National Update

New roles from April

As we come to the end of March with parts of NEoLCP work finishing and other elements continuing as part of NHS Improving Quality (NHS IQ), I am pleased to confirm the following roles that NEoLCP members will take up from 1 April:

NHS IQ appointments
- Claire Henry: Head of Improvement Programmes (long-term conditions and end of life care)
- Jackie Main: Directorate Co-ordinator (long-term conditions and end of life care)
- Kate Henry: Communications Lead

Transferring into NHS IQ Delivery Team
- Anita Hayes: Leading work programmes on transforming eolc in acute hospitals and electronic palliative care co-ordination systems (EPaCCS)
- Rick O’Brien: Social Care Lead for eolc work programmes
- Elaine Bayliss: Programme Manager for EPaCCS
- Rachel Timms: Business Planning and Development Manager
- Sally Cook: Business Support Manager
- Amanda Read: Project Administrator for eolc work programmes

Public Health England
- Katie Lindsey: Project Manager for NEoLCIN and eolc information standard
- Kerry Archer-Dutton: Project Administrator for NEoLCIN and eolc information standard

External appointments
- Eleanor Sherwen: Patient Experience Manager, Essex LAT
- Margaret Holloway: returns to full-time academic work with the University of Hull.

Top international award for Claire

We are delighted to announce that Claire Henry has won the lifetime achievement award at the International Journal of Palliative Nursing Awards 2013.

The award ceremony, hosted by IPNP in collaboration with Macmillan Cancer Support, took place earlier this month in central London. Claire is pictured with journal’s Consultant Editor, Robert Becker.

Speaking afterwards, Claire said, “I’m truly honoured to have been nominated, let alone receive such a significant award. It is testament to the invaluable people I have cared for and those I have had the privilege to work for and with throughout my entire career. I am overwhelmed receiving this award.”

On behalf of everyone at the Programme I would like to say how proud we are of Claire and to thank her for everything she has done to make a difference to people’s lives and deaths. She has been an inspirational leader and a wonderful role model. More details of the awards appear on page 2.

Anita Hayes
Deputy Director

NEoLCP impact revealed

A rise in the last eight years in cancer deaths at home and in hospices and a fall in hospital deaths suggests the NEoLCP has helped more people to die in their preferred place of death, according to a new study.

The study, of cancer deaths in England between 1993 and 2010, was led by Dr Wei Gao and Professor Irene Higginson from King’s College London. It was funded by the NIHR HS&DR Programme and published in PLOS Medicine.

Throughout the study period, the authors found that hospital was the commonest place of death – accounting for 48% of cancer deaths - while 24.5% deaths were at home and 16.4% in hospices.

The authors say the downward trend in hospital deaths has coincided with the launch of the NEoLCP.

Claire Henry
National Programme Director
March 2013
LCP represents best practice, say consultants

Nine out of ten UK palliative medicine consultants say that the Liverpool Care Pathway represents best practice for the dying patient, according to an online survey by the BMJ and Channel 4’s Dispatches programme.

The same proportion of consultants said they would choose it for themselves if they were dying from a terminal illness and over 97% of consultants thought that the pathway allows patients to die with dignity when used correctly.

Almost three quarters (74%) of the palliative medicine consultants also thought that recent negative press coverage had led to less use of the LCP. Sixty per cent said patients and relatives had asked them not to use it and 80% said staff were apprehensive about relatives’ complaints.

Despite the media reports, hardly any doctors thought that pressure on beds or other resources had influenced decisions to use the pathway. Only 13% of all doctors agreed that hospitals should be offered financial incentives for using the pathway, with over half (58%) disagreeing.

Dr Fiona Godlee, BMJ Editor in Chief, said: “The recent adverse media coverage has been misleading and has damaged patient care. I hope this survey goes some way to restoring public confidence in the pathway as a reasonable and compassionate choice for patients and their families when making decisions about end of life care.”

Baroness Julia Neuberger will be holding sessions with families and carers to listen to their experiences of the LCP as part of her review. The next session will be on 16 May in Preston. The review is also asking for submissions from professionals, either as individuals or from organisations. The closing date for responses is 5 April. For more information email liverpoolcarepathwayreview@dh.gsi.gov.uk.

New CVD report urges end of life care reforms

Many people with cardiovascular disease are receiving suboptimal care at the end of life and are not dying in the place of their choice, says the Department of Health’s new Cardiovascular Disease Outcomes Strategy.

The report says that 62% of CVD patients still die in hospital despite the fact that the majority would prefer to die in their usual place of residence. Fewer than 1% are dying in hospices. More encouragingly, the proportion dying at home or in a care home has risen from 37% in 2004 to 43% in 2011.

The report recommends that people should be able to spend the closing stages of their lives in their preferred place of care and to die there. In addition “there should be fewer patients dying in hospital and when they do they should experience better care”.

It outlines what needs to be done to improve end of life care for people with CVD. These include timely identification of those in the last year of their life, training key staff in assessment of supportive care needs and advance care planning and ensuring people’s care needs are documented on registers.

Two other important drivers of change will be the spread of electronic palliative care co-ordination systems (eFaCCS) and implementation of the Transforming End of life care in acute hospitals initiative, both of which are now being taken forward within the new NHS IQ.

