palliative and End of Life Care Network) have made all the supporting materials to deliver the workshops freely available at: www.endoflifecumbriaandlancashire.org.uk/six_steps.php

The programme continues to evolve. Recent features being added to the webpage include electronic audit tools and updated material. A facilitators' online forum was launched in October 2011 enabling facilitators from across the country to share ideas and presentations and to support each other.
www.endoflifecumbriaandlancashire.org.uk/facilitators.php

Many care homes have now completed or are approaching the end of the programme and are reporting positively on its impact for their residents, families and staff. A formal evaluation is due to commence across the North West which will explore the different delivery models, an economic appraisal and an assessment if its impact.

Work is also underway to develop a Six Steps to Success End of Life Care Programme for Domiciliary organisations and their care workers.

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The NEoLCP's 2012 report *Critical success factors that enable individuals to die in their preferred place* identified the development of care homes as one of nine critical factors in enabling people to do so. The report was based on contributions from commissioners and providers from seven PCTs. Investment in training for care home staff was seen as a priority to enable individuals to remain within the home, reduce unnecessary hospital admissions and ensure rapid discharge back to their home (based on preference). Other factors included use of nationally recognised tools or their equivalent, for example Advance Care Planning, Preferred Priorities for Care, Gold Standards Framework and Liverpool Care Pathway.

Supporting People to Live and Die Well: Phase 2 implementation

The NEoLCP's Social Care Framework (SCF) – '*Supporting People to Live and Die Well'* – was rolled out between July 2010 and March 2011 through regional roadshows in each of the nine Association of Directors of Adults Social Services regions (ADASS) and through promotion at health and social care conferences and events. During this phase eight test-sites were also commissioned which reported in June 2011 and their results were disseminated at a showcasing event in October 2011. The NEoLCP enjoyed good support in this programme of work from the Department of Health's Social Care Directorate's Deputy Regional Directors and is keen to identify a joint action plan for Phase 2. A similar process is underway with ADASS: both partnerships are key to the success of the social care end of life care initiative to ensure sustainable service improvements in end of life care support and to embed these as part of the core business of Council's, local Commissioning Groups and Health and Well Being boards.

In Phase 2 the programme has identified three core workstreams:

Workstream 1: Embedding the Social Care Framework in front-line practice, service development and delivery in the regions.

This work is focused on specific initiatives put forward by the regions for NEoLCP support. The (modest) financial support is treated as pump-priming only, the intention being that these are not time-limited interventions but should become embedded in ongoing practice. The projects currently supported are

1. A Community Response to End of Life Care **(**Nigel Walker - Creative Commissioning)
2. Supporting Integrated Working Between Social Care and Primary Health Care (Yorkshire and Humberside Social Care End of Life Care Strategic Leads Group)
    - Hull workstream - Raising Primary Care professionals' awareness of the role of social care in end of life care.
    - Wakefield workstream – Support the effective contribution of domiciliary care workers to end of life care in multi disciplinary team meetings.
    - York workstream – Support the effective contribution of home care staff in end of life care pathways of care delivery.

3. Developing a Good Death Charter for People with Dementia and their Carers (North East Good Death Charter Group/ North East Dementia Alliance)
4. Using Action Learning to Embed End of Life Training in Social Work Teams (East Lancashire Palliative Care Partnership/Cumbria and Lancashire End of Life Network/Lancashire County Council)
5. Delivering Integrated End of Life Care Training through joint Social and Health Care Professional Education (Merseyside and West Cheshire Palliative and End of Life Care Network)
6. Developing Training from the *Prisons Route to Success* (Prisons RTS Project Working Group/Merseyside and Cheshire Palliative and End of Life Care Network)
7. End of Life within Dementia Care Homes **(**Derby City Council/Derbyshire CCG/Making Space)
8. A Joint Social and Health Care Training Needs Analysis and Scoping Exercise for the Delivery of Integrated End of Life Care (Norfolk County Council/Norfolk Community Health and Care NHS Trust/NHS Great Yarmouth and Waveney/NHS County Workforce Group/Anglia Cancer Network).
9. An approach to localised involvement and development in support of people at End of Life - including family carers and people living and dying with dementia (South of England Health and Social Care Partnership)
10. End-of-life intervention skills: consultation and education for Bromley social care staff (St Christopher's Hospice/London Borough of Bromley).

In addition to these specific initiatives, work is ongoing to develop networks of end of life care leads in local Councils and end of life care champions across social care.

Workstream 2: Maintaining and developing strategic partnerships, innovation and service implementation in the social care world

- ADASS: The ADASS executive group have endorsed an advisory audit and RAG rating system for end of life care which will more systematically assess progress on the delivering of the end of life care social care framework in local areas and will be used to disseminate, promote and network best practice. The advisory framework will provide a focus on
    - awareness raising through Council, Public Health and Voluntary and Community Faith sector networks in end of life care
    - identifying robust joint commissioning of end of life care
    - integrated service delivery models across health and social care
    - contract and service specifications covering end of life care standards

    - networks between specialist palliative care and generic social care teams, end of life care needs into core assessment, support planning and personalised systems
    - early identification for end of life care needs and best use of the Mental Capacity Act
    - workforce and devolvement initiatives supporting end of life care across the social care sector; and
    - promoting culture change in Councils in relation to end of life care.

  This will complement ADASS guidance supporting the implementation of the Care and Support White Paper and related project work on the Palliative Care Funding pilots.
- National Institute of Health Research School for Social Care Research: end of life care remains a key research question for them. The London School of Economics is to undertake modelling and economic evaluations of selected Phase 2 interventions in Yorkshire and Humberside and London.
- College of Social Work: co-badged a *'Route to Success'* (RTS) guide for achieving best quality practice in social work when supporting people with end of life care needs. The guide was developed by a stakeholder group and launched in July 2012. The College of Social Work is also considering pursuing the possibility of an end of life care community of interest forum for its members.
- Association of Palliative Care Social Workers (APCSW): coordinating the development and maintenance of the end of life care champion's network for NEoLCP.
- Social Care Institute of Excellence: development of their end of life care platform and other dissemination activities.
- Skills for Care: they worked closely to support the implementation of the Social Care Framework in the Phase 1 roadshows and there is continuing liaison over e-learning and other initiatives.

***Workstream 3**: Promoting end of life care in social work practice and social work education.*

There are three parts to this workstream

- The *Route to Success* guides and the College of Social Work community of interest forum
- Rolling out training and mentoring schemes for qualified social workers from test-sites and phase 2 projects.
- Securing end of life care modules in social work qualifying programmes. Though at a comparatively early stage, knowledge and skills around death, dying and bereavement has been inserted into the amended Professional Capabilities Framework for social workers. We are also working with the Joint University Council Social Work Education Committee (which coordinates policy and developments across higher educational training establishments in

social care policy and education) and the College of Social Work on a proposal to develop a curriculum guide in end of life care to accompany the Professional Capabilities Framework.

TEST - Training; Engagement; Services; Transferability and Sustainability

As part of the objective to ensure a rigorous approach to best quality practice, evidence and tools developed from Phase 1 have been mapped across these four themes to produce a signposting document as a core resource for Phase 2 of implementing *'Supporting People to Live and Die Well'*. This will be widely disseminated in hard copy as well as being online. The aim is also to convert the learning from the ten projects listed above into an interactive resource which can be more widely used and disseminated.

