

November 2012

Theme: EPaCCS

National End of Life Care Programme

Improving end of life care

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End of life care in the spotlight

End of life care continues to be a high profile topic. Media coverage is ongoing around the Liverpool Care Pathway, end of life care has been highlighted as a priority area in the new NHS Mandate and it is also proposed for inclusion in the NHS Constitution (see News page 2).

While much media coverage has been balanced, helping to stimulate informed debate, we are concerned with some scaremongering reports which propagate misinformation. We know that as a direct result heightened fears and anxieties are being seen in daily practice.

As an organisation we will continue working with the media and partner organisations to contribute to an informed discussion which leads to continued improvements in end of life care.

In the meantime, it is important to commend the work of health and social care staff dedicated to providing the best possible care for people who are dying and their families. This is by no means an easy job.

Publications offer

From now until the end of December, we will be relaxing the restrictions on the number of hard copies of our publications that can be ordered free of charge. We would like to disseminate as much information about end of life care as possible to health and social care staff across the country.

To obtain copies please email

information@eolc.nhs.uk. A full list of our publications can be found [here](#) - please note that some are download only.

Transition



As mentioned in last month's newsletter, responsibility for end of life care will move from the Department of Health to the new NHS Commissioning Board as part of the NHS reforms. It will sit within Domain 2, long-term conditions, and will be led by Dr Martin McShane.

The Commissioning Board is setting up a new Improvement Body, which from 1 April 2013 will bring together elements of work from the following organisations:

- National Cancer Action Team
- National End of Life Care Programme
- National Technology Adoption Centre
- NHS Diabetes and Kidney Care
- NHS Improvement
- NHS Institute for Innovation and Improvement.

Again, exact arrangements are still under discussion as to the new organisation's priorities, what work will be taken forward and how, and how it will be resourced.

The National End of Life Care Programme in its current form runs until 31 March 2013. In addition to continuing with our ongoing workstreams over that period, we are working hard to ensure that key end of life care

priorities are supported and taken forward as part of the new NHS landscape. For example, we can confirm that the National End of Life Care Intelligence Network will continue to operate as part of Public Health England from April 2013.

We will keep you updated on developments as promptly as we can during this time of transition and uncertainty and would like to express thanks for your continued support.

1% pack for GPs

Find your 1%



A new [resource pack](#) is available to help GPs support people to live and die well. The A6 Find your 1% pack contains postcards with resources and top tips on identifying people at the end of life, having end of life care conversations, putting plans in place and managing and co-ordinating care.

There are also links to further information and space to record the contact details of local organisations which GPs may need to be in contact with. Hard copies of the packs can be ordered by emailing information@eolc.nhs.uk.

Claire Henry
National Programme Director
November 2012



News

New projects examine people's experiences of care



The NEoLCP is to co-ordinate a number of projects looking at people's experiences of care in the last days of life with a view to making continued improvements.

Recent media coverage has highlighted a number of examples where people have reported that care in the last days of life has not been of high quality. The cases quoted often mention the *Liverpool Care Pathway* (LCP) and seem to centre on training and communication issues.

The LCP has much support from organisations involved in the delivery of end of life care. A [consensus statement](#) supporting its use was released in September by more than 20 leading organisations.

The Programme will work with a number of hospital trusts to undertake a snapshot review of complaints received about end of life care. This will include complaints relating to the use of the LCP and any communication or perceived communication issues.

Dying Matters will talk to people whose loved ones have been cared for by health and social care staff using the

LCP, to explore what worked well and what could have been done better. Meanwhile the Association for Palliative Medicine and a range of national organisations will work to understand the opinions of clinicians about integrated care pathways (ICPs) for the last days of life, which includes LCP.

Findings will be shared with the Department of Health and the NHS Commissioning Board and will be made publicly available in the New Year.

Care and Support Minister Norman Lamb commented: "Everyone wants to see appropriate care and support offered to dying people in their final days and hours. To do this we need to know how patients and families feel about the care they receive. And we need to make sure that health professionals have the best tools to help them with this sensitive work."

Claire Henry, Director of the NEoLCP, said the VOICES survey had shown most relatives were happy with the care their loved one received. "However, we also know that there are improvements to be made so that every person receives the same high quality of care at the end of their life.

"I'm pleased that these projects will listen carefully to the experiences of members of the public and of professionals. This is crucial if we are to continue improving care."

The NHS has updated its entry on the LCP on the NHS Choices [website](#), publishing details about the pathway's origin, its goals and its guidelines and commenting on recent media coverage.

Celebrating the Day of the Dead



Dying Matters held a 'Day of the Dead' celebration in London on 1 November based on the Mexican festival where people remember family and loved ones who have died. The event, at-

tended by members from across the country, featured an altar where attendees could place photos and stories of their loved ones, as well as a celebration with Mexican food, drinks and music.

Plans to feature end of life care in NHS Constitution

The right of patients, families and their carers to be involved in all discussions and decisions about end of life care is to be included in the NHS Constitution under new proposals.

The proposed amendments, which also include new rights relating to complaints and mistakes as well as a pledge on single sex accommodation, would be the first major changes since the NHS Constitution was introduced three years ago.