Bradford and Milton Keynes among IJPN award winners

Bradford Teaching Hospitals Foundation Trust Palliative Care Team won the multidisciplinary teamwork award at this year’s International Journal of Palliative Nursing awards in London. The Milton Keynes Hospital Palliative Care Team came second.

The Bradford team (pictured) has implemented the AMBER care bundle and made links with the locality end of life care register for the first time nationally as well as creating e-learning packages.

The Milton Keynes team developed a referral check form with ward staff to ensure that they have all the information to hand. A helpline within the office for patients and families has also been established and a business case for a link palliative discharge coordinator has been developed for the local high-security prison.

Dr Hattie Roebuck from St Joseph’s Hospice in Hackney and Jaryn Go and Breeda McManus from Barts Health won the non-cancer award for their development of palliative care symptom control guidelines for patients with end-stage renal failure in the community. The aim is to retain patients at home and increase the confidence of GPs and others in managing symptoms and prescribing medication.

Other prize-winners included Imelda King from Nuffield Health, Guildford Hospital, who won second prize in the palliative care nurse of the year award with Vanessa Gibson from St Richard’s Hospice, Worcester coming third. Dr Lisa Boulstridge, from Heart of England NHS Trust, came third in the educator of the year award and Valerie Peacock from Northern Ireland Children’s Hospice was third in the development award.
Most out people in care homes have dementia, says report

Four out of five people living in care homes – more than ever thought before - have dementia or severe memory problems, according to a new Alzheimer's Society report.

Although excellent care exists, only 41% of relatives surveyed said their loved ones enjoyed good quality of life. Despite this, almost three quarters of relatives would recommend their family member's care home.

The report, *Low Expectations*, also found that:

- Less than a third (30%) of the public believe people with dementia are treated well in care homes.
- The main factor (48%) the general public would look for in choosing a care home is training of staff.

New guide asks 10 key end of life care questions

The NCPC and Marie Curie Cancer Care have launched a new guide to help people in their local area scrutinise and hold MPs, GP commissioners, councillors and other decision-makers to account on end of life care.

The guide, entitled *10 Questions to ensure good end of life care in your area*, sets out the key information people need to champion end of life care in their local area.

The guide is intended to help ensure that end of life care is a top priority at a local level. As well as setting out 10 questions to ask locally and suggestions of who to ask these questions of, the guide provides links to where people can find additional information about end of life care provision.

In the foreword to the guide, Fabian Hamilton MP, Chair of the All-Party Parliamentary Group on Hospice and Palliative Care, points out that on average, 4,250 people will die in each constituency in England during the lifetime of a Parliament. “Thousands more will be bereaved as a result. We only have one chance to get it right for them and their families; there are no dress rehearsals for dying.”

Simon Chapman, Director of Policy and Parliamentary Affairs at the NCPC, said it was vital not to lose sight of people with end of life care needs in this period of transition. “By ensuring that they are aware of the key questions to ask local politicians and other decision-makers, members of the public can play an important role in holding them to account.”

Imelda Redmond, Director of Policy and Public Affairs at Marie Curie, said: “We know many more people face real problems accessing the care they need. This publication will help the public to have a greater understanding of what local services should be available to them.”

Call for better end of life care for people with liver disease

People with advanced liver disease may benefit from both active medical management and palliative and supportive care, according to a new report from NHS Liver Care and the NEoLCP.

*Getting it Right: Improving End of Life Care for People Living with Liver Disease*, examines the challenges of delivering good end of life care, including how to discuss it with patients and relatives, the assessment, planning and co-ordination of high quality care in different settings, as well as pastoral needs and care after death.

The report suggests that integrating active and palliative care would allow active treatment of medical crises while preparing the patients, those close to them and the clinical team for the possibility of death. It says a culture change is required to help healthcare professionals deal with this issue openly and proactively and ensure that patients and their families get the support they need as early as possible.

“Deaths due to liver disease are rising, and it is a significant issue for all health care providers,” said Dr Elizabeth Kendrick, co-author of the report and Chair of the End of Life Clinical Innovation Team at NHS North East.

“At our best, care is co-ordinated, communicated and compassionate, but this is not always the case. There are too many people with liver disease who may benefit from both active medical therapy and supportive care,” said Dr Eliza-
The National End of Life Care Programme has come a long way since it started life with a team of just two – a director and a PA - some seven years ago. At that time our brief was to raise awareness of end of life care and to expand the use of end of life care tools, underpinned by education and workforce development.

The team and its remit have expanded enormously in the intervening years and it is clear from the contributions in this issue that its impact has been felt far and wide.

Probably the watershed moment came in July 2008 with the launch of the National End of Life Care Strategy, along with the six step care pathway, which laid down a blueprint for ensuring greater access to high quality end of life care. The renamed National End of Life Care Programme was to play a critical role in that journey with a new remit to support local providers and commissioners in implementing the strategy while at the same time collating and sharing the ever-expanding examples of good practice.

We think most people would agree that over the last five years we have, through our collective efforts and partnership working, more than met that brief – although there is always more to be done and we are, of course, only halfway through the planned strategy.