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

Electronic Palliative Care Coordination Systems (EPaCCS)
The acute sector - the Transform Programme
Carers Strategy
Hospice capital grants

"The NHS has no idea what was going on. The GP and Hospital were strangers".
"I found all the various agencies did not speak to each other".
"I know everything is down to money but care at home needs thorough overhauling".
"I am sure he would have appreciated an occasional visit from his GP, then I think his doctor would have realised how much his condition had deteriorated".
"It was the hospital and the residential care home that got him the care package that was put in place".
"The nurse consultant in palliative care was fantastic and once he agreed the end of life pathway everything improved".
"In her final days (at home), her GP and staff were really good and understanding to Mum and us. The District Nurse came daily for the last three days and she was also very good ... and was with us when Mum passed away, which we appreciated a lot".

First national VOICES survey of bereaved people, July 2012

Communication, both between care providers and between professionals and the public, is a constant refrain in the End of Life Care Strategy. This Chapter focuses on the work in hand to improve this aspect of quality and productivity.

EPaCCS

Electronic Palliative Care Coordination Systems (EPaCCS) is the term now in use for the locality end of life care registers described in the End of Life Care Strategy.

Following successful pilots from October 2009 to March 2011, evaluated by Ipsos MORI,[2] the National End of Life Care Programme (NEoLCP) has led on spreading uptake across England.

EPaCCS provide a means of recording and communicating key information about people's wishes and preferences for end of life care. They aim to improve coordination of care so that end of life care wishes can be met and more people are able to die in the place of their choosing and with their preferred care package. As well as making significant improvements in care quality EPaCCS should also have

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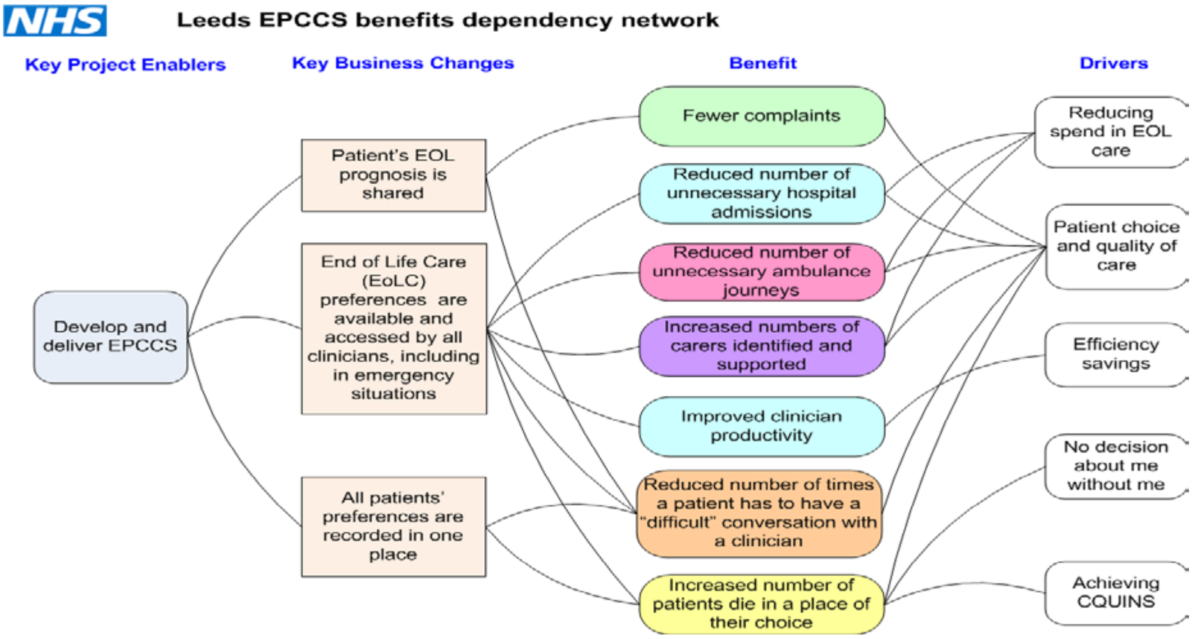
[2] End of Life Locality Registers Evaluation: Final Report. Ipsos MORI. June 2011. Available: http://www.endoflifecareforadults.nhs.uk/publications/localities-registers-report

the potential to generate efficiency savings through reductions in unwanted and inappropriate interventions and emergency admissions to hospital[3].

The benefits dependency diagram below, reproduced by kind permission from Karen Henry, Palliative Care Team Leader Leeds Teaching Hospitals Trust, summarises where and how EPaCCS is expected to improve the quality and efficiency of services.



Building on the learning from the pilots, the NEoLCP and the Department developed a national information standard (End of Life Care Co-ordination: core content[4]), which has been approved by the Information Standards Board for Health and Social Care. The standard was published on 20 March 2012 and specifies the core record content to be held in end of life care coordination systems, facilitating the consistent recording of information by health and social care agencies and, with the consent of the individual, supporting safe and effective management and sharing of information.

Implementation Guidance[5] has been published to support commissioners, health and social care organisations and IT systems suppliers in implementation of the standard and EPaCCS and to inform local decision making. The standard requires

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[3] The information strategy for public health, adult social care and for the NHS in England (Dept. of Health, May 2012) http://informationstrategy.dh.gov.uk/category/case-studies, , /, http://informationstrategy.dh.gov.uk/epaccs,
or http://informationstrategy.dh.gov.uk/end-of-life-care-intelligence-network/

[4] End of Life Care Co-ordination: core content. http://www.endoflifecareforadults.nhs.uk/strategy/strategy/coordination-of-care/end-of-life-care-information-standard

[5] End of Life Care Co-ordination Implementation Guidance. National End of Life Care Programme. March 2012. http://www.endoflifecareforadults.nhs.uk/publications/implementation-guidance

all IT systems and software supplier contracts for new EPaCCS issued after 20th March 2012 to specify the requirement for systems to be compliant with the new standard. Where an EPaCCS is already in place, suppliers must ensure systems are compliant by 1 December 2013.

The standard allows for local determination and configuration of the electronic record systems and platforms. Local areas may decide to extend data items beyond the core requirement depending on their own circumstances. A wide range of different implementation approaches are currently being adopted, including Advanced Health and Care (Adastra), SystmOne, McKesson and Summary Care Record (SCR) reflecting the regional differences in systems and size of the locality being covered. Other systems such as EMIS Web and the Medical Interoperability Gateway (MIG) are similarly being considered.

National implementation has also been supported by specialist technical support from the Department of Health's Informatics team. In particular, they have been working on development of Interoperability Toolkit (ITK) interoperability specifications to enable EPaCCS to be used easily regardless of system supplier. Working in collaboration with the ITK team, work is underway to define interoperability specifications that will enable different clinical systems to share data consistently within stringent clinical governance rules. This will ensure that clinical needs are met to support co-ordinated care for people with long term conditions and those approaching the end of life.