BMA Director of Professional Activities, Dr Vivienne Nathanson, said it was already established good medical practice that doctors involve those close to the dying patient about end of life decisions. "However, where patients are capable of making decisions, their views about who should be involved in their care must take priority.

"If patients are not competent, decisions should be made by the clinical team in partnership with close relatives. The best interests of the dying patient must be the focus of care."

The closing date for the [public consultation](#) on the NHS Constitution proposals is 28 January 2013.

End of life care has also been identified as a priority in the first mandate between the government and the NHS Commissioning Board, setting out the ambitions for the health service for the next two years.

The mandate is structured around five key areas where the government expects the board to make improvements. These areas correspond to the five parts of the [NHS Outcomes Framework](#), including enhancing quality of life for people with long-term conditions and ensuring people have a positive experience of care.

One of its priority areas, where it expects particular progress to be made, is improving standards of care, especially for older people and at the end of people's lives. It also wants to see improvements in the diagnosis, treatment and care of people with dementia.

For more information, visit the [NHS Mandate website](#).

New grants for dementia-friendly environments



The government is to make £50 million available to create care environments for people with dementia that help reduce anxiety and distress and ensure people feel safe.

NHS trusts and local authorities will be expected to work in partnership with care providers to help tailor hospitals and care homes to the needs of people with dementia. The care providers involved will need to sign up to the Dementia Care and Support Compact, which commits them to providing first rate care and support for people with dementia and their families.

Research by [The King's Fund](#) demonstrates that good design can help with the management of dementia. People with dementia are calmer and less likely to get lost or become

distressed in an environment designed with their needs in mind.

Organisations that bid successfully for money will be able to adapt care homes and hospitals using design principles tested in The King's Fund pilots.

Every project will involve people with dementia, their families and carers, to make sure the designs meet their needs. The projects will form part of a national pilot to showcase the best examples of dementia friendly care environments. The lessons learnt from the projects will be used to advise local [Health and Wellbeing Boards](#) on how to create better environments for dementia care.

The successful projects will begin from April 2013.

More people achieving their wishes through EPaCCS

People who agree to be placed on electronic palliative care co-ordination systems (EPaCCS) receive enhanced care and are more than twice as likely to die at home or in hospice as the national average, according to the latest NEoLCP survey of those areas using the system.

The survey of nine geographical sites also showed that only 18.5% of those on the system died in hospital - compared with a national average of over 50% - and that 59% achieved their preferred place of death.

The figures come from a newly conducted survey – *EPaCCS mid 2012 report* – which reveals that 10 sites have now implemented EPaCCS fully while another 14 have implemented it partially. A total of 25,177 people are now on EPaCCS across the country, representing around one in seven deaths in those areas.

The survey also describes the IT systems the various projects are using as well as outlining access arrangements, ISB dataset compliance and performance data.

The NEoLCP has published a supporting paper on EPaCCS: [Making the case for change](#), which is intended to support commissioners in developing a business case for establishing EPaCCS.

The material in the report can fit, or be modified, to a range of business case templates and includes the key drivers and evidence for establishing EPaCCS as well as case studies and additional information to demonstrate where benefits have been achieved. The appendices include information on potential savings and efficiencies as well as considerations around key stages and issues for implementation.

EPaCCS mid 2012 report is available to registered users on the NHS Networks [EPaCCS online forum](#).

See also features pages 4-8.

People with dementia 'face greater end of life care problems'

Many people with dementia are not dying in the place they want to, with their families unaware of their end of life wishes because of a double stigma around dementia and death, according to a [new report](#) from the Alzheimer's Society.

My Life Until The End: Dying Well With Dementia says that only 6% of people with dementia are dying at home compared to 21% of the general public.

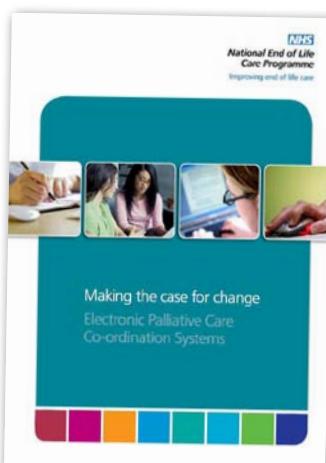
The report, which interviewed people with dementia and their carers, found that in many cases people with dementia had not discussed their wishes around death and dying so no-one was able to put services in place to make their wishes a reality.

The Alzheimer's Society is calling for greater awareness of the importance of talking about death and dying. This includes planning end of life care in advance to help make the final days of more people with dementia as good as possible and ensuring they are where they want to be.

The report also says people with dementia are often not treated with dignity at the end of their lives. A lack of ability to communicate and the fact that some people may have lost the capacity to make decisions makes end of life care especially challenging and complex.

Jeremy Hughes, Chief Executive of the Alzheimer's Society, said: "It's hugely worrying that so many people with dementia are not ending their lives the way they wish or deserve to. People with the condition deserve to die with dignity, without pain, and in the place of their choosing as much as anyone else."

Simon Chapman, Director of Policy and Parliamentary Affairs at the NCPC, said: "Our work consistently shows that planning for the future, including the end of life, is empowering and life-affirming. Once done, people can get on with living life, safe in the knowledge that their wishes are known when the time comes. But they need support from professionals, family and friends to make this happen."