It is impossible to summarise all we have achieved in a few words. But it includes a great sense of commitment and energy towards making change happen and a wealth of helpful publications and resources, notably the routes to success series and the hugely influential Social Care Framework. There have been a range of important projects at local level such as the locality registers, now known as EPaCCS, and communication skills pilots. And we have seen the establishment of the 300-plus end of life care facilitators and social care champions network, the introduction of the information standard ISB 1580 for end of life care co-ordination and vital national initiatives such as the e-learning resource e-ELCA and the National End of Life Care Intelligence Network (NEoLCIN).

Just as importantly, we maintained a relentless focus on a person-centred approach to end of life care where the wishes of the individual and their family are paramount. The Programme’s user involvement network, the Dying Matters Coalition and the influential Finding the Words DVD are just some examples of this commitment.

It has been a remarkable seven years which, we believe, have helped transform the experience of many, many people at the end of their lives.

And of course this is not the end of the road. Under the leadership of NHS Improving Quality Delivery Team, for example, the commitment to the Transforming end of life care in acute hospitals initiative and EPaCCS will continue throughout 2013/14.

We would like to thank all our many partners for their continued energy and support. We also want to extend a special thank you to National Clinical Director Professor Sir Mike Richards and his two deputies Dr Teresa Tate and Professor John Ellershaw, as well as our colleagues at the Department of Health end of life care policy team, for their help and guidance in overseeing the Programme.

Claire Henry, Anita Hayes
Director, Deputy Director, NEoLCP
‘My involvement with facilitator network never felt like work’

Eleanor Sherwen  
National Programme Manager, NEoLCP

Committed, enthusiastic, innovative, positive, sharing, responsive, humorous, thoughtful, person-centred, generous and strong - these are just some of the words that spring to mind when I think of the National End of Life Care Facilitator Network and its members. It is one of the work streams that I have been proudest of, not only in my work at the NEoLCP but also in my working career.

When I joined the NEoLCP in June 2010 the facilitator network became one of my main work streams. In fact I had been involved with the discussions around the network even before I joined the Programme as I had previously worked as a facilitator.

The network was launched in June 2010 with the aim of providing support and guidance to the facilitators, a central hub for networking and a means to share good practice and innovation. The establishment of 10 regional networks followed in 2011. Regular conference calls were arranged to allow the regional leads to feed back to one another and the national team to share information, celebrate success and explore ways of overcoming challenges.

It has been an enormous pleasure to have worked with the regional leads - their support and energy has been second to none. I firmly believe the facilitators have been the key driving force in improving the delivery of person-centred end of life care for all and will continue to be so. Each one has contributed to the increasing numbers of those dying within their usual place of residence and the underpinning work to support those improvements.

As a Programme we often say how we would love to bottle the sheer buzz and energy that has been so evident at the facilitator conferences. It has been an honour to be part of that process. It has also led to a number of friendships - many of which I know will remain.

Just before Christmas I was handed a little package from one of the regional leads. Inside it there was a ceramic heart with the words “Laugh often, talk much, sit long” - words that I think are applicable to all!

Confucius said: “Do something you love and you will never do a day’s work in your life.” My involvement with the facilitator network has always been a pleasure and has never felt like work.

‘There’s been a collegiate approach to getting things done’

As I come to the end of my short but very sweet secondment with NEoLCP it’s a good time to reflect on what has been achieved since I joined in August 2012. I had worked with the NEoLCP for a number of years through the Association of Directors of Adult Social Services (ADASS) so it has been both positive and enriching to then become a fully signed-up member of the Programme. There has been a real camaraderie and collegiate approach to getting things done and I have had the chance to work with a group of experts and professionals who are completely dedicated to improving end of care. No stone has been left unturned in pursuit of this goal.

What the NEoLCP does really well is collaboration and integration. It believes strongly in bringing people together across health and social care in common cause. I have really appreciated how colleagues have been so keen to learn about personalisation in social care and how this way of working can be used to improve services in a healthcare setting. I have also been impressed by the time and attention given to ensuring that the content of the Programme’s resources is written in ways which are relevant and accessible to the social care sector.

Rick O’Brien  
Social Care Lead, NEoLCP

The NEoLCP has been an excellent example of partnership working between policy and implementation teams. With EPaCCS, for example, the Department developed the policy and piloted it with support from the Programme. When we moved to implementation the Programme took on the lead with DH in support. EPaCCS’ successful roll-out in turn is based on the Programme’s USP of forming supportive partnerships with the wide range of organisations involved in commissioning and providing services. This is just one example: there are many others. And they’ve been a brilliant set of colleagues to work with.

Tessa Ing  
Deputy Director, Cancer and End of Life Care, Department of Health
The impact of the NEoLCP has been huge. When you’re working at grassroots level you think I’m just a little cog in the wheel, the national team won’t be interested in me. Whereas they have encouraged, promoted and supported so many small projects. And often it’s the little things that are so valuable to the patient who is dying.

You can feel isolated as an end of life care facilitator. But the Programme lends support and credence. So, for instance, if we’ve got a meeting with a commissioner and don’t know what tack to take, it’s good to get a national perspective from one of the team.

It’s also been great to have the opportunity to come together at facilitator network events. A lot of people have said that these events have given them confidence and have been very affirming. The network has enabled friendships to evolve.