The focus this year therefore has been to provide central support to localities through:

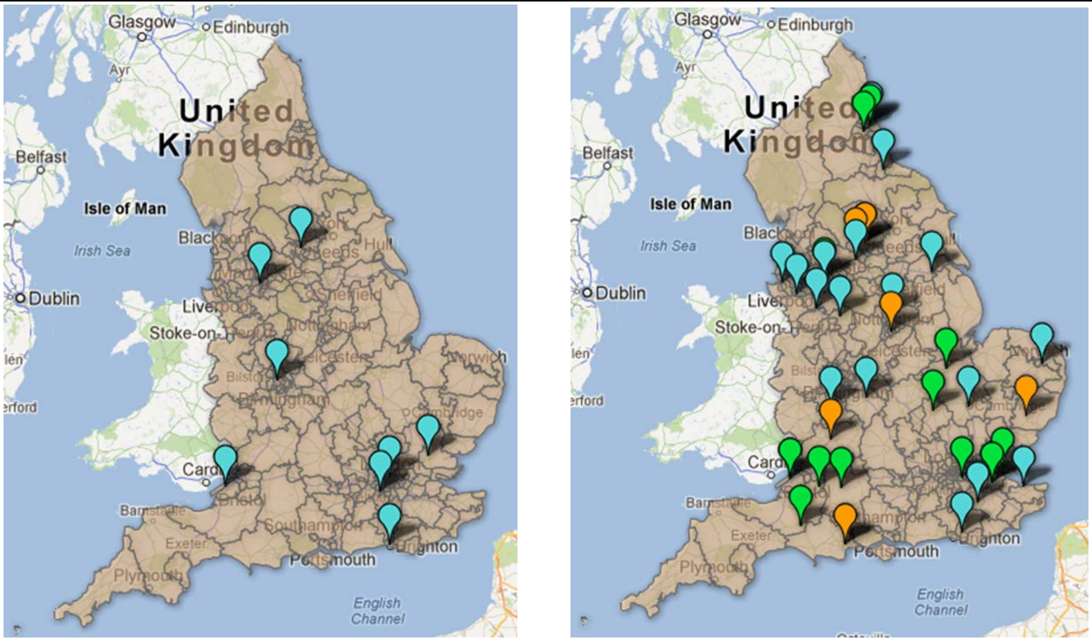
- facilitation of widespread implementation and uptake of EPaCCS;
- assessment of EPaCCS' impact on improving the quality of end of life care in supporting delivery of preferred place of care and preferred place of death; and,
- delivering the information standard and developing national enablers, such as the interoperability standards, to support data sharing across different clinical systems.

Over the last year the national EPaCCS implementation project team has -

- ***Facilitated deployment of the information standard in relevant health and social care organisations and supported appropriate use of the guidance;***
- ***Provided central support to local EPaCCS implementations across localities in England;***
- ***Developed a collaboration space on NHS Networks for sharing of good practice and discussion of key issues for implementers;***
- ***Provided central technological and informatics support for local delivery of strategic EPaCCS solutions***
- ***Provided a central monitoring function to periodically monitor the progress', spread and impact of EPaCCS;***
- ***Reviewed the national information standard as required by the Information Standards Board for Health and Social Care;***
- ***Provided support and issue resolution to organisations implementing the standard.- evidenced by website, call handling/query management protocol and risk log/escalation process for clinical safety issue; and***
- ***Held a number of regional EPaCCS roadshows to showcase best practice.***

Locality register pilots (2010-11) update

Mid 2012 EPaCCS status



Blue: Pilot sites, Green: Full implementation, Orange: Partial implementation, Blue: Projects being planned

Map data © 2012 Basarsoft, GIS Innovatsia, GeoBasis-DE-BKG (©2009), Google, Tele-Atlas 2011 Google [ed note: Please display attribution within or immediately adjacent to the visual, and ensure it is readable]
CCG geographical data sourced from NHS Commissioning Board

While these maps show the central host for each EPaCCS it does not show their coverage. EPaCCS vary in size. In the South West, the EPaCCS led from Weston covers almost the entire SHA region, while London's Coordinate My Care is city wide. Other EPaCCS are smaller.

In South Essex PCT of those people who were on the EPaCCS register and stated a preference 70% achieved Preferred Place of Death.
Of those dying whilst on the register, 18% died in hospital, whereas 46% died at home.

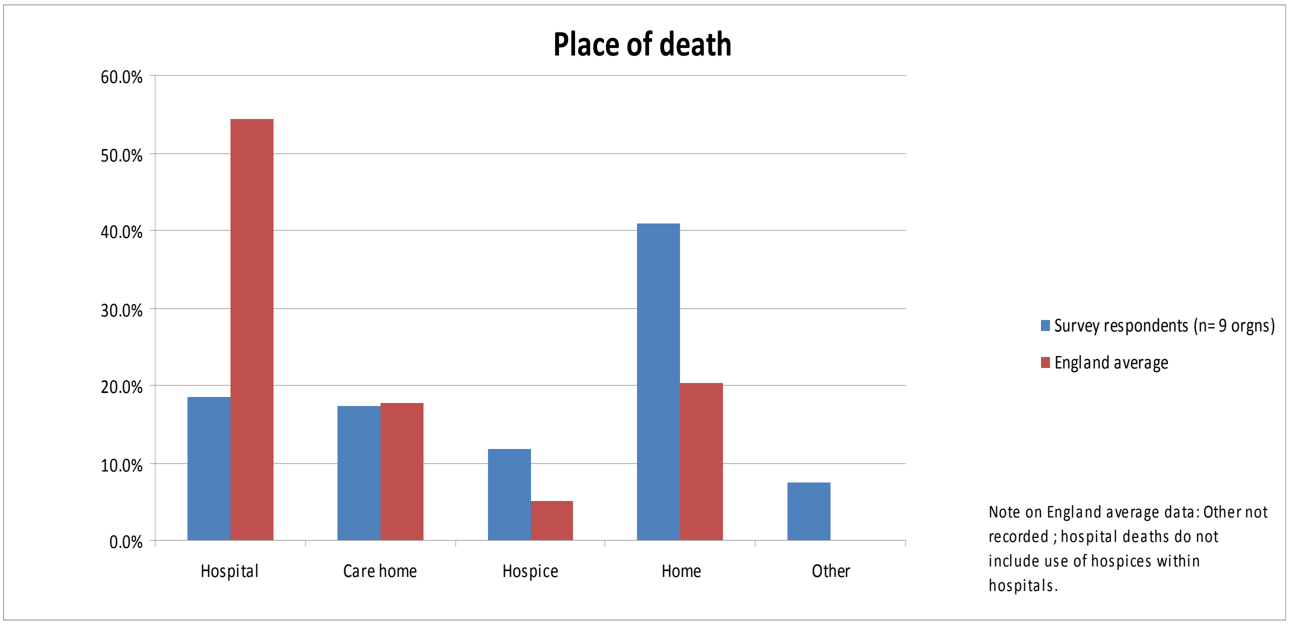
In London, where Coordinate My Care (McKesson, Liquid Logic) is being rolled out as an SHA-wide EPaCCS, 2198 patients had a record on its EPaCCS system. Of those that have died on the register, (n= 429) figures show that 51% died in their usual place of residence (DiUPR) whilst 24% died in hospital; the national DiUPR rolling average for the same time period is 41.7%. The quality of end of life care in London is undergoing radical change; the EPaCCS is an important part of that change.

In the South West their EPaCCS system now supports 14 PCTs across the region, sharing end of life care preferences with out of hours services, GPs, A&E, community health providers, social care and specialist palliative care. Controlled access to the record is via a shared web

Salford has built on its own integrated record also called Co-ordinate My Care. Early data show that actual place of death, where known, for those added to their system during 2011-12 was 61% care home (residential or nursing), 27% at home, and 6% in hospital. The high percentage shown for care homes reflects the fact that in Salford there is a dedicated Care Homes Practice that has been at the forefront of identifying, and recording details for, patients in their last year of life.

Where EPaCCS is becoming established it is also beginning to show outcomes. While sample sizes are still small, some sites report achieving Preferred Place of Death for 70% to 80% of those on a register. Deaths in hospital have more than halved for others.

When the place of death data is compared for all EPaCCS early adopters (who provided relevant data) against the English national average baseline data there is emerging evidence that EPaCCS are helping to support people to achieve choice and to die in their usual place of residence (if such is their wish).