EPaCCS

Our theme this month is EPaCCS – the electronic successor to the locality end of life care registers. A growing number of sites across the country are adopting the system and, as we report, the early results are impressive with more people achieving their wishes and preferred place of death while fewer people die in hospital.

In a wide-ranging overview we also explain the interoperability toolkit, provide an update on the national information standard and spell out the many benefits the new approach offers for commissioners

Why a co-ordinated system can change people's lives

Electronic Palliative Care Co-ordination Systems (EPaCCS) offer a new way of recording and sharing information about an individual with their consent. Anita Hayes explains why they are so important for good end of life care

Good end of life care is all about providing the right care in the right place at the right time. But although there are many examples of individuals, carers and professionals working together to achieve a good death, sadly it remains the case that many miss out.

When this happens the consequences can be devastating for both the individual and their family. The fear of some sort of communication breakdown at the critical moment can also cause huge anxiety for those approaching the end of life.

As Sanjay, who has MS and contributed to our recent DVD about people's experiences, puts it with feeling: "I don't want to be in a crisis and then everybody makes assumptions based on misinformation and that becomes quite a horrific and difficult end of life."

Individuals who are approaching the end of life should be confident their wishes and preferences for how they are cared for and where they are to die are not only recorded but also acted upon. Yet at the moment too few people are being identified as approaching end of life at an early enough stage to plan their care – and one of the main challenges remains effective co-ordination between the many services responsible for that individual's care.

It is for this reason that over the past year the NEoLCP has been supporting the development of EPaCCS (Electronic Palliative Care Co-ordination Systems), a successor to locality end of life care registers. The aim is to provide a single point where all relevant information about an individual can be recorded and then shared – with the individual's consent – with all those who need to know.

This follows a recommendation in the End of Life Care Strategy calling for the setting up of locality registers and a series of pilots testing out different approaches to electronic registers between 2009 and 2011. It also aligns with the end of life QIPP agenda which supports early identification of people approaching the end of life and then planning their care.

The principal benefits of such an approach will be to identify people at an earlier stage of their journey

CASE STUDY

Edward*, an elderly man with lung cancer, decided after being discharged from hospital following a chest infection that he did not want to go into hospital again and wished to die at home.

These wishes were added to the EPaCCS by his local GP and a Just in Case box was organised. The multidisciplinary team discussed his ongoing care at their monthly GSF meetings.

Eventually there was a crisis and since it was night-time the out of hours staff were contacted. Because they were able to see what his preferences were they then contacted Edward's GP and district nurses who were able to ensure he died peacefully at home as he had wished.

** Not his real name*

and so ensure they have an opportunity to die in their place of choice with their preferred care package. It should also enable people with advanced long-term conditions to be picked up at an earlier stage and to have their care preferences recorded and their care co-ordinated.

EPaCCS can also have wider organisational benefits. This includes not only better communication between the different services involved in end of life care but also reductions in unnecessary interventions and fewer inappropriate emergency hospital admissions.

The early evidence from sites using EPaCCS suggests the system is helping more people to achieve their choices and to die in their usual place of residence. Some sites report achieving the preferred place of death for 70-80% of those on the register while deaths in hospital have been more than halved.

As our case study shows, the benefits of achieving people's wishes at the end of life are almost incalculable. And this, above all, is why it is so important to continue to roll out EPaCCS across the country.

ABOUT THE AUTHOR

Anita Hayes, Deputy Director of the NEoLCP

How EPaCCS is helping people to have a 'good death'

Uptake of EPaCCS is growing – and the early results from sites using the system are encouraging. Here we report on the experiences from different parts of the country and list some of the lessons learned

Over the last year the number of areas using the EPaCCS system has grown dramatically and its benefits for patients and their families is becoming clearer. According to a NEoLCP survey earlier this year 14 sites are now implementing the system fully and 10 more partially.

The degree of activity in each area varies considerably. In the South West, for example, EPaCCS now covers almost the entire strategic health authority with more than 5,000 people listed on the electronic register. Meanwhile its equivalent in London – Co-ordinate My Care – is being rolled out across the whole city and already has over 2,000 people on its register. In other areas the coverage is often more limited.

But it is already evident that people using EPaCCS have a much greater chance of achieving their wishes and preferences about end of life care.

This level of success has been largely mirrored in other sites. Salford, for example, had 865 people on its integrated electronic record between April 2011 and March 2012 of whom 42% achieved their preferred place of death and just 6% died in hospital. South Essex PCT had 1,053 on the register during the same time period with 70% achieving their preferred place of death, 46% dying at home and 18% dying in hospital.

Meanwhile Bedfordshire's Partnership for Excellence in Palliative Support (PEPS) has linked EPaCCS to a centrally-held electronic register supported by 15 different organisations. The service, which was launched in December 2011, offers a single telephone number and central hub, hosted by Sue Ryder, providing co-ordinated palliative care 24 hours a day, 365 days a year.

