Newsletter

May 2012
Theme: Housing

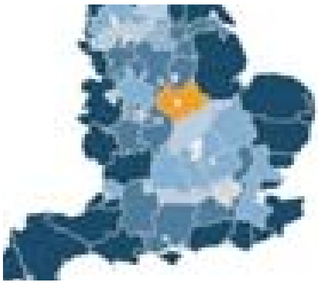
NHS
National End of Life
Care Programme
Improving end of life care

IN THIS ISSUE:

National Update

A roundup of what's happening at the National End of Life Care Programme

New local profiles



The National End of Life Care Intelligence Network (NEoLCIN) has produced a new set of end of life care profiles for every primary care trust in England.

The profiles include over 40 end of life care indicators relating to population, deaths, place of death, cause of death, deaths in hospital, care homes and end of life care spend.

Each profile gives a snapshot of the PCT's position compared with national and SHA averages. The PDF profiles will be useful for commissioners and providers when discussing local service need.

As with the current local authority profiles, the data is also presented in the InstantAtlas tool in table, chart and map formats. This online interactive data tool makes it easier to compare indicators across trusts. The information will be transferred to CCGs once the new boundaries have been finalised.

The Network is also planning new local authority profiles, which will include some social care indicators for the first time. These will be available later this summer.

If you have any comments about the profiles please contact information@neolcin.nhs.uk or use the feedback form on its website.

LGBT event

A special event showcasing research, policy and practice about end of life care for LGBT people will be taking place at the Millennium Gloucester Hotel, London on 21 June. The event, which is organised by the NEoLCP, NCPC and University of Nottingham, is aimed at those receiving and providing end of life care, especially those from health social care and third sector organisations. For more information see the Programme's website.

Autumn conference – early bird offer

Just a reminder that our annual national conference, *In the end, care counts*, takes place at the Church House Conference Centre, Westminster, London on 16 October. The standard delegate rate for the one-day event, which runs from 10.30am to 4pm, is £120 but an Early Bird Special rate of £99 is available until 30 June. For details of how to register at this special rate, click here.

The conference, which will be a combination of plenary and workshop sessions, will focus on commissioning and providing high quality end of life care. It will highlight service innovation and the critical success factors which support people to die in their preferred place of death and will be of particular interest to commissioners of services across health and social care.

The keynote addresses will be given by Jim Easton, National Director of Improvement and Efficiency, Department of Health and Professor Sir Mike Richards, National Clinical Director for Cancer and End of Life Care at the Department of Health.

Signposting flyers

The NEoLCP has created a range of new signposting materials that focus on specific areas of end of life care. The four-page flyers cover commissioning, dementia, nursing and bereavement, each highlighting key information and resources that health and social care staff may wish to be aware of. The materials are available to download here and hard copies can be ordered by emailing information@eolc.nhs.uk.

Further materials will be made available over the coming months with a focus on occupational therapy, care homes, social care and intelligence. If you have suggestions for other areas of end of life care where similar materials would be helpful, please email kate.henry@eolc.nhs.uk.

Awareness Week film

As part of its annual Awareness Week Dying Matters has produced a film highlighting the importance of making people's end of life wishes clear. *I Didn't Want That* features five scenarios, including choosing where to die, whether to be resuscitated, leaving a will and planning a funeral, and examines what can happen if people don't make their wishes known. For more about the week, see News page 3.

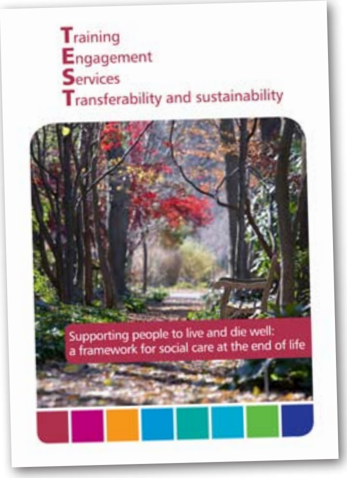
Claire Henry
National Programme Director
May 2012

News

Putting social care implementation to the TEST

The National End of Life Care Programme has produced a new report designed to help staff implement the social care framework in their area according to local need and resources.