Source: England average - NEOLCIN end of life care profiles - Place of death 2008-10 - http://www.endoflifecare-intelligence.org.uk/profiles/pct/atlas.html

Source: EPaCCS mid 2012 survey

Additional EPaCCS benefits are also being reported across early adopter sites including:

- The ability to co-ordinate care for long term conditions patients who may be entering their last year of life;
- Provision of a single point of access for key end of life care information about people that helps support patient choice and avoid unnecessary hospital admission. This is further enhanced where the EPaCCS is linked to a care co-ordination system such as that employed in Bedfordshire;
- EPaCCS implementations facilitating wider end of life care service transformation and education programmes;
- The availability of key data from EPaCCS is supporting QOF reports, as currently being used within the South West, and is informing future commissioning plans; and,
- EPaCCS implementations are bringing clinicians, commissioners and IT leads together to work collaboratively to help deliver a good death; sharing data is just one of many ways in which this can happen.

Key points for EPaCCS implementation

- Ensure full compliance with the information standard
- Link implementation to other strategic projects such as 111 roll out and care co-ordination centre developments as has been done in London, South Central and South of Tyne and Wear
- Assess the current IT infrastructure and landscape and build upon the best of what already exists – don't restart from scratch
- Involve all key stakeholders; be clear about the vision and get senior 'buy-in' across health and social care from the start. GPs were top priority for rollout for the majority of early adopters, followed by community providers, out of hours and ambulance services, and acute hospitals. Don't forget commissioners.
- Collect baseline data to support the case for change and allow measurement of change over time
- Be realistic about what can be achieved.
- Consider a phased approach to implementation across care settings
- Local datasets, in addition to the core data set that complies with the information standard, will need to be agreed and coding identified/developed.
- Agreeing an approach to reporting and monitoring will be of benefit. In Somerset, a reporting template is in use of which others are taking note
- Recognise that N3 access is a key issue to be addressed

Next Steps

Building on well established links with partners working on long term conditions (LTC) we are now working across programmes to integrate and look for shared solutions. For example, all of the ITK work will support activity across the LTC, end of life care and frailty pathways as a key system redesign/enabler to facilitate delivery of care nearer to a person's usual place of residence.

- See http://www.endoflifecareforadults.nhs.uk/strategy/strategy/coordination-of-care/end-of-life-care-information-standard for detailed information on EPaCCS
- The national EPaCCS implementation team will be initiating widespread consultation on the interoperability standards in the early autumn. http://www.networks.nhs.uk/nhs-networks/qipp-digital-technology-and-vision

Areas are adopting EPaCCS in ways which meet their own local need.

NHS Bedfordshire - Partnership for Excellence in Palliative Support (PEPS)

Across Bedfordshire, a single telephone number and central hub hosted by Sue Ryder was established to co-ordinate all palliative care 24 hours a day, 365 days a year using a shared electronic record on SystmOne. Led by NHS Bedfordshire and Sue Ryder, 15 organisations now work in partnership to improve the experience and continuity of care for patients in the last 12 months of life. PEPS also supports generalist health and social care professionals to provide care at the patients' place of choice which is predominately at home.

Senior nurses are the first point of contact on the phone for patients, families, carers and health and social care professionals so that the most appropriate health or social care professional is identified to help patients in a timely manner.

An electronic palliative care coordination system (EPaCCS) was developed to enable sharing of patient information utilising SystmOne. An information-sharing protocol and patient consent forms are in place to support this.

Other services have been extended to enable equity across the county – eg. Face to Face palliative nurse assessment out of hours, a palliative care support worker service and extended hospice admission times.

Organisations committed to working together to deliver PEPS through signing a memorandum of understanding. Individual meetings were also set up with CEOs and a project group involving clinicians developed the operational policy.

The service is being evaluated, working with ScHARR (School of Health and Related Research at Sheffield University). Since it began on 29th December 2011, 476 people have been registered with PEPS. Figures to the end of May 2012 showed that of 156 deaths 69% were at home (including residential and nursing homes), 8% in hospital and18% in a hospice.

Initial findings are positive, and include:

- Improved integration of acute and community care through hospital engagement.
- The MDT team, through working with PEPS, are discharging patients home more rapidly. The local hospital is now looking to install a SystmOne read only facility to support this process.
- The co-ordination centre has been instrumental in supporting families between discharge and start of care package arrangements.

Feedback about the service has been very positive from GPs, patients and their relatives. Patients and families report feeling “secure” and “not feeling left alone”,

“Rather than giving long and complicated explanations about the different roles of people who might get involved in care, this single point of contact is much less confusing for patients. They can also be confident that they can make one call when they need help and someone else will decide who is best placed to help them and arrange that contact." (NHS Beds GP)

Jo Marshall
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The acute sector – the Transform Programme

Whilst the End of Life Care Strategy places great emphasis on community based services to support people to be cared for at home, hospitals continue to play a major role in care at the end of life. Many people will need some hospital care in their final year and for many, hospital will be the right setting for their final days, whether or not it would be their first choice as a place of care. It is therefore crucial that we continue to work to improve hospital based end of life care so that a 'good' death can be achieved wherever the setting.

The NEoLCP is addressing this specifically through the Acute Hospitals Transform Programme, working with 25 Acute Trusts representing 43 hospitals from across the country in a 12 month programme based on implementing *The route to success in end of life care – achieving quality in acute hospitals* (NEoLCP, 2010). Each Trust has been supported by a comprehensive *Transforming end of life care in acute hospitals 'How to' guide* developed in partnership with the NHS Institute for Improvement and Innovation (NEoLCP, 2012). The guide recommends that boards develop a trust level end of life care action plan, an education and training plan around end of life care and monitor the quality and outcomes of individual care / patient experience. Education and training good practice examples highlighted amongst many others during the programme have included:

- one to one training for consultants Laura.McTague@dbh.nhs.uk; and,
- end of life care training included in induction / preceptorship courses Carolyn.Harper@ghnt.nhs.uk

While noting that direction and support from an 'executive lead' is crucial, the NHSI Productive Ward approach used within the *'How to'* guide centres on encouraging and supporting frontline staff to consider for themselves how their working practices and services can be streamlined and improved. Ward leaders and champions are identified as particularly important in supporting this change process.

The guide follows the six step end of life care pathway which formed the basis of the route to success. For each step of the pathway it outlines key actions, examples of good practice and sources of information and support. Rather than introducing yet more new tools the Transform Programme's main emphasis is on the implementation of five key existing system wide enablers (case studies shared throughout this report):

- Advance Care Planning

- Electronic Palliative Care Co-ordination Systems
- The AMBER Care Bundle
- The Rapid Discharge Home to Die Pathway
- The Liverpool Care Pathway.

Now entering its second phase the programme will be working with approximately 40 more acute hospitals nationally to share key learning and service improvements which have been achieved using simple productive principles and the five tried and tested key enablers.

Phase One participating Trusts

Phase 2 Trusts will:

- Receive electronic and hard copies of the *'How to'* guide, containing useful resources and podcasts;
- Be supported by neighbouring Phase 1 sites;
- Be provided with simple metrics that help them measure their own success;

- Be invited to an end of first year event at the Royal Society of Medicine in December 2012;
- Be invited to a national sharing event with Phase 1 and Phase 2 sites in March 2013.

Carers' Strategy

The Coalition Government continues to take forward the commitments set out in *Recognised, valued and supported: next steps for the Carers Strategy*.