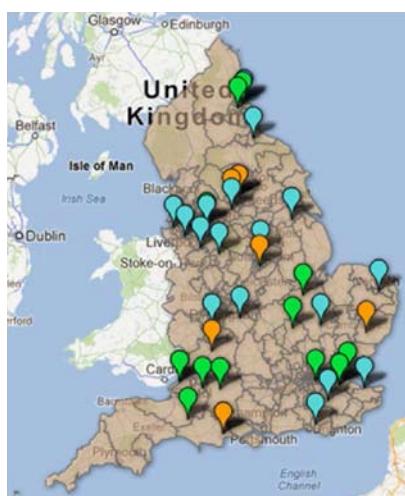
By the end of July there had been 330 deaths recorded on the register of which 65% were in people's usual place of residence, 22% in hospice and 12% in hospital.

The feedback from GPs, patients and families has been extremely positive so far. Relatives report that they feel secure and "not 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," commented one local GP. "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."

Advice on implementation:

- Involve patients and their families at every stage
- 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 start 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 roll-out for the majority of early adopters, followed by community providers, OOH 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
- 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 and developed.
- Agree an approach to reporting and monitoring. In Somerset, a reporting template is in use
- Recognise that N3 access is a key issue to be addressed.



In NHS London, for instance, around 60% of deaths occurred in hospital in the two years immediately preceding the launch of CMC in four trusts. The latest figures, for August 2012, show that of 429 people who died while on CMC, 80% achieved their preferred place of death and only 24% died in hospital. More than half (51%) died in their usual place of residence, 12% in hospice and 13% in other locations.

The figures also show that 84% of those who said they wanted to die in their care home achieved their wish, compared to 66% of those wanting to die at home, 41% who wanted to die in a hospice and 69% (9 out of 13) in a hospital.

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

Measuring progress on EPaCCS implementation

QIPP's Digital Lead Rob Benson reports on two large-scale surveys of EPaCCS activity around the country and outlines the next steps – for those already using the system and those considering adopting it

We have now carried out two surveys of progress on EPaCCS, one at SHA level at the start of 2012 and another at PCT level in July 2012.

What is clear from these surveys and other events we have held is that real progress is being made and a regional approach is starting to take shape.

This has been particularly noticeable in areas that originally piloted the systems. London is now aiming to deploy a system across the city. The South West has gone from a pilot in Weston Area Health Trust to take in most of the region. In the North West, the pilot in Salford has led to a more regional approach.

Of 46 PCT-level respondents to the latest survey, 30% said that EPaCCS has been implemented throughout the area. Another 22% reported partial implementation; another 35% said that planning has started. It is on the agenda for most.

A total of 1,168 deaths have been recorded here. Of these 47% died at home and only 6% in an acute hospital. In addition, the numbers of people currently on the register with a non-cancer diagnosis are similar to those with cancer.

The latest survey shows that a total of 25,177 people are on EPaCCS, accounting for one in seven of all deaths in the areas covered. Of those on the system 3,950 are reported as having recorded their preferred place of death, with 1,502 (38%) having achieved that to date.

Adastra is reported as the system most in use, with 10 of the 14 sites who have implemented it fully using this system. Partial implementations use a mixture of Adastra, SystmOne, and other systems. EMIS Web, System C and Graphnet are in use. The Summary Care Record is also being considered. However, no perfect system exists – it depends on what suits the local environment.

Eight projects were fully compliant with the Information Standards Board dataset and another 21 had some work to do. Only three were non-compliant. Consent to both upload and view records was available for 17 of 37 respondents.

Access was best for GPs, specialist palliative care and out of hours teams across the board. Social care had little to no access.

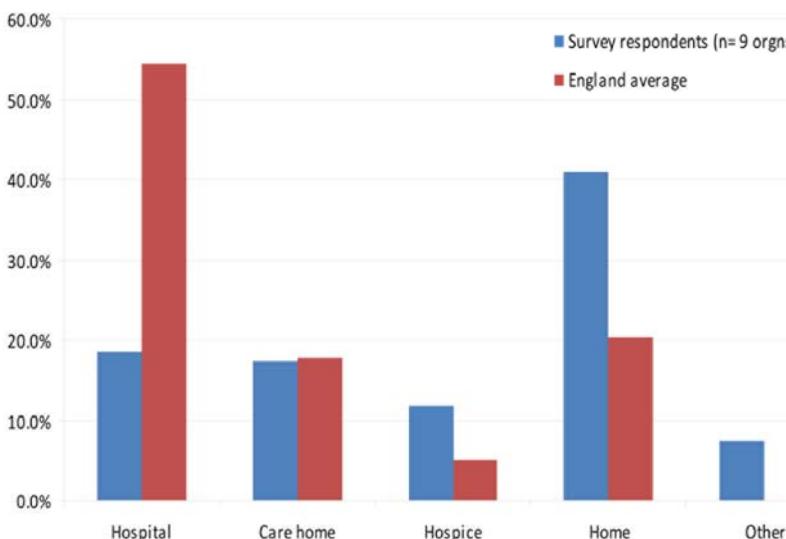
Analysis of the use of EPaCCS in London shows that community and hospice staff members are the ones most likely to update the EPaCCS record followed by hospital staff and then GPs.