The TEST report is based on the work carried out by eight test sites as well as feedback from a number of roadshows held last year. It offers a signposting and mapping tool designed to enhance and develop a range of initiatives for improving social care at the end of life.



Training
Engagement
Services
Transferability and sustainability

Supporting people to live and die well:
a framework for social care at the end of life

TEST is an acronym for the four broad themes that have been identified as critical to success - Training and mentoring, Engagement, Service models and Transferability and sustainability.

For instance, there were widespread calls in the roadshows for improved training and better access to training, not just for frontline staff but also for managers. The report includes a number of useful tools and resources.

Effective engagement with a range of stakeholders also emerged as a significant driver for improved end of life care. Equally, failure to engage with significant parties such as senior managers was one of the factors most likely to inhibit success.

The report also identifies a number of low cost interventions and tools that would help to embed end of life care in existing mainstream structures and service delivery models.

And it highlights the importance of transferability and sustainability in building capacity on the scale which is required for the vision outlined in the framework to be realised.

The Programme plans to use TEST to structure both work with the Association of Directors of Adult Social Services (ADASS) and support for the regions in developing local responses to implementing the framework.

To find out more click here.

Government plans new strategy for long-term conditions

The Department of Health is leading the development of a cross-government strategy for long-term conditions that will contain a range of shared goals, including early diagnosis and joined-up services based around “individuals’ biological, psychological and social needs”.

The strategy will set out a vision for how services such as health, social care, education, housing and others can work together to improve life chances and outcomes for people living with long-term conditions.

This vision will cover helping to prevent or delay the onset of conditions, preventing deterioration and helping to develop joined-up services to support people living with long-term conditions. The strategy will not cover specific details of service delivery.

Anyone wishing to comment on the plan should contact the department by 15 June. The strategy is expected to be published by the end of 2012.

Over 15 million people in England have a long-term condition. Their care accounts for 70% of the health and social care budget.

Road shows highlight the benefits of EPaCCS in end of life care

A total of 230 clinicians, IT leads, commissioners and end of life care facilitators attended NEoLCP-organised road shows in London, Leeds and Birmingham to discuss the implementation of the Electronic Palliative Care Co-ordination Systems (EPaCCS) across the country.

Participants heard from a number of early implementers about the benefits of a co-ordinated approach. The South West, for instance, now has many thousands of people on EPaCCS.

Of those on EPaCCS only between 1 and 10% are now dying in hospital, said Julian Abel, Consultant in Palliative Care in Weston super Mare (pictured). Meanwhile the number with non-cancer diagnoses has increased while the system has also encouraged standardisation of reporting.

Implementing EPaCCS offered real benefits to individuals in helping to support advance care planning and choice, he said. “If you’re going to ask people about where they want to die you have to make sure that information is available to the broader health community because otherwise you can’t respect their wishes. At the same time you need to make sure that everything is in place to help them die in their place of choice.”

It was also important to recognise that one size did not fit all and that different models would suit different localities depending on their particular population needs and IT resources.

The key, participants were told, was to get started rather than focusing on the obstacles. As Dr Abel said: “Don’t believe people who say you can’t do it – even when the reasons sound plausible. And remember: meetings can cost more than the annual revenue costs of implementing EPaCCS.”

For more information see the NEoLCP website.

GPs and public reluctant to discuss dying, says survey

More than a third of GPs have never initiated a discussion with a patient about their end of life wishes, according to a new survey of GPs and the public coinciding with this year's Dying Matters Awareness Week.

The survey by ComRes also found that only a third of GPs have asked a family member about their end of life wishes and 35% have talked to someone about their own wishes.

Just 56% of GPs have written a will, almost half (48%) have not registered to become an organ donor or do not have a donor card and only 7% have written down their end of life care wishes or preferences. The research also found 22% of people wouldn't feel comfortable discussing their end of life wishes with their GP.

Although more than half of Britons (54%) have been bereaved in the last five years and a third think about dying and death weekly, 25% said they felt uncomfortable discussing dying with those close to them. Only sex is more taboo than dying, with 39% feeling uncomfortable discussing sex with family and friends, compared with money (23%), religion (14%) politics (13%) and immigration (11%).