The Department of Health funded a programme of activities by the RCGP, Carers Trust and Carers UK to increase awareness of carers' needs for support among health care professionals. This programme included the appointment of GP Carer Champions and volunteer Carer Ambassadors, the provision of in house training and the dissemination of good practice. The Department is planning to build on this work programme further in 2012/13, including extension to the acute hospital sector and community nursing.

Independent evaluations of two Department of Health funded initiatives were published in November 2011:

New Approaches to Supporting Carers' Health and Well-being: Evidence from the National Carers Strategy Demonstrator Sites programme
http://www.sociology.leeds.ac.uk/circle/news/new-approaches.php

Training and Supporting Carers: the National Evaluation of the Caring with Confidence programme
http://www.sociology.leeds.ac.uk/circle/circle-projects/completed-projects/evaluation-of-the-caring-with-confidence-programme.php

In June 2012 the Department of Health co-hosted a National Summit with Employers for Carers, which kick started some joint working to consider what further steps might be taken to support carers to remain in paid employment, if that is what they wish to do.

Carers are central to the Government's proposals for care and support as set out in the White Paper *Caring for our Future* and the draft Care and Support Bill. We will be legislating to extend the existing rights to a carer's assessment and provide carers with a new entitlement to support to meet their needs. For the first time carers will be placed on the same legal footing as the people they care for.

The draft mandate for the NHS Commissioning Board, which will be at the heart of the accountability relationship between the Department of Health and the Board from April 2013, contains a specific objective to improve the support that carers receive from the NHS by earlier identification of carers and signposting to advice and by working collaboratively with local authorities and carers' organisations to enable the provision of a range of support.

Hospice Capital Grant

In May the Department announced a new £60 million capital grant scheme for hospices. This scheme is open to both adults' and children's hospices. Help the Hospices are managing the scheme and have run a series of roadshows to help hospices to understand the process and requirements. The eligibility criteria are available on their website. The deadline for applications is 5 November and successful hospices will be informed of the outcome in March 2013.

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

Rapid discharge
Liverpool Care Pathway
Death certification
Bereavement
Tell Us Once

"When she was in hospital, she wanted to come home to die. There was a lot of stress on the family."
"The (hospital) staff were very supportive to us as a family for which we were very grateful. We as a family were allowed to stay with him 24/7 and we looked after all of his needs."
"My husband died peacefully. Staff were kind and considerate and it was a comfort to me and the family".
"My whole family found the attitude of the doctors and nursing staff deplorable. We should put in a complaint but due to our sadness we just wanted to remove ourselves from the hospital as quickly as possible".
"The McMillan nurse provided the best - and only - emotional support for both mum and our family. We had confidence in her care".

First national VOICES survey of bereaved people, July 2012

Rapid discharge home to die pathway (Transform Programme Key Enabler)

Many hospitals now operate a rapid discharge scheme to enable dying patients to be transferred home within 24-48 hours. Some are even working towards discharge within four hours for especially urgent cases.

All this requires clear pathways based on local procedures and close co-ordination between all those involved. It also needs to take account of local working practices. For example, some district nursing services will not care for someone at the end of life if there is not a hospital bed within the home, so this may need careful advance planning.

The handover of medication is also important. This means good documentation is needed, using local prescription formats, to ensure that the medications started in hospital can be given by community staff without having to wait for a GP to prescribe them.

Ideally a member of the hospital staff should accompany the person home where they would be met by community staff. Face-to-face handovers tends to be more effective, although this is not always possible.

Another critical element is careful, sensitive discussion with the individual and their family so they understand the implications of a transfer. It also makes sense to place relevant information on Electronic Palliative Care Coordination Systems (EPaCCS), where established, to ensure care is co-ordinated between the different services.

Royal Liverpool and Broadgreen University Hospitals Trust

The Royal Liverpool and Broadgreen University Hospitals Trust has been operating a rapid discharge pathway for the last 10 years. Two years ago the Hospital Specialist Palliative Care Team made a number of changes to bring it into line with version 12 of the Liverpool Care Pathway for the Dying Patient.

A stakeholder meeting was used to address several key themes that had the potential to delay the smooth operation of the discharge process. These were:

- the release of key medications from pharmacy;
- the production of equipment for the home; and
- the speed of response of the ambulance service.

In most cases this was a matter of speeding up the process but with equipment, for example, it could be a matter of deciding which the priority was: locating the right equipment or getting the patient home. The key was flexibility and placing the patient’s wishes at the heart of everything.

The team also established two levels of urgency for those awaiting rapid discharge. In future it would aim to discharge level one patients within six hours while level two patients would be discharged within 12-24 hours.

The result has been a more streamlined service with all those who expressed the wish to go home to die achieving their wishes within the allotted time. Inevitably, in such a fast-moving scenario, some change their minds. Some families start going through the process and then for one reason or another they find they can’t do this and the patient stays in hospital.

The key to success is close co-ordination and good teamwork, working very closely with the discharge planning team. Joint meetings with them and, especially, with the patient and family are key to find out what their expectations are.

An average of 30 patients return home each year through the rapid discharge pathway, and so far none has had to be readmitted or re-referred.

The Liverpool Care Pathway (LCP) for the Dying Patient

The LCP is a multi-professional, outcome-driven document that provides an evidence-based framework for the delivery of care in the last days or hours of life. The use of the document should be underpinned by an implementation, education and training programme and sit within the governance agenda of individual organisations. It has been identified as best practice within the National Institute for Health and Clinical Excellence (NICE) *Guidance for Supportive and Palliative Care*, was highlighted as one of three end of life care tools by the Department of Health and is recommended in the End of Life Care Strategy and Quality Markers.

Version 12 of the LCP, which was published in December 2009, retains the focus of earlier documents on communication, information and comfort care in the last hours and days of life. It also includes an algorithm to support the identification of the dying phase and more explicit goals on hydration, nutrition and skin integrity.

Over 2,000 organisations in the UK are currently registered with the LCP central team, including hospitals, hospices, care homes and home teams. In addition more than 20 countries outside the UK are working with the LCP.

Cheshire and Mersey Critical Care Network[12]

The Marie Curie Palliative Care Institute Liverpool (MCPCIL) has been running a pilot for the last nine months to introduce the latest version of the LCP into all 11 intensive care units within the Cheshire and Mersey Critical Care Network.

The project, funded by the Merseyside and Cheshire Cancer Network, has identified key champions in each site who meet on a monthly basis to discuss progress. They are also responsible for delivering education and training to their staff.

The LCP is an integral part of intensive care where, inevitably, the number of unexpected deaths tends to be high. One major difference from other areas of care is that the pathway may only come into play when decisions are taken to withdraw treatment and this may be very shortly before the patient's death.

When a patient is on a life support system then discussions start to take place involving the family and multidisciplinary team. If it is decided to withdraw treatment, the space of time between withdrawal and death can be measured in hours or even minutes.

So far 10 of the 11 sites have achieved their targets of providing training to the majority of CCU staff and have also placed an average of 17.5 patients on the adapted LCP. One site has been unable to meet the targets and will not therefore take part in the auditing process.

A final report on what has been achieved will be produced shortly.

The LCP and its associated audit, the National Care of the Dying (Hospitals) audit, is referenced in the NICE Quality Standard.

National Care of the Dying Audit Hospitals (NCDAH) Round 3

This audit has run now for three rounds to track progress on the implementation and use of the Liverpool Care Pathway for the dying patient (LCP). The third audit was able to draw on clinical data from over 7,000 individuals (from 127 NHS Trusts) whose care was supported by the LCP.