Most respondents were willing to share contact details (56 of 77) and information about their projects (49) and most (63) predicted they would be able to respond to the survey again in six months' time.

Next steps:

- Get a good team together – harness enthusiasm and expertise from commissioning, clinical and IT functions
- Involve key users such as ambulance trusts and those involved with people with long-term conditions
- Remember that patients will have access to records in 2015. Work with them to develop and implement these records
- Find out what you have already – learn from others' experiences
- Refer to the resources on offer, such as the NEOLCP's implementation and record-keeping guidance
- Invest time in developing and building new working relationships – it will pay off in the long run
- Remember that developing an effective electronic system requires appropriate resources and IT expertise
- Connect with others – join the NHS Networks EPaCCS project support website.

PLACE OF DEATH. EPaCCS v NATIONAL AVERAGE



Source for national figures: NEOLCIN end of life care profiles: Place of death 2008-10

The latest survey showed that, for nine sites that provided figures on place of death, deaths in hospital were around a third of the national average, deaths at home were twice the national average while deaths in hospices were more than twice the national average (see diagram above). These sites had, in total, 17,360 people on their registers. Sample sizes are still small, but these are good signs.

For one site, 80% of those on a register who expressed a preference for place of death, and had actual place of death recorded, achieved their wish.

Meanwhile in Somerset, where EPaCCS is now firmly established, there are clear signs that the use of the system can have a dramatic contribution to people's place of death.

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Data collection: the importance of getting it right

Data is central to the new systems. Here Katie Lindsey gives an update on the national information standard while below Adam Hatherly explains how a new interoperability toolkit can help different IT systems to 'talk' to each other

The end of life care co-ordination national information standard (ISB 1580) specifies the core record content to be held in EPaCCS or other end of life care co-ordination systems.

By providing a standardised data set, the standard facilitates consistent recording of key information by health and social care agencies. It also supports safe and effective management and sharing of information with the consent of the individual. And it supports transfer of information between different IT systems.

The standard was published by the Information Standards Board for Health and Social Care earlier this year. The specification provides full details of the standard's 47 data items, including SNOMED and Read codes, which are available on the ISB [website](#).

[Implementation guidance](#) and professional [record-keeping guidance](#) are also available to help implement the standard.

The standard is always kept under review and the following changes, which will be published shortly on the website, have now been agreed:

- Updating the standard with new SNOMED/Read codes

- Improved coding for data item 34: DNACPR decision made
- New subset of codes to be added to the data item 23: Formal carers involved in care: professional group
- Code changes for the data items to record first and second choices for Preferred Place of Death. These will now align with the Community Information Data set.

A further review of the standard will report to the National Information Standards Board in January 2013.

It is important for us to know if there are any issues that arise in implementation and if you have any suggestions for improvement. Please let us know:

- How the standard has helped you improve recording and communication of end of life care preferences and choices
- Your views on the implementation guidance
- Your views on the record-keeping guidance
- Comments about the data items or data codes
- Any other suggestions or comments for improvement of the standard.

Please send your comments to: information@eolc.nhs.uk

How interoperability will help share information across boundaries

There is no single IT system for EPaCCS. As a result different areas have adopted very different implementation approaches to fit with their IT strategies and priorities. These include systems from Advanced Health and Care (Adastra), TPP, McKesson, and SCR.

- look in multiple places to find information
- Lack of consistency in key functionality such as patient access, information governance, reporting and monitoring of outcomes, and supporting patients who move between localities.
- Links with other care planning solutions such as those for patients with long-term conditions.

Existing Enablers

- ISB Standard and Implementation Guidance
- Guidance on technical approaches for sharing care plans
- Guidance on secure patient registration for online services
- Digital Technology Initiatives Register

Future Enablers

- New ITK specifications to support care co-ordination
- Guidance on clinical coding for EPaCCS
- Guidance on the use of the Summary Care Record
- Guidance on Single Sign-On and NHS Smartcards

National enablers for EPaCCS that exist currently and those planned for the future

The national information standard allows for local determination and configuration of the electronic record systems and platforms, based around a core set of information which local teams can extend if required to support local needs.

The diversity of approaches presents some challenges – for example:

- Double-entry and synchronisation between systems many of which hold some or all of this already.
- Managing multiple local "hubs" – many NHS organisations span localities, requiring clinicians to

To help overcome some of these problems the QIPP Digital Technology team provides specialist technical support to local teams, including advice, guidance and local technology 'roadmaps'. It is also developing a series of interoperability specifications in conjunction with the Interoperability Toolkit (ITK) Programme. These will enable different clinical systems to share data consistently - within stringent clinical governance rules.

The work will include defining the specifications and requirements for an electronic notification between systems, and for sending an EPaCCS record, either immediately or on-demand.

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

For more information on the interoperability work visit the [ITK NHS Networks page](#) or contact qippdt@nhs.net.

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How the new system can benefit commissioners

Elaine Bayliss explains why EPaCCS is good news for commissioners looking to provide the best possible care with the most effective use of resources. She also offers a guide to how to take things forward

Patient choice lies at the heart of good end of life care. Yet, as we know, people's choices about where and how they are cared for and die are not always being achieved at the end of life.