Sandra Vargeson
End of Life Care Co-ordinator, Sussex Community NHS Trust

“We have seen a culture change around end of life care”

Margaret Holloway
Social Care Lead, NEoLCP

“End of life care is everyone’s business” is something which now resonates across the UK. But it is remarkable to note that when the End of Life Care Strategy was launched in 2008 only a handful of specialist palliative care social workers saw themselves as having an important role in end of life care. It was in this context that the social care workstream of the NEoLCP began its work to raise awareness of the crucial role which social care must play if the strategy was to succeed.

How have we achieved such a step change in the social care sector? From the outset it was imperative that end of life care was seen as an embedded part of mainstream social care’s business and not an add-on extra delivered by a handful of specialists. We tackled this by working with an advisory group of senior social care professionals as well as representatives from service user groups, to draw up a framework to guide social care practice at the end of life. This document, Supporting people to live and die well: a framework for social care at the end of life has been extensively used as the starting point for local strategies action and business delivery plans. And through these mechanisms end of life care is gradually becoming an integral component of good social care for all people who are supported in their own homes through the final phase of their life.

At the heart of social care at the end of life – and the key driver of UK social care policy - is personalisation. It is underpinned by a concern for dignity and personal worth, respect for the individual and choice and control. Making end of life care truly person-centred is fundamental to quality of life and social care has played a key role in this.

Since the launch of Supporting people to live and die well there has been a significant culture change in social care around end of life care, with a growing number of local and regional initiatives, pilot projects and, just as importantly, changes in routine procedures, such as service commissioning, to address end of life care needs.

Best to leave the last word to Graham Brown, a participant in the West Sussex HOPE project for people with dementia and their carers, who tells us what that means for him: “Dying at home, I don’t think you can beat it really”.

Sarah Waller
Programme Director, Enhancing the Healing Environment Programme, The King’s Fund

The team has had an extraordinary impact across the country. Its ability to gather and synthesise intelligence from so many areas has produced not only a range of very accessible written materials but also made them the first point of call for any aspects of information on end of life care. It has been a real hub of innovation and best practice and a fantastic signposting organisation.

It has given tremendous support to our work to improve environments for care at end of life. The team’s work has been of great benefit particularly in areas of healthcare, such as prisons and for people with dementia, where the need to provide palliative and end of life care to patients and to support relatives is increasing.

Sandra Vargeson
End of Life Care Co-ordinator, Sussex Community NHS Trust

The implementation of the Social Care Framework (SCF) has gone from strength to strength. Some of the SCF audit returns completed by adult social care departments demonstrate the sea change that has taken place in the social care sector in assessing and delivering end of life care services. This was reinforced when we ran our four regional road shows which were attended by over 600 people. The audience reflected a wide range of social care backgrounds and the workshops showcased many excellent projects supporting SCF implementation.

Of course we all want to see continued improvements in the end of life care, which is the reason for developing the end of life care champions and facilitators network. Hundreds of staff and managers across the country have now registered an interest in the network which should give further momentum to supporting improvements in their local areas.

What a fitting way to sign off. The NEoLCP has left a firm foundation for the future and that is something to celebrate.
‘This is an organisation that is seen as a “trusted hub”’

Glenis Freeman  Project Associate, NEoLCP

For nearly two years I have worked with the Programme and my overarching memory from this time has been the opportunities offered to people to develop, expand their knowledge and skills base and generally break down boundaries.

This hasn’t just been about members of the core team. These opportunities have been available to people like myself on contract, those brought in on secondment and those working in frontline services who have driven things forward, often in their own time, because they were engaged, valued and encouraged to challenge their perceived limitations.

One of my proudest achievements has been to be part of the original team that initiated and developed e-ELCA in response to the 2008 Strategy, which I also had a role in producing in my Department of Health days. While at the Programme I have been able to continue to contribute to this work, which has resulted in easier access to e-ELCA as well as the e-ELCA resource pack launched in late 2012.

It has also been a delight to work for an organisation that is thought of by others as a “trusted hub”. This was evident from feedback I received when undertaking surveys for the Programme that required a number of telephone conversations involving a huge range of people across sectors. Many of these fascinating conversations often veered off the topic into a really good natter about other areas of their work that they wanted to share and took me into areas I had little previous knowledge of – but I learned fast!

After 30 years at strategic NHS and Department of Health level I was initially surprised that so many people wanted to speak to me when I was gathering information for the Critical Success Factors report and it was so refreshing that people spoke openly and were not guarded with their comments. I put this down to the respect and trust people had in the Programme and its team.

‘I was moved by people’s openness in sharing their stories’

Katie Lindsey  Project Manager, NEoLCP

It is hard to believe that I have been with the Programme for over three years. I joined the team in 2009 as a project manager to support the Communication Skills Pilot Project for one year... and stayed. The Programme has certainly achieved a lot during its lifetime – often through its engagement with partners - and I feel very proud to have played a part. I would like to share an example of partnership working that I will take forward with me.

There is nothing more powerful in end of life care than the real stories and feedback of those people and their families who have actually experienced the process. That was the starting point for the hugely popular Finding the Words DVD which the Programme produced as part of the joint communication skills pilot organised by the Programme and Connected in 2010-11. It was users themselves who proposed developing a training resource to support staff in their conversations with people approaching the end of life – and from that was born Finding the Words.