Organisational data

This time 131 hospital Trusts submitted data into the organisational element of the audit, an increase of 13% over Round 2. The data suggest the use of the LCP is relatively well spread throughout each individual trust, with almost all wards (90%) using the LCP to some extent. The proportion of all patients whose care was supported by the LCP national core document or 'matched alternative' has increased since NCDAH round 2 (R2 21%; R3 31%) which suggests that the LCP is becoming more embedded in practice within each participating hospital Trust. There is also an increase in the amount of education and training offered in care of the dying for medical staff (R2: 74%; R3: 90%).

Clinical data

178 hospitals (from 127 Trusts) submitted a total of 7058 individual patient data sets this time, which is a 13% increase on Round 2. Encouragingly, these showed that where assessments were recorded in the last 24 hours, the majority of patients were documented as comfortable.

There was wide variation in hospital performance for goals relating to conversations with the patient regarding awareness of dying, and addressing cultural, spiritual or religious needs. This suggests that practice across different hospitals may be very different, but this is an area of particular interest when compared to the experience of hospital care recorded through VOICES. However, where the data were recorded, they showed that where it was not possible to enter into discussion with the person these issues have been addressed with the relatives or carers:

- 94% of relatives/carers were given a full explanation of the care plan (LCP); healthcare professionals were able to discuss this with 56% of people at the end of life;
- 97% of relatives/carers were aware that the person was dying; healthcare professionals were able to discuss this with 58% of people at the end of life;
- 90% of relatives/carers were given the opportunity to discuss any spiritual/religious/cultural requirements at this time; healthcare professionals were able to discuss this with 61% of people at the end of life.

Leeds Teaching Hospitals Trust – Equivalent LCP

An equivalent LCP (ELCP) was developed to ensure that Intensive Care Unit (ICU) patients, who may die imminently once life sustaining treatment is withdrawn, receive high quality care akin to those patients who are cared for in accordance with the Liverpool Care Pathway (LCP). The ELCP is a four page document that addresses communication with relatives or carers, spirituality, medications, discontinuation of interventions and organ donation. The ELCP includes a withdrawal of support algorithm to assist the Multi-Disciplinary Team (MDT) in their decision making. Initially the Specialist Palliative Care Team engaged with staff from five ICUs across Leeds Teaching Hospitals Trust (LTHT) in an effort to understand the reasons behind poor adoption of the ICU LCP (11% use in comparison with 42% use of the generic LCP throughout the rest of LTHT (*April 2011-Oct 2011)*).

Critical care teams felt that the LCP was too lengthy, took too long to complete and assessment time intervals were inappropriate to be of any value to those patients who were expected to die imminently upon withdrawal of life sustaining treatment. The new document was designed collaboratively between specialist palliative care team members and critical care staff using an iterative process giving careful consideration to the four domains of care covered by the LCP – physical, psychological, social & spiritual. The emphasis was on the facilitation of optimal care delivery supported by concise documentation.

Since the introduction of the ELCP in ICU there has been a 20% increase in use of end of life pathways within LTHT ICUs. In March 2012, 43% of patients who died on LTHT ICUs were treated according to an end of life care pathway. It is anticipated that this will continue to rise with an estimated 50% of patients in ICU who die being cared for in accordance with the ELCP or LCP by March 2013.

The next step to ensure the delivery of high quality end of life care in critical care environments is the implementation of the ELCP in A&E departments.

The Leeds Teaching Hospitals Trust End of Life Care Pathway Facilitators play a key role in sustaining the use of the ELCP through training, support, monitoring and audit.

Death certification

The Department has been piloting a new medical examiner service to improve the robustness and accuracy of death certification. This will meet a recommendation in the Shipman report which found that the public had lost confidence in the current processes. The new system will apply to all non-coronial cases regardless of whether the family chooses cremation or burial. The Health and Social Care Act 2012 provides for the new service to be run by local authorities. The Department will consult on the draft regulations later this year. Implementation is due to begin in April 2014.

Bereavement

Last year we reported publication of a set of draft Quality Markers for bereavement. These were considered by NICE as part of the process for developing the Quality Standard for end of life care for adults, which covers bereavement issues.

The Birmingham Bereavement Project

This project was hosted by University Hospitals Birmingham Foundation Trust in collaboration with the Heart of England Foundation Trust and NHS West Midlands. It involved establishing a model for providing seamless bereavement care, including a help and support service for those who had been bereaved.

Bereavement staff aimed to contact all bereaved relatives four weeks after a death to discuss how they were and whether they had any questions or concerns.
During the pilot 1,856 bereaved families were offered the service and 725 took up the offer of the call. The vast majority – 94% - required only one call but a small minority needed further help. The report of the pilot says "It is believed that these follow-up phone calls facilitated early intervention and [resolved] situations which, if left unaddressed, would have resulted in a costly formal complaint."

The project was boosted by becoming an early adopter of the new death certification process. This led to more open and honest communication with families, enhanced training and education for junior doctors and provided more accurate information about causes of death.

The report recommends that the project – which has been shortlisted for a *Nursing Times* award - should continue in both participating trusts and that six-monthly reviews should be established to ensure its benefits are maintained.

A new advice website and helpline has been set up as part of the project.
http://www.birminghambereavementadvice.co.uk/about-us.php

Tell Us Once

Guest contribution by Jonathan Stampton, Tell Us Once Delivery Partnerships Team

Bereavement is a very difficult time for people and it doesn't need to be made harder by government red tape. The *Tell Us Once* service makes reporting a death easier and saves people having to notify numerous central government and council services.

Before *Tell Us Once*, on average, a person experiencing a bereavement would have to contact government seven times. Each time they often had to post off a death certificate which could be expensive as well as time consuming.

Tell Us Once is a much easier way to report a death and there are three channels to choose from: a face-to-face interview, dedicated telephone line or online service. The service notifies 28 key local and central government departments and services in a single appointment with the local authority. These services include: State Pension; Council Housing; Council Tax Benefit; UK Passport; Library Services; Personal taxation; and Driving licence.

Tell Us Once is now available in 80% of local authorities in England, Scotland and Wales and coverage will rise to about 90% in the next few months. Although voluntary, the new service is popular with the people that use it and where it is available, is already chosen by about 70% of people reporting a death.

Further information can be found at: www.direct.gov.uk/death-tellusonce Contact: Jonathan.stampton@dwp.gsi.gov.uk

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

Commissioning in the new NHS
NICE Quality Standard and benchmarking tool
End of Life Care Quality Assessment
Workforce - e-learning
Personal health budgets
Palliative Care Funding

> "I wish to say that the care my mother received during the last few hours and minutes of her life was to an excellent standard. As you can tell, it is my lasting and peaceful memory and that was all due to the thoughtfulness of the staff at X University Hospital."
> "Ward X was dreadful for him; the nurses did not seem to care. .. Ward Y: the doctors and nurses were marvellous; they cared about him and us, the family".
> "The most distressing thing was being unable to get help with toileting etc due to time pressures of staff. He found it very distressing when the bell was ignored".
> "We did feel that the 'system' let Dad down. His condition was inadequately managed and our concerns ignored or dismissed".
>
> *First national VOICES survey of bereaved people, July 2012*

Commissioning in the new NHS

Over the last year the National End of Life Care Programme (NEoLCP) has been engaging with emerging Clinical Commissioning Groups (CCGs) to understand how best to support them as they take on responsibility for commissioning end of life care services. They are now working with a network of about 100 CCGs. They ran a series of six events across the country which attracted 600 delegates and which were well evaluated.