The most worrying statistic here is that while up to 70% of people regularly say in surveys that they would prefer to die at home, the majority in fact are still ending their days in hospital. While we have made improvements in this area we still need to do more to support those people who want to be cared for or to die at home.

Encouragingly, there is growing evidence from local implementation sites that EPaCCS offers a way of meeting many more people's end of life care wishes, first through earlier identification and then better communication of these people's wishes. This, in turn, is supporting better co-ordination of care.

That should be very good news for commissioners who are simultaneously looking for high quality end of life care combined with the most efficient use of resources.

And critically, of course, the fact that anyone whose name is placed on EPaCCS has to give their consent also ensures the individual remains at the centre and there is "no decision about me without me".

EPaCCS should appeal to all clinicians because it helps to identify that small but very important cohort of patients approaching the end of life who may be known to a wide range of professionals who may not always be aware of each other's involvement.

For commissioners this should ensure that all the different organisations involved with the individual's care are talking to each other, making it more likely they will achieve fully co-ordinated care in line with clinical need and patient choice. This in turn can help to reduce unnecessary hospital admissions, decrease the average number of bed days and cut down on LAS transfers. Above all it offers the prospect of improved quality and experience of care for people and their families.

Importantly, EPaCCS' electronic data systems will provide up-to-date information on this group of people that can be invaluable for planning future care. It can,

for example, share information with consent about a patient's prognosis, make their care preferences available to all clinicians, including out of hours and emergency services, and ensure that all this information is recorded in one place in a standardised format.

Additional benefits being reported across early adopter sites include:

- 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 (see page 5)
- Facilitating wider end of life care service transformation and education programmes
- The availability of key data from EPaCCS can support QOF reports, as currently being used within the South West, and is informing future commissioning plans.

In addition EPaCCS can help ensure patient safety through greater co-ordination between professionals, improved access to key information, better communication of ADRT and DNACPR decisions, improved communication about the nature and location of anticipatory medication and the avoidance of unwanted or unnecessary interventions.

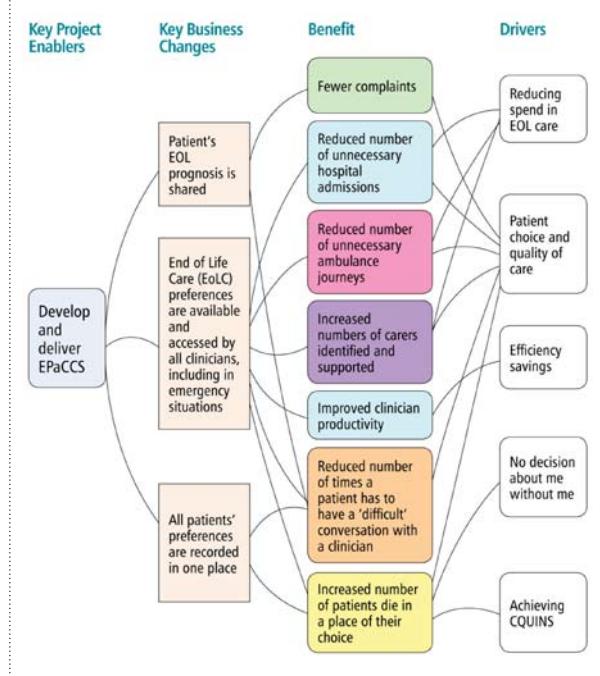
EPaCCS also supports the QIPP agenda of delivering efficiency savings while improving the quality of end of life care.

A summary of the key patient, carer and system benefits are captured clearly in the diagram (left) reproduced with kind permission from the Leeds EPaCCS Implementation team.

Next steps as a commissioner:

- Know what is going on in your area about EPaCCS development plans – identify the catalyst for change and initiate conversations with key stakeholders about implementation
- Be an intelligent customer. Ensure that requirements to share end of life care preferences across organisational boundaries via an EPaCCS and compliance with the information standard for end of life care is specified into your end of life care service contracts
- Think about hosting your own regional roadshows to initiate / support implementation
- Be aware of existing support mechanisms. Join the [EPaCCS online forum](#) for information and online support
- Let us know about your plans so that we can keep abreast of how EPaCCS is supporting your end of life care service improvements and can share your successes with others
- Download our [Making the case for change](#) paper, which captures the key commissioning drivers for implementing EPaCCS.

STRATEGIC BENEFITS OF EPACC'S



important cohort of patients approaching the end of life who may be known to a wide range of professionals who may not always be aware of each other's involvement.

ABOUT THE AUTHOR

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FOCUS ON SCOTLAND

Vision of end of life care that is driving change

In this focus on end of life care in Scotland we describe some of the major initiatives that have followed the publication of the country's national action plan in 2008. We also examine the impact of one initiative on a local GP practice

Historically palliative and end of life care in Scotland was led by visionary people, mainly from the independent hospice sector. A series of government-backed initiatives in the last decade have helped to raise its profile, leading in October 2008 to the publication of *Living and Dying Well*, the country's first national action plan for palliative and end of life care.

The plan set out the Scottish Government's vision of how palliative and end of life care should be provided and detailed actions to be undertaken to ensure the provision of quality services. *Living and Dying Well: Building on Progress* was published in January 2011 and recorded progress against these actions together with the next set of actions for NHS boards to undertake.