Despite this, most people can see the benefits of more open discussion: 78% of the public and 88% of GPs agree that if people felt more comfortable discussing dying, death and bereavement it would be easier to have our end of life wishes met.

The research also found:

- 83% agree end of life care for older people and people who are dying should be as much of a priority for the NHS as care for newborn babies. People aged over 65 are most likely to think this (94%) and people aged 18-24 the least likely (68%)
- Over half of all people (59%) say that on the whole people who are dying in Britain are not treated with dignity and respect by health and care professionals
- Just 25% of people who have been bereaved said they received the support they needed.

Hundreds of events around the country were held to mark this year's Awareness Week. They included a photographic exhibition at the Truman Brewery in London (see photo above) and the launch of the *Last Laugh* short film, featuring comedian Alexei Sayle. The winners of the first ever creative writing competition to take death as its subject were also announced.

St Christopher's new competency framework

St Christopher's Hospice in collaboration with the Modernisation Initiative (MI) has developed an end of life care competency framework for health and social care support workers as well as generalist and specialist nurses.

The aim is to create a dynamic, user friendly competency resource framework that accommodates the relationship between specialist and generalist practice in acute and community settings. It was developed by a working party with representatives from Southwark and Lambeth PCTs, Guy's and St Thomas' and Kings College Hospital. Southwark Adult Social Care also contributed.

The authors studied nationally agreed end of life care competences documents as well as those already proposed by the collaborating trusts and organisations. They have designed a resource framework which aims to reflect the interface between generalist and specialist care providers.

It is anticipated that organisations will customise this framework to provide their own competency assessment tools. It is available to download on the St Christopher's website.

Skills for Care unveils new end of life care qualifications

Skills for Care has launched new end of life care qualifications for those working in health and social care as a direct response to the NEoLCP's framework for social care at the end of life *Supporting people to live and die well.*

The framework, published in 2010, recommended the development of nationally accredited units for end of life care training on end of life care for workers in the social care sector.

The new qualifications also build on the work of *Common Core Competences and Principles for End of Life Care*, joint work carried out by Skills for Care and Skills for Health to underpin learning and development for health and social care workers in end of life care.

The new qualifications are:

Level 2 Award: Awareness of End of Life Care. A single unit award designed to provide a basic understanding of end of life care for those who work in the health and social care sector.

Level 3 Award: Awareness of End of Life Care. Made up of three mandatory units to help the learner to provide support to individuals and their families in end of life care, and in particular during the last days of life

Level 3 Certificate in Working in End of Life Care. Supports the learner to further develop their understanding of end of life care, especially around advance care planning, to develop specific communication skills and to demonstrate competence in managing symptoms and pain in end of life care.

Level 5 Certificate in Leading and Managing Services to Support End of Life and Significant Life Events. A CPD qualification to support managers to demonstrate how they can lead and manage end of life care services that promote positive experiences for individuals and their families at the end of life.

The qualifications have been developed in conjunction with a wide range of employers including Marie Curie Cancer Care, the UK Home Care Association and Barchester Care in addition to a number of hospices.

The new qualifications can be downloaded from the Skills for Care website.

Housing

This month we look at end of life care and housing – in particular extra care housing. Two years ago the NEoLCP together with Housing 21 produced a learning resource pack for those caring for, or giving support to, people with life-limiting conditions in extra care housing. In this issue we report on new research that will inform an updated version of the pack this summer.

We also discuss how many residents see extra care not as the end of the road but an opportunity for new possibilities. And we look at a scheme in the North East to help people at the end of life stay in their home longer

Achieving end of life care in extra care housing

Residents in extra care housing should be able to end their days there if they wish. Chloe Carter reports on new research that highlights what helps – and hinders – in achieving this goal

Extra care housing is increasingly understood as providing a 'home for life' for most of its residents. And that should mean that they have the right to die there as well.

With its accessible units, communal amenities and responsive, adaptable care, extra care housing is well-placed to deliver high quality, person-centred end of life care. Over 80 schemes have been funded by the Department of Health since 2004 and more public, private and third sector developments are planned.

New research by the Housing Learning and Improvement Network and the International Longevity Centre, funded and supported by the NEoLCP, is uncovering some of the factors that both enable and challenge the delivery of end of life care in this type of housing.

The results are to be included in a new version of the *End of Life Care in Extra Care Resource Pack* for extra care staff – building on the original work by Housing 21 – which will bring together updated guidance, new tools and a wealth of practice case studies.

The updated pack, due to be published this summer, is intended to share best practice to ensure that extra care housing becomes a home for life for an even greater numbers of residents. One key finding is that staff working in extra care housing are committed to enabling residents to die at home if they choose to do so.

Focus groups of nursing, care and housing staff from extra care sites across England have significantly contributed to the project. Staff candidly shared their experiences of end of life care: the successes, the regrets, the challenges and their commitment to residents' care and support. One of the comments made in the first focus group was: "I very much see that we should be offering that opportunity to any person who wants to die at home and we should go to any length possible to enable that to happen." That sentiment has been a running theme throughout the project.

Extra care housing staff find developing good working relationships with local people, organisations and services to be crucial in enabling residents to receive good quality and responsive end of life and to die at home. "Relationship-centred care" rather than "person-centred care" is perhaps how we should describe the extra care housing approach.

While the focus groups and subsequent conversations with leading experts have celebrated successes, they have also identified a number of challenges. In particular there seems to be a lack of understanding in the wider health and social care sector about what extra care housing has to offer. As a result, staff frequently have to take on the roles of advocate and negotiator to ensure residents receive the best end of life care possible.

Specific issues identified include difficulties encountered with Continuing Care Funding panels, as well as with NHS and local authority practices of hospital discharge and rehabilitation.

Some focus group participants expressed concerns about the variations in the delivery of end of life care across providers, regions and beyond. "Everything is inconsistent," one commented. "If there could be consistency nationally then that would be a really big tick for us, but every NHS, health authority, PCT and local authority all have slightly different approaches."

Staff also identified how their relationship-centred care suffered if local reorganisations took place but weren't well-communicated. The updated resource pack – which includes contributions from across the country and different types of extra care housing schemes – will be a source of information, advice and guidance on working across these boundaries.

The updated pack will support staff to prepare for some of the challenges but it will also celebrate the commitment of extra care housing staff to enabling residents to die at an extra care home if they choose to do so. The work has been supported by the research project's steering group, made up of representatives from the nursing and medical professions, extra care housing experts and dementia experts among others.

How residents live life to the full – right to the end

Staging rock concerts, sky-diving and writing their memoirs are just some of the life goals that residents have achieved. And, says Chloe Carter, they are encouraged to approach the end of life in the same spirit

Starting the conversation about end of life continues to be one of the greatest challenges for staff. However, some extra care housing sites have found innovative ways of making the conversation easier for staff and more comfortable for residents.

By encouraging residents to identify life goals, enabling them to achieve them and focusing on living life to the full, a conversation can sometimes organically lead onto discussing the residents' wishes for the end of life.

For the baby boomer generation especially, retirement housing doesn't always fit with their image of a fulfilling, adventurous or even hedonistic retirement. Those stereotypes about what it means to be elderly become even more restricting when someone approaches the end of life. However, it doesn't have to be like this. Some extra care residents and staff are demonstrating that the stereotypes can be overturned.

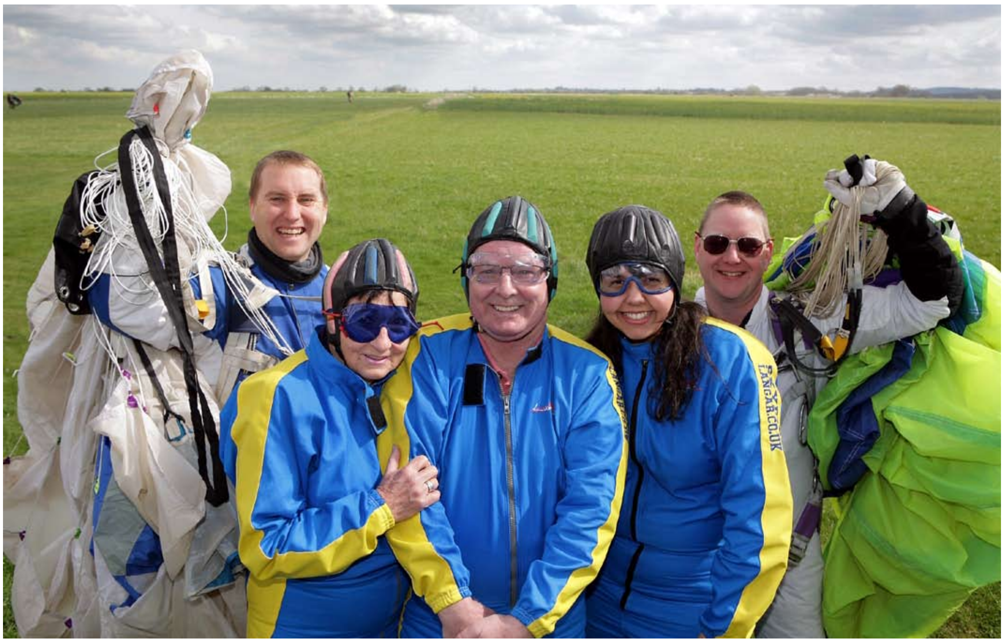


Photo credit: © ExtraCare Charitable Trust

Bill Hodder, a resident at ExtraCare Charitable Trust's Lark Hill Village, is pictured (centre) preparing with other team members to take part in a tandem parachute jump in aid of charity

Case studies collected for use in the refreshed version of the *End of Life Care in Extra Care Housing Resource Pack* include examples of residents staging rock concerts, establishing cross-regional pool tournaments, creating graffiti tags with local teenagers and going speed dating.

As well as these community activities, individual residents – including those with life-limiting conditions and/or a terminal prognosis – are achieving both long-held and newly-identified life goals. Sometimes referring to them as their 'bucket list', residents are sky-diving, driving tanks, refereeing football matches and writing their memoirs, to name but a few examples.

Extra care housing staff are enabling residents not only to live life to the full and achieve life goals – even jumping out of planes with them – but also to approach the end of life in the same spirit. Enabling a resident to determine their wishes for the end of life becomes an extension of their existing focus on outcomes, choice and control.

One participant in the focus groups summed up the staff approach: "It's about being sensitive but it's not about wrapping people up in cotton wool. It's about ensuring that people know that, irrespective of what stage of life you are at, there are still lots of opportunities and people there to support you to achieve them."

One of the challenges staff can face is convincing a resident's loved ones that these things are possible. This can be especially difficult for families who are coming to terms with their loved one being at the end stages of life. "It's just about reminding the families that the prognosis is not the end, even though they have started the grieving process of losing their parent, or sister or family member."

There are challenges and discussions to be had about living life to the full. Trying to achieve life goals is not a panacea that overcomes the difficulties of starting conversations about the end of life.

That said, the results of the research illuminated an unexpected reflexivity to the approach. As one staff member put it: "I think people can concentrate on having a sense of fun if they have made the plan and the decision that they are going to be dying – when it comes – here; that there won't be a move to a residential home and then a nursing home and then onto the hospice...I think it's very important for people who want to make decisions. Not everyone does but taking away the anxiety and indecisions about what will happen is a huge part of starting the 'rock and roll' lifestyle. "

The refreshed resource pack will contain further information, advice, resources and case studies about end of life care in extra care housing, including approaching conversations about the end of life. It will be launched this summer and will be available through the Programme's website.

ABOUT THE AUTHOR

Chloë Carter, Researcher,
International Longevity Centre
Tel: 020 7340 0440

MORE INFORMATION

For more information on extra care housing, visit the Housing LIN's website: www.housinglin.org.uk.
See also www.ilcuk.org.uk

Supporting people to stay in their own homes

A pilot project run by national housing association Home Group is helping people at the end of life to stay in their own home. As Andrew Cole reports, it could have big implications for other clients across the country

Most people say they want to die at home yet, as we all know, the majority in fact end their days in hospital. And sometimes that can be for the most trivial of reasons.

Keith Aungiers, Lead for the North East's *Good Death* Programme, gives the example of an elderly man who needed the light fixing in his home. However, instead of a handyman being brought in to sort the matter out, he was assessed as being vulnerable and admitted to hospital where he subsequently died.

"If something could be done quickly to put right what was wrong that would have allowed the person to stay at home as he wished. An unnecessary admission would have been avoided as well as saving the health services a lot of money," says Keith.

Photo credit: *The Shields Gazette*

Lynda Rann, who suffers from bronchiectasis, has a specially adapted bed to help her stay in her own home

A new project run by the national housing association Home Group within the North East is seeking to avert that scenario by helping people at the end of life to stay in their own home, if possible right the way through to their death.

The nine-month pilot, entitled *A Good Death,* began in September 2011. It is already offering a range of support to people in their homes, including repairs, adaptations and living aids, but it is hoped this will shortly extend to volunteer befriending services.

It has received funding from the North East Health Innovation Cluster, with additional funding coming from Newcastle Science City. It is also supported by Marie Curie and Age UK.

So far 46 people have been taken on to the pilot – already more than the total of 40 who were expected to access services by the time it finished in June. Referrals have come from a range of different organisations with many of the participants not being Home Group tenants.

The project is run by a support worker Jeannie Penman, whose role is to assess needs and provide resources, together with one volunteer.

It also has a small budget – amounting to £1,000 for each client on the scheme – which can be used to buy in resources or support that will help individuals to remain at home, explains Rachael Byrne, Home Group Executive Director of Care and Support.

As a result Lynda Rann, who lives in a rented flat in Jarrow and has the incurable lung disease bronchiectasis, was able to buy a specially adapted bed which she couldn't have afforded otherwise and so would probably have had to be hospitalised. She has also been provided with a Dictaphone to allow her to record some final messages for her daughter.

The organisers also purchased a dishwasher for another woman who has to sterilise her equipment 15-20 times a day. And they have bought two laptops to allow clients to get in touch with their relatives though Skype.

There have been a couple of direct referrals from hospitals wanting to discharge patients. One man was unable to return home because he had a leaky roof, for instance. "Our role was to work with the landlord to get it fixed more quickly and so get him home earlier."

The programme has also trained a couple of volunteers to act as befrienders although this initiative is at an early stage. Many of the project's clients are very isolated, explains Rachael, and the idea is that volunteers could help them with things such as cutting the grass, assisting with bills or simply being there for a chat. It would also free up the support worker to take on a more supervisory role.

After just six months it is too early to say whether the project is helping people to die at home where this is their choice. "What our clients would tell you is that it has certainly improved their quality of life," she says. Some have also been able to stay at home much longer than otherwise would have been possible – but a proper evaluation won't be available until later in the year.

If the pilot is successful Rachael hopes it may be extended to the rest of Home Group's clients across the country as well as to other housing associations in the north east. Encouragingly, the project has already started to attract interest from PCTs and local authorities elsewhere.

So far, she says, the project has been a big success. "It's one of the things that makes me feel most proud," she says. "It challenges your own personal views.

"I really do think as a landlord that provides so much care and support, this is our responsibility. We should be able to improve somebody's ability to stay at home longer. Everyone at Home Group is very proud of the scheme so far and we're thrilled that it's happening."

CONTACT DETAILS

Les Woodward, Home Group's Area Business Manager, Operations North.
- 0191 4954242 or 07739 303073

Commissioning tools: lessons from the frontline

In recent months eight sites across England have been involved in testing a set of tools to support end of life care commissioning and planning. Here three of those sites report on their experience – and the lessons learnt

The National End of Life Care Programme in collaboration with a number of partners has developed a suite of tools to support end of life care commissioning and service planning.

Between September 2011 and March this year eight sites across England have been involved in testing the tools locally, learning what they involve and how to implement them and then putting them into action. The reports of their early experiences are to be found below.

The process began when 13 local teams were invited to attend master classes last summer where they found out more about the tools and their potential. The teams were invited to come forward to test and help further refine the tools. As a result eight were selected as 'early adopters' of one of the three models. These teams were then supported by the developers to use the tools to address local issues and need.

There are three modelling tools:

- *Yorkshire and the Humber Co-Design Model*
  Uses ONS and Secondary Use Services data to look at how many people who died in acute hospitals could reasonably have ended their days in an alternative care setting. It also calculates the cost implications for a local population.
- *The Skills for Health Functional Analysis*
  This tool identifies the community workforce skills required to ensure quality care