The events featured the Critical Success Factors (CSF) which the NEoLCP published this year. Following consultation with PCTs the consensus was that delivering high quality end of life care locally depended on a small number of CSFs:

- Strong commissioning and clinical leadership;
- Use of nationally recognised drivers that attract payment – Local Enhanced Services (LES) and Commissioning for Quality and Innovation (CQUINs);
- Flexible budgets and care packages – integrated care;

- Use of nationally recognised tools or their local equivalent – advance care planning (ACP), Gold Standard Framework (GSF), Liverpool Care Pathway (LCP), Preferred Priorities for Care (PPC), (After Death Audits) ADAs and Continuing Healthcare (CHC) Fast Track Pathway;
- Shared electronic information systems – Electronic Palliative Care Coordination Systems (EPaCCS);
- Clearly defined access to 24 hour cover;
- Development of care homes – service improvement in the acute sector will not be achievable without improvements in care homes;
- Use of facilitator roles and co-ordination of care across boundaries – integrated care;
- Training to support staff delivering end of life care.

Improving End of Life Care Services by moving to outcome-based contracts

The strategic end of life care (EoLC) Programme for NHS South of England Central was established in 2010. One of its first priorities was to bring together EoLC commissioners and providers from across health and social care and the statutory, voluntary and independent sectors to produce recommendations for contract negotiations. Given the success of this work, in 2011 EoLC was the first area chosen to implement outcome-based contract recommendations across acute, community, mental health and care home providers. Ensuring the contract inclusions follow the patient pathway, and are the same across all sectors and settings, means there are no perverse incentives in the system. Localities can work together on how most effectively to achieve the ultimate outcome of people achieving their preferred place of death. As this process has evolved it has also been possible to help providers move to a position where they can achieve this outcome, initially by asking that processes are in place for advance care planning and more recently that where people do not achieve their preferred place of death reasons for this are audited and an action plan put in place across the locality.

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NICE Quality Standard and guidance for commissioners

In November 2011 the National Institute for Health and Clinical Excellence (NICE) published a Quality Standard for end of life care for adults, followed in December by a *Guide for commissioners on end of life care for adults*, accompanied by a commissioning and benchmarking (CAB) tool.

The Guide applies to all adults approaching the end of life. It provides links to condition-specific materials but the overall message is that a generic approach will meet most needs. It is also clear that end of life care involves the NHS, social care and the voluntary sector.

The Guide is intended to support implementation of the Quality Standard, which itself broadly follows the structure of the end of life care pathway set out in the End of Life Care Strategy, with a special section for workforce.

In the CAB NICE has brought together the best available financial information for end of life care. It allows commissioners to select their local population and compare it against the national average and it will then model savings based on reducing the numbers of deaths in hospital. The guide also suggests that commissioners should carry out more detailed local analysis of factors such as admissions in the last year of life, type of admissions and variables such as cause of admission and condition. This in turn is supported by the locality profiles developed by the National End of Life Care Intelligence Network (NEoLCIN) and available on their website.

The NEoLCP has been working in partnership with commissioners to develop a web based toolkit which provides a one stop shop by identifying the relevant resources and sources of information and data to support effective end of life care commissioning. The toolkit is built on a four stage commissioning cycle and promotes joint working across social and health care services and is available on the NEoLCP website.
www.endoflifecareforadults.nhs.uk/

End of Life Care Quality Assessment (ELCQuA)

ELCQuA is an online tool available on the NEoLCIN website which allows localities to record, track and benchmark their progress against the Quality Markers and Measures published by the Department of Health in 2009. These are currently being updated to bring them into line with the NICE Quality Standard.

Workforce

Workforce development underpins the majority of end of life care service improvements as it not only increases levels of competence and confidence but also contributes to shifting behavioural change around end of life care. Examples of this can be seen in other sections of the report such as GP training in initiating conversations to support the *'Find your 1% Campaign'* and *Quality End of Life Care for All*, the partnership training between hospices and acute hospital nurses to support the Transform project.

Multi Professional Education and Training (MPET) funding has enabled local projects to be developed and embedded. The new opportunity for local commissioners and providers is to establish links to Local Education and Training Boards (LETBs) to influence decisions around education and training investment. Each constituent provider organisation within the LETB will be able to contribute to the identification and agreement of local priorities for the local workforce.

Nationally Skills for Care, Skills for Health and the NEoLCP produced an updated edition of their work on competences *Developing end of life practice: A guide to workforce development to support social care and health workers to apply common* *core principles and competences for end of life care.* Work is also planned to build on both the end of life care competences and the e-learning programme, End of Life Care for ALL (eELCA), to the Qualifications and Credit Framework (QCF). Developments include mapping elements of the 6 Steps programme for Care Homes to QCF.

eELCA now has 156 sessions to enable all health and social care staff free access to end of life care learning materials. Work has been undertaken in Oxfordshire to develop a series of blended learning pathways for volunteers, Band 5 nurses and GP Trainees with specialist palliative care services, acute staff, ambulance staff and out of hours staff. These pathways are being tested and should be widely available by the end of the year. e-Learning for Health and NEoLCP have launched a resource pack *e-ELCA getting started and support pack* which aims to help individuals or training facilitators get started and use it to best meet their own and professional needs.

Southport and Ormskirk NHS Trust – eELCA Case Study

Southport and Ormskirk NHS Trust have developed a new approach to end of life education. We are a large Integrated Care Organisation with two hospital sites and cross boundary primary care is a large part of our workforce. Our plan was to develop an education programme which all grades of staff can access and allows the staff the freedom to choose the level of education they require for their job and/or interest. We developed the name “Skills Set Challenge”

The basis of the Skills Set Challenge was the use of e-ELCA as a theoretical background to all education. By using the eight different “branches” or subject matters within e-ELCA we grew a “tree” of education. Each “branch” of the tree relates to a particular topic such as “symptom management”, and will have a bronze, silver and gold level within.

The e-ELCA sessions within each module have been allocated to a “bronze”, “silver” or “gold” level, and are being used as the theory to back up face to face teaching and established courses available within the Trust and Queenscourt Hospice.

There will be some skills training available within certain levels of the Challenge and reflective practise and case studies will cement knowledge already achieved. Staff will be encouraged to start at a bronze level and work their way around all the “branches” of the tree. Once all areas have been covered a Bronze Award will be presented in the form of a bronze edged pin badge depicting an oak tree.

Staff will be able to further their knowledge should they require or wish by undertaking course work at both silver and gold level. Similar awards will be available relating to the level of education achieved. Education already obtained, by the way of courses undertaken can be evidenced as part of the new pathway. Each level will require staff to evidence their achievements by the collection of certificates of e-ELCA modules completed and any training/courses attended. This will develop into an End of Life education portfolio.

e-ELCA was the basis for the new approach to end of life education and the overwhelming incentive to use the modules was the ease of access, the quality of education provided and the ability to use/study with e-ELCA at home, away from the work environment.

Initial trials have proven a positive response and we aim to roll out Trust wide in the coming weeks to coincide with the London Olympics.

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NHS Midlands & East – East of England End of Life Care ABC Education Programme for Group B Staff

The ABC education programme is funded for two years and is available to all Group B Staff (health and social care professionals who frequently deal with end of life care as a part of their role) in acute and primary care trusts throughout the East of England. This free of charge, blended learning programme (e-learning and face to face sessions with an identified mentor) is based upon the End of Life Care Strategy (2008) and end of life care core competencies (2009). It is designed to give learners a broad introduction and overview to end of life care.