Living and Dying Well has already led to a number of national developments. These include the Scottish Palliative Care Directed Enhanced Service (DES), the electronic Palliative Care Summary (ePCS) and the NHS Scotland *Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Integrated Adult Policy*.

Key to the success of *Living and Dying Well* is its dual emphasis on a person-centred approach to care and care planning and on the importance of communication, collaboration and continuity of care across all sectors and at all stages of the patient journey.

Those values also form the basis of the Scottish Government's *Healthcare Quality Strategy for NHS Scotland*, launched in May 2010. The *quality strategy* recognises the importance of anticipatory approaches and advance care planning, based on dialogue between patients, families and all the individual professionals involved, as a key component of person-centred care.

Below we discuss in more detail how some of these initiatives have been implemented and embedded throughout Scotland.

THE SCOTTISH PALLIATIVE CARE DIRECTED ENHANCED SERVICE (DES)

Over the last four years the Scottish Palliative Care Directed Enhanced Service (DES) has been encouraging primary care teams to identify, plan treatment and share information with patients as they enter the palliative care phase.

In 2010 the University of Edinburgh undertook an in-depth evaluation in six practices in three health boards to understand how it was working and identify how to make it more effective. The university examined all deaths in the previous six months and interviewed staff and patients as well as observing multidisciplinary palliative care meetings

It found that in 2010 29% patients were on the palliative care register (PCR) in Scotland prior to death, with a variation between practices of 10-38%. Most people who died when on the PCR died at home while not being on the register was associated with dying in hospital.

There were many reasons for the low identification of patients. Some GPs relied on personal intuition and clinical judgement rather than specific guidance. Others were reluctant to add a patient to the register until the patient was fully aware of their prognosis. And others were uncertain about the benefits of including some patients - especially those with non-malignant conditions - on the PCR. They felt it did not change clinical care although they did acknowledge improved information-sharing and access to services.

District nurses, on the other hand, saw more tangible benefits from including patients on the PCR as it opened a gateway to services such as specialist palliative care, carer support, sitter services and priority OOH care. Patients and relatives similarly spoke positively of the personalised care and improved access when on the PCR.

The evaluation revealed that patients included in the DES greatly benefited from better co-ordinated care, with most dying at home. However, most patients who died did not benefit as they were not identified. The new version of the DES, introduced in April, now specifically guides primary care teams to identify more patients approaching the end of life, using tools such as the *Supportive and Palliative Care Indicator Tool* (SPICt).

The DES has also been adjusted so that practices reflect on 10% of all their deaths at their multidisciplinary meetings. Its facilitation is a major component of *Living and Dying Well* in Scotland. Further research is under way to enable practices systematically to identify patients by using regular computer searches and team reviews.

NHS SCOTLAND'S DNACPR INTEGRATED POLICY

In May 2010 NHS Scotland published Europe's first fully integrated national policy for Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision-making and communication in adults.

Based on previous work from NHS Lothian, the policy was a response to a specific recommendation by the Public Audit Committee following the Audit Scotland publication *Review of Palliative Care Services in Scotland*. *Living and Dying Well* also requested an integrated approach to DNACPR.

All Scottish health boards committed to implementing the policy by October 2010. Shortly after this the Children/Young People Acute Deterioration Management (CYPADM) Policy was also published and implemented across Scotland.

These integrated DNACPR policies aim to prevent inappropriate, futile and/or unwanted attempts at CPR. They are intended to help ensure an individual's wishes are followed at the end of life irrespective of whether they are being cared for in hospital, hospice, care home or in their own home.

The policies have now been implemented across all Scottish health boards, NHS 24 and the Scottish Ambulance Service. The adult DNACPR policy is supported by the Scottish Care Homes regulatory body, all Scottish Police Forces and the Crown Office and Procurator Fiscal Service.

HOW DES IS CREATING A SEA CHANGE IN ONE PRACTICE

The rolling out of Scotland's Directed Enhanced Service to local GP practices has changed the way Iain Jamieson's practice organises palliative care in a number of ways. But perhaps most importantly, it has helped to change the primary care team's mindset, he suggests.



Dr Iain Jamieson (right) with GP partner Dr Satyesh Sharma

Iain works in a small family practice in a fairly deprived area of Irvine on the west coast of Scotland with a large number of elderly patients, meaning morbidity and mortality rates tend to be high.

The introduction of DES around three years ago had the effect of "opening our eyes even further to looking at palliative care in a different way," he says.

"Although as GPs we were aware that palliative care is more than cancer care, we hadn't had any reason to come together as a group and adopt a group approach to this. So it started to unify what we should be doing."

At the same time it encouraged everyone to renew their focus on the patient and consider what might be possible to do for them. Iain says it has led, among other things, to the practice placing more patients on the palliative care register.

It also helped turn national policy into practical reality, he suggests. "We had been dimly aware of weighty tomes such as *Living and Dying Well* but in the real world of general practice policy things like that can slip under the radar. With the DES it focused our minds – it gave us a springboard and also a benchmark to measure progress."

It has also helped to widen the scope of palliative care meetings beyond those with end stage cancer to, for instance, those at high risk of repeated emergency admissions. "These are people who may be at the end stage of illness so in a way this helped tie up two ends of things."

But over and above this, it has begun a "paradigm shift" in how the practice's doctors see end of life care. Asking the "surprise question" – would you be surprised if this patient died in the next year? – has been in some ways "mould-breaking", says Iain.

"As GPs we really deal with cure and you can almost see any death as a failure." There's also a strong emotional element to many relationships. "As a GP you have usually known these people for years and sometimes you just don't want it to be true," he says. "You don't want to think this is the last year I'm going to know this person."

For this reason those conversations that first broach the subject and try to tease out people's end of life care wishes can be difficult. On the other hand, says Iain, the business-like approach of DES can be a help. "When you have to do it, it makes it a bit easier somehow. It's one of those things that you know has to be done so it spurs you into action."

He recognises there is still much to be done. The new version of DES, for example, expects practices to reflect on 10% of deaths at their multidisciplinary meetings. This has not yet been implemented, says Iain, although they do already discuss 'significant events' for palliative care patients. "This will give a different perspective to that and will probably involve more people in the meetings."

He also feels the practice needs to refine its approach to advance care planning. Although he has these conversations at the moment he doesn't always write everything up in the patient's notes. "I suppose my reservation is that I don't want to be prescriptive. I don't like to write the script before it's actually happened."

But overall he feels DES has been invaluable and is starting to introduce an "emotional sea change" within the practice. "Personally, one of the things that has changed for me is seeing end of life in a positive light as opposed to a medical failure. That is a very big cognitive leap but it's an important one."

News in Brief

Dementia progress

The three champion groups have published a [report](#) giving an update on the first seven months of the Prime Minister's Dementia Challenge. *Delivering major improvements in dementia care and research by 2015: A report of progress* outlines the groups' aims, achievements and ambitions.

Housing resource



A new resource pack is designed to encourage and support cross-sector co-operation across housing, health and social care. The [Hospital2Home](#) pack seeks to highlight the key role of housing in enabling an independent and healthy later life and offers practical ideas to support a joint approach across sectors and professions.

Integration awards

End of life care will for the first time be one of the categories in next year's Care Integration Awards, organised jointly by *Health Service Journal* and *Nursing Times*. The entry deadline is 1 February 2013 and award winners will be announced at the Grosvenor House, London on 9 July. For more information click [here](#).

King's courses

King's College London is offering intensive [short courses](#) on palliative care as well as an MSc, PG Dip and PG Cert in palliative care. The deadline for MSc applications is 30 November. For more information visit the [website](#).

Innovation appeal

The High Impact Innovation website, which was developed to support the spread and diffusion

of significant innovation across the NHS, is now seeking a second wave of high impact innovations to be carried forward into 2013/14. To submit your idea, visit the [website](#). The deadline is 20 November.

Cancer measures

The National Cancer Peer Review (NCPR) Programme has issued Cancer of Unknown Primary (CUP) Measures as part of the Manual for Cancer Services. It is anticipated these measures will be included in the 2013/14 round of peer review. The measures can be found on the CQuINS [website](#).

SCIE's new films

The Social Care Institute for Excellence (SCIE) has launched three new social care TV films on the theme of end of life care. They cover [co-ordination of care](#), [personalisation](#) - the need to discuss death and dying and [supporting staff in care homes](#).

Dementia deaths

Dementia is the second highest cause of death in women and the fifth highest in men, according to new [figures](#) from the Office of National Statistics. Dementia accounted for over 25,000 deaths among women and almost 8% of total deaths in England and Wales in 2011.

MBE for Mandy



Dying Matters and NCPC campaigner Mandy Paine has received an MBE from Prince Charles in recognition of her end of life care work. Mandy, who has COPD and needs to use oxygen 24 hours a day, featured in the NEoLCP's *Finding the words* [publication](#). Most recently, she recorded a song to raise funds for NCPC.

COMING EVENTS

GSF conference

The GSF Annual Conference, *Living well until you die*, takes place at the Quaker Meeting House, Euston Road, London on 28 November. For more details contact the GSF Centre on 01743 291 895 or email info@gsfcentre.co.uk.

Community engagement

This year's Help the Hospices conference, held in partnership with the Forum of Chairmen of Independent Hospices, focuses on community engagement and will take place at the Palace Hotel in Manchester from 29-30 November. For more information about the conference, [click here](#).

Transforming acute care

The NEoLCP and Royal Society of Medicine will be holding a one-day conference on transforming end of life care in acute hospitals on 6 December at the RSM, London. To book online go to the RSM [website](#).

Science or art?

A one-day study day entitled *End of life care in 2012: Science or Art?* takes place at 76 Portland Place, London on 7 December. The themes for the study day include new developments in end of life care, non-malignant disease and ethical issues. To find out more visit the Royal Surrey County Hospital [website](#) or email victoriarobinson@nhs.net

Community development

NHS South of England will be holding a conference entitled *Community development: The next step forward for end of life care* on 22 April 2013 at Redwood Hotel & Country Club, Bristol. For more information click [here](#) or email liz.rees@westonhospicecare.org.uk.