We commissioned a film company to develop the DVD and then set up a day where people with a life-limiting condition as well as bereaved carers could be filmed discussing what had happened to them, how they felt about it and what the lessons were for health and social care professionals.

It was a challenging and emotional day. The group was committed to the task and all members were extremely open and honest in discussing very personal and sometimes painful memories. But although they admitted afterwards that it had been a challenging experience most also found it had been helpful on a personal level and they saw it as a way of leaving a legacy.

It is a day that I will never forget. I was very moved by people’s generosity and openness in sharing their stories and the caring support they gave each other.

The DVD, together with a supporting workbook, has proved to be very popular. It can be used flexibly to support training, for staff to work through on their own or in groups or as part of a communication skills training course.

It is clear that the project has made a real difference to practice. It also underlines one of the key messages from the communications pilots, which is the value of engaging users in developing, delivering and evaluating training.

“The Programme is so important in shaping people’s end of life care. I was involved in the Finding the Words DVD. That was very helpful to a lot of professionals and they have said they have found it useful in talking to people at the end of life. Doctors and nurses shouldn’t be frightened to ask us.

Being involved with the Programme and the NCPC has helped me make a positive out of a negative and hopefully my involvement has helped improve things for others coming after me.”

Mandy Paine  User
Barnsley’s End of Life Care Team has introduced the PPC across the borough.

“Sometimes, despite a clinical team’s best efforts, treatments do not give the results they hope for and a patient’s recovery may be uncertain. That is where the AMBER care bundle, which was first developed at Guy’s and Thomas’ Foundation Trust, can help to make sure that all staff know about the patient’s condition and are working together to give the best possible care and support.

I was involved in the NEoLCP’s Finding the Words DVD and it seems to have had a major impact. Recording that DVD was the first opportunity I really had to speak honestly and openly about looking after my son during his terminal illness. I was alongside people who had similar experiences and I felt safe to talk. I remember afterwards I felt totally drained but also like I was walking on air because I’d had the chance to be really honest about some of the things I’d like to see changed.

As a result of doing that DVD I’ve been asked to run training courses for nurses from the local hospice. I’ve also been delighted to meet people at conferences who say what a big impact it had on them and their working practices. It helped them focus on putting the patient and their needs first.

Despite all the changes and upheavals I’m reasonably optimistic about the future. People are talking about end of life care and now we’re actually seeing projects that will lead to major changes in the way we deliver end of life care - and that is a direct result of the Programme.

Tony Bonser
Carer

There is a strong focus to make sure patients and their loved ones are involved in making decisions around their care. Patients benefit as they have frequent overview, more consistent communication and their involvement can make a difference in their preferences being met.

I worked as part of the multidisciplinary team that designed the AMBER care bundle. I remember some time after this meeting and talking to Anita Hayes about what we were trying to do. No doubt I used phrases such “reliable design”, “Plan Do Study Act” cycles of change and involving patients in the developments. We had a really animated discussion and before I knew it, the NEoLCP team proposed that we conducted a feasibility study in the East Midlands.

We were apprehensive. It felt like we had put together a kit car and were asking someone else to do the road testing before we had a chance to do this thoroughly ourselves. The confidence of the national team that the tool was ‘road worthy’ gave us reassurance and this approach gave an even better way to ‘road test’ a tool since it allowed a quick assessment on whether or not it would benefit patients in other hospitals.

Vindication of this approach came when we got feedback from a consultant about a patient who had died suddenly but not altogether unexpectedly in one of the original East Midlands pilot hospitals. What is of note is that his family left a message on the ward improvement book (they are the only people to have done this!) to say how positive their experience of care had been. Though undoubtedly there were other aspects to this, I am sure that the inception of the AMBER care bundle and our constant discussions with the family about their relative was part of this care experience. Without the national team, we would not have had the confidence and direction to support the wider use of the AMBER care bundle.

Eleanor Sherwen
National Programme Manager, NEoLCP

Les Storey
National Lead for PPC

Advace care planning (ACP) is one of the key aspects of ensuring that an individual has a good death, in the place of their choosing. And the Preferred Priorities for Care document, which was first developed in 2001 and revised to the current version in 2007, is an important part of that process.

We are extremely proud that something that started as a local initiative for people in the community with cancer is now being used as a matter of routine across the country. Most importantly, it is providing opportunities for individuals with wide-ranging condi-
One of the NEoLCP’s key aims has been to support health and social care staff across the country to implement the end of life care pathway, ensuring that everyone, no matter what their background, has access to the same high quality of care as they approach the end of their lives.

The route to success series was created to provide practical support and guidance to staff responsible for delivering end of life care, helping them through each step of the pathway with information, resources and practical tips. At a time when there was limited national information available for staff on best practice in end of life care, these guides were, and still are, in huge demand.

We have now produced more than a dozen publications focusing on a range of topics including care homes, acute hospitals, social work, people with learning disabilities and LGBT people.

There is no doubt they have filled a gap and had a significant impact. An independent evaluation by the Institute of Healthcare Management in December 2012 found most people felt the guides were either “very helpful” or “helpful” and that they had improved quality in their organisations.

The guides were reported to be useful as education and training aids, in co-ordinating care and in bringing different groups of staff together. They have also been used to develop local end of life care strategies and highlight to trust boards the importance of end of life care.

One comment from a care professional probably sums up the feelings of many: “They are well written, easy to follow, well-illustrated and applicable to many different staff – an excellent resource which condenses the specific issues and signposts differing situations to be empowered and have choices about their own end of life care as demonstrated in numerous case studies (see February 2012 newsletter).

The PPC is at heart about the importance of conversations, about finding out people’s wishes and establishing where they would prefer to be cared for and where they would prefer to die.

These conversations capture so much more than where it is someone would like to be cared for – they also reveal how and what is important to them as individuals. And there is a growing body of evidence, from local audits to national evaluations, demonstrating the huge impact the PPC is having.

Meanwhile an easy read version of the PPC was published in 2012. This has been extremely well received and is being adopted across many parts of England.

As part of the implementation process the Programme has developed many resources to support individuals and organisations implementing and sustaining advance care planning. The final online resource, ACP it all ADSE up, brings together all the information in one place.

It has been a pleasure for us to work with so many committed individuals and organisations over the last five years. It is also heart-warming to see how the influence of the PPC continues to spread. Its adoption has even reached New Zealand and Australia.

“They have clearly filled a gap and had a significant impact’

Kate Henry
Communications Lead, NEoLCP

The Programme was great at finding and bringing together people from all walks of life and all parts of the UK to discuss issues around end of life care from the perspective of service users, carers, ex-carers and health and social care professionals.

Listening to other people’s experiences of receiving care and providing care helped to form a more rounded view of the progress that has been made since the introduction of the National End of Life Care Strategy in 2008 and to assess what is working well and what is not. All this happened within a supportive environment that enabled people to speak very personally and openly about their experiences and have the satisfaction of knowing that not only were their views being listened to, they would also have an impact on decisions being taken.

Helen Findlay
Carer
Most people, given the right care and support, would prefer to die at home. Yet when we began the QIPP end of life care national workstream in 2010 only around 20% of people died at home; a further 18% died in a care home while 55% were dying in hospital, the least favoured choice. This mismatch can result in inappropriate hospital admissions and bed days, futile and sometimes unwanted treatments, dissatisfaction and complaints.

Our workstream focused on increasing the active identification of people approaching the end of life with the intention of improving people’s care experiences through better planning and care management. Key to this was integrated health and social disciplines but brings them together.”

From a personal perspective this has been one of the most rewarding parts of my role. Bringing together the knowledge, experience and enthusiasm of staff across the country and turning that into best practice publications that can benefit so many is what we’ve been all about. It has been inspiring to work to a shared purpose with such committed and passionate people and has made this without a doubt the most fulfilling role I’ve had.

You can find out more about the series and access the complete set of guides, support sheets and evaluation reports on the [website](#).

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**‘It’s rare for passion and professionalism to work together’**

Rob Benson  
*Former Digital Lead, QIPP end of life care workstream*

During my time on the QIPP end of life care workstream I met a range of vastly intelligent and resourceful people who dedicate themselves to making a difference to our dying days. In terms of achievements, I would single out the work I took part in around EPaCCS.

This involved tapping into a network of individuals across the country and encouraging them to share their experiences on the NHS Networks web platform. Such knowledge exchange is a tough nut that the NHS is only just beginning to crack. But there were some hopeful discussions around coding, templates, reporting and the like that I think were useful to at least a few people. More than that, I hope people made connections across the country with others going through the same thought processes.

I know that many people formed those connections in the various regional events in which I took part. It is rare for passion and professionalism to work together, as it does in this field. It was never more evident than on these occasions. Bringing such people together will have benefits for years to come. It was great to be a small part of that team.

My abiding memory of the time will be those connections and the potential they have to realise good end of life care. There is a worldwide end of life care community out there. I hope I played a small part in supporting some of that community.

It was a great honour and pleasure to work with the people involved in end of life care. Whether it was the NEoLCP, Dying Matters or the many others from this field, all had a great attitude to the work involved and were tireless in their efforts. Working with them was certainly a highlight of my career in the NHS.

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**‘Success is due to all those passionate about end of life care’**

Elaine Bayliss  
*Programme Manager QIPP EoLC National Workstream, NEoLCP*

Most people, given the right care and support, would prefer to die at home. Yet when we began the QIPP end of life care national workstream in 2010 only around 20% of people died at home; a further 18% died in a care home while 55% were dying in hospital, the least favoured choice. This mismatch can result in inappropriate hospital admissions and bed days, futile and sometimes unwanted treatments, dissatisfaction and complaints.

Our workstream focused on increasing the active identification of people approaching the end of life with the intention of improving people’s care experiences through better planning and care management. Key to this was integrated health and social disciplines but brings them together.”

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The Birmingham East and North (BEN) family liaison service is helping to improve patient choice at the end of life and is cutting hospital admissions.
Over the last year I have had the privilege of working as an End of Life Care Management Lead with the Programme and discovering first hand its truly open, collaborative and listening team spirit. It has been an exciting forum where clinicians came together with shared aims and values for improving care for everyone at the end of life. I have no doubt this transformational leadership has led to significant improvements in end of life care across the whole of England.

During this time it has been exciting to take an active, strategic role in the Find your 1% campaign, helping to identify more people who can then become engaged in making choices and decisions about the care they want to receive at the end of life.

I have also enjoyed the chance to help clinical teams learn new leadership skills, as set out in the NHSE Change model, which can be used to rally others to action for a shared purpose. It was great to see that in this safe environment, colleagues felt able to share their personal stories about end of life care. This has had a big impact in motivating those listening, raising their passion and commitment to take activities forward.

A week later a colleague related her personal story at a large conference and was very well received. To me this showed how putting a little of your own personal experience into a presentation moves and inspires others to action.

Initiating conversations, enabling decision-making and co-ordinating care across pathways are key to ensuring that we all live and die well. As a result of my experience in the team, I feel I have strengthened my personal leadership skills. And through the Find your 1% campaign I have also been able to influence and support the roll-out of the Transform programme and the electronic palliative care system (EPaCCS).
‘ELCQuA is now a robust tool that is fit for purpose’

Katie Lindsey
Project Manager, NEoLCP

I have been involved in supporting the intelligence arm of the Programme since 2011 and have been working with a wide range of stakeholders to help improve the data and intelligence available to drive quality improvements in end of life care. Information and feedback on performance are an essential part of good end of life care as well as helping in planning priorities for future service improvement. And ELCQuA offers exactly that.

ELCQuA, or to give it its full title, End of Life Care Quality Assessment Tool, is a free online self-assessment tool designed and developed by NEoLCIN that enables organisations to benchmark against national quality standards and to support local service improvement.

The tool ensures consistent reporting, which enables comparisons with other organisations and encourages the sharing of good practice. It also tracks performance over time and is freely available to service providers and commissioners of end of life care in England.

First launched in May 2011, a new version of ELCQuA was produced in December 2012 which aligns with the NICE quality standard for end of life care. It has also been updated to make it more user friendly.

The redevelopment was led by a project team which had the benefit of input from Elaine Owen, End of Life Care Service Improvement Lead for Acute and Specialist Services with Cheshire and Merseyside Clinical Network, and Julia Chisnell, previously End of Life Care Programme Lead for South West SHA, who already had considerable experience and expertise in applying the tool.

The performance measures included in the revised tool followed a widespread consultation with stakeholders as well as a review of best practice guidance. People were very generous in sharing their ideas and expertise and at some points it felt as though we had too much information but we got there in the end and I feel confident we have a robust tool that is fit for purpose.

There has been considerable interest in the new version and we have been pleased to hear about organisations’ plans and ideas for using the tool – for instance, developing a CQUINS to support commissioning and implementing across CCG and CSU areas. It is still early days and we welcome feedback as we plan to continue to improve and update the tool in response to user requirements.

‘Response is because frontline people want to get it right’

Chris Sutcliffe
Project Support, EoLC Acute Hospitals Initiative, NEoLCP

The route to success - improving quality end of life care in acute hospitals was published in 2010. But although many copies were ordered we had little evidence to support whether the recommendations were being acted upon.

In the autumn of 2011 it was agreed to work with up to 10 acute trusts on implementing five key evidence-based enablers – that is, ACP, AMBER care bundle, EPaCCs, Rapid Discharge home to die and the LCP - considered to have the biggest impact on the quality of care provided for those in the last 12 months of life.

To support this we began to produce a How to
The NEoLCP has been very much at the heart of what’s going on in end of life care. It’s quick to respond if there’s a recognised need: the facilitators’ network, at both national and regional level, is a prime example of that. It has a good strategic overview as well as a strong grasp of what’s happening locally. So when it speaks about end of life care nationally it can speak with confidence because its information is based on what is actually happening at the grassroots. It also responds very quickly to any inquiries or requests for support.

As a network we were lucky enough to get financial support from the Programme for our work with social care. We’ve also had some funding for prisons and homeless work and that’s been brilliant.

Elaine Owen
End of Life Care Service Improvement Lead for Acute and Specialist Services, Cheshire and Merseyside Clinical Networks

The NEoLCP is to be commended for all it has achieved. The Programme has appeared undaunted by the inevitable challenges it faced and leaves a rich legacy of publications, relationships, new data and intelligence.

We at Help the Hospices have enjoyed the relationship that has grown over the years and are delighted to continue some of the good work it has championed. Where hospices have been part of the programmes of improvement these opportunities have proved mutually beneficial and valuable.

There is so much to be done to get palliative and end of life care right for the future and this will only be achieved through partnership working and joined-up efforts. The Programme has provided a template of collaboration during its lifetime, which we shall seek to continue. This is key to maintaining the momentum and building on the Programme’s achievements, of which it should be very proud.

Heather Richardson
Chief Executive, Help the Hospices

‘VOICES surveys resulted in the most astonishing response’

The 2008 End of Life Care Strategy recommended that a survey of bereaved relatives should be undertaken to gain some information on the quality of care of people in the last three months of life. This has resulted in the most astonishing response, from more than 22,000 people, for the first 2011 survey and a similar number for the second, which is yet to report. The respondents not only completed a modified Voices questionnaire but many also described in detail their experience of the care provided.

The headline findings are now well known, showing high quality care for many with only 24% rating the overall quality as fair or poor, and most people being treated with dignity and respect most of the time. However, it mattered where people lived, with a 20% difference between the highest and lowest scoring PCT clusters. It also mattered where they were cared for, with hospitals scoring least well in a variety of measures including emotional support and personal care. On the whole younger people with cancer had the best overall experience of care followed by those with dementia.

At each reading of the report new facts can be picked out: 23% of patients were aged over 90; only 32%, mostly those with cancer, knew they were going to die; 56% of people dying in care homes had
We have changed what is known about the patterns of care

Julia Verne
Director for Knowledge & Intelligence (South West) and Clinical Lead, NEoLCIN
South West Public Health Observatory

The National End of Life Care Intelligence Network (NEoLCIN) has mined the treasure chest of routine data sources to expose variations in end of life care by local authority, age, cause of death, gender and socioeconomic group.

Since its formation in 2009 we have produced 13 specialist end of life care reports and helped develop easy to use end of life care statistics. In addition we have produced a series of ground-breaking national end of life care profiles for primary care trusts and local authorities.

These profiles present information about cause and place of death, the number and rates of terminal hospital admissions, mortality, social care information and demographic contextual data. This allows localities to compare the need for end of life care services in their area with neighbours and similar areas across England.

The content is available in two forms, a factsheet for each locality and a web based interactive atsles. We are now planning further profiles for the new clinical commissioning groups and for acute hospitals.

Our end of life care reports cover a wide variety of topics including deaths in older adults, deaths from cardiovascular disease, deaths from liver disease and deaths and deprivation.

In addition we are contributing to the palliative care funding pilot and recently influenced the development of future end of life care quality measures by analysis of audit data collected from a number of hospital trusts.

We have also worked closely with sites who have EPaCCS, assessing the impact of these initiatives in terms of patient preferences and quality of care.

We have greatly enjoyed working with members of the NEoLCIN team, colleagues at the Department of Health, clinicians, managers, researchers and charities. This close integration has had a mutually beneficial effect on all our work.

NEoLCIN will be part of Public Health England from 1 April. The profile tools, reports and lots of other end of life care information will all still be available from www.endoflifecare-intelligence.org.uk. People interested are encouraged to sign up for email alerts.
News in Brief

Awareness week
This year’s Dying Matters Awareness Week runs from 13-19 May. Dying Matters has produced a number of resources including a leaflet setting out five things that everyone should do to prepare for the end of life plus contact details for helpful organisations.

Margaret edits BJSW
NEoLCP Programme Manager Margaret Holloway is guest editor of a special issue of the British Journal of Social Work next month. The title is Death and Social Work – 21st Century Challenges and it includes an editorial highlighting the work of NEoLCP.

Spread and adoption
The NHS Institute for Innovation and Improvement has produced a Spread and Adoption tool which supports the NHS Change model, especially the ‘spread of innovation’ component.

Leadership programmes
The NHS Leadership Academy will be rolling out foundation, mid- and senior level leadership programmes for up to 25,000 NHS staff, starting this September. The emphasis in all three programmes will be on helping leaders in the NHS support their staff in delivering caring and compassionate services.

Healthcare assistant review
A new independent review will look at how the training and support of healthcare and care assistants can be strengthened. The review will report back to government at the end of May.

New regional centre
North London Hospice has recently become a regional centre for end of life care training for care homes. The hospice will support providers such as GPs and care homes through the GSF in Care Homes Programme. As a regional centre, North London Hospice will increase the number of care homes adopting the scheme and improve the quality of care provided across the south east.

New research on boards
Only 54% of Health and Well-being Boards have set out what they plan to do to meet the needs of dying people, according to a new report from the NCPC. Nearly a quarter have still not made publicly available a draft strategy.

Personal health budgets
A consultation on extending the scope of personal health budgets is now under way. For more information click here.

Interdisciplinary guide
The NEoLCP has produced a guide to effective interdisciplinary teamwork in end of life care. Optimising the role and value of the interdisciplinary team: Providing person-centred end of life care describes the benefits of this approach and offer practical suggestions for delivering it.

Research project
St Wilfrid’s Hospice, Chichester has run an end of life care education and evaluative research project aimed at enhancing end of life care in care homes and ensuring the sustainability of supporting innovations. The executive summary of its final report is now available.

Dementia pack
The NCPC Dementia Steering Group has produced a new resource pack which includes all the organisation's key dementia resources. More details about the pack, which covers a range of issues from starting conversations to multi-agency partnership, are available on the website or by emailing publications@ncpc.org.uk.

COMING EVENTS
Palliative care course
St Christopher’s Hospice in London will be holding an international multi-professional week in palliative care from 16-20 September. The course, which brings together professionals from a variety of settings and countries, costs £750. For more information please visit the website.

Oncology update
St Catherine’s Hospice will be running an oncology update event for palliative care cancer nurse specialists and doctors, other specialist nurses and GPs on May 1 at the hospice in Lostock Hall, Preston.

Loss and grief
St Catherine’s Hospice in partnership with Derian House Children’s Hospice will be holding a study day on May 17 at the hospice exploring loss and grief for young adults (16 to 25 years old) with life-limiting conditions and their families and carers.