The programme makes use of 10 ‘essential’ e-learning sessions from the national programme of over 150 sessions within e-ELCA. The education is based upon the five competency areas:

- Overarching Principles
- Advance care planning
- Assessment
- Communication Skills
- Symptom management, comfort and well being

This introductory course is designed to be flexible and takes approximately 6 hours over six weeks. The e learning sessions are now available as a single learning pathway on Oracle Learning Management (OLM) which is hoped will make access much easier for trainees. At the end of the e-learning students are encouraged to reflect on their learning to demonstrate the transition of theory to practice and are invited to take part in a consolidation workshop.

Due to difficulties with accessing the e-learning via OLM or eLearning for Health (eLfH), the East of England facilitators also provide the education via face to face workshops which are proving to be successful (see quotes below) and now over 800 Group B staff have been trained to date.

“I really enjoyed working through the 10 modules, which I could do at my own pace. I have learnt a lot and will hopefully make a difference to my patient care. I am now using the references to read more about end of life care”. (Staff Nurse, Oncology, Anglia)

What will change because of this experience? “I feel more confident at talking around these issues [end of life care] well before a patient is too ill to consider the situation and make plans personal to them. I realise that I have often been with patients who are so ill that sensible communication is past”. (GP, Essex)

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Opening the Spiritual Gate (e-OSG): *Reaching a critical mass of the workforce by the addition of e-learning.*

"People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences" (NICE, Quality Standard for end of life care for adults, 2011)

An established face to face study day to raise spiritual awareness 'Opening the Spiritual Gate' (OSG) is delivered to the health and social care workforce across Merseyside & Cheshire Cancer Network (MCCN) and Greater Manchester & Cheshire Cancer Network (GMCCN). The course consists of four modules or sessions:

- 'Understanding Meaning' - definitions, distress, religious needs, rites & rituals;
- 'Communication' - opening, maintaining and closing conversations in which the person is able to voice concerns and encouraged to make their own plan as well as dealing with questions about the health professionals own beliefs;
- 'Recording & Reporting' - consideration of how to document and hand over sensitive issues concisely and accurately, whilst maintaining confidentiality;
- 'Pulling it all together' - exploring how to meet national & network guidance, action planning for future care and mapping local spiritual resources.

MCCN funded Edgehill University to work with MCCN Spiritual Care Group to convert the OSG course to a 4 week, facilitated, constructivist, e-learning format.

As with the face to face version the facilitators are health professionals, role modelling the point that assessing and addressing spiritual needs of patients is a responsibility of everyone.

Eleven e-learning courses have been delivered now to 90 mixed health and social care professionals, compared to the 763 face to face. The main difference between the face to face and online OSG seems to be the opportunity for richness and depth of discussion due to greater anonymity and time for reflection and consolidation of thought, as well as the support each individual cohort provides for one other.

Many participants have said that this course has changed practice and documentation. Where whole, smaller, organisations have delivered the course to their entire workforce, audits are underway to demonstrate the differences that this has made.

Formal evaluation of the face to face and e-learning course is being undertaken this year and the course is proving of interest to individuals and organisations further afield.

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Personal health budgets

Personal health budgets are one way of giving people more choice and control over how their health needs are met, but they are new to the NHS. A pilot programme involving around half the PCTs in England has been running since 2009 and is due to end in October with the publication of an independent evaluation report.

Subject to this evaluation, personal health budgets will be rolled out more widely, with CCGs being able to offer them on a voluntary basis. The longer term aim is to introduce a right to a personal health budget for everyone who could benefit, with people receiving NHS Continuing Healthcare being the first to have a right to ask for one from April 2014.

A number of stories are available at: www.personalhealthbudgets.dh.gov.uk/About/Stories/ which describe what is involved and how people have used their personal health budgets. The examples include people paying for personal assistants to care for them or a loved one in their own home or using complementary therapy to help with pain relief.

Palliative Care Funding

The End of Life Care Strategy Third Annual Report referred to the work undertaken by the independent Palliative Care Funding Review.

One key conclusion of the review was that “There is a stunning lack of good data surrounding costs for palliative care in England.” It recommended that a number of pilots be set up to collect data and refine its proposals due to the lack of good quality data currently available. The Government accepted this recommendation.

In November 2011 the Department issued a call for expressions of interest in being a Palliative Care Funding pilot site. The response to this call was overwhelming, with a total of 65 submissions being received. Ministers selected and announced the seven adult and one children’s pilot site in March 2012.

The pilots are all local partnerships and the adult sites are being led by:

- NHS North Yorkshire and York
- St Christopher's Hospice, London
- University of Sheffield
- University Hospital Southampton NHS Foundation Trust

- The Heart of Kent Hospice
- Poole Hospital NHS Foundation Trust
- Royal Wolverhampton Hospitals NHS Trust

The pilot for children's services is a consortium being led by the following organisations:

- East of England Child Health and Wellbeing Team
- West Midlands Paediatric Palliative Care Network
- Great Ormond Street Hospital, London
- Northwest Children and Young Peoples Palliative Care Network

The pilots will collect the data that will provide the information we need to test the Palliative Care Funding Review's recommendations. The Government has provided £1.8 million funding support for the pilots over two years to March 2014.

This funding was increased in July this year to £3.6 million, following publication of the Care and Support White Paper. The White Paper considered there to be much merit in the Palliative Care Funding Review's recommendations on a fully integrated health and social care system at the end of life. The additional funds will enable the palliative care funding programme to look in detail at this proposal.

The Palliative Care Funding Pilots Working Group, chaired by Professor Sir Mike Richards, has been established and is monitoring the progress of the pilots.

Appendix – publications from the National End of Life Care Programme and the National End of Life Care Intelligence Network

- The route to success in end of life care – achieving quality for social work (July 2012)
- The route to success in end of life care – achieving quality for lesbian, gay, bisexual and transgender people (June 2012)
- TEST (Training, Engagement, Services, Transferability and sustainability): Supporting people to live and die well (May 2012)
- What do we know now that we didn't know a year ago? New intelligence on end of life care in England (NEoLCIN, May 2012)
- Planning for your future care (February 2012) and foreign language versions published in April 2012: Arabic, Bengali, Mandarin, Polish, Punjabi and Urdu
- End of life care co-ordination implementation guidance, record keeping guidance and record keeping summary (March 2012)
- Deaths from Liver Disease: Implications for end of life care in England (NEoLCIN, March 2012)
- The route to success in end of life care - achieving quality in ambulance services (February 2012)
- Transforming end of life care in acute hospitals: The route to success ‘how to’ guide (February 2012)
- Evaluating NEoLCP’s work to support and promote the integration of social and health care (The University of Nottingham, February 2012)
- Developing end of life care practice: A guide to workforce development to support social care and health workers to apply the common core principles and competences for end of life care (NEoLCP, Skills for Care, Skills for Health, February 2012)
- Critical success factors that enable individuals to die in their preferred place of death (February 2012)
- Deprivation and death: Variation in place and cause of death (NEoLCIN, February 2012)
- Independent evaluation of social care test sites (Centre for Housing Policy, the University of York, January 2012)
- When a person dies: guidance for professionals on developing bereavement services (Bereavement Services Association, Primary Care Commissioning, NEoLCP, October 2011)

- The route to success in end of life care – achieving quality in prisons and for prisoners (September 2011)
- Routes to success: achieving quality environments for care at end of life (August 2011)
- Preferred Priorities for Care tool support resources, including easy read version, electronic version and support sheet, (September 2011)
- End of life care in extra care housing: a learning resource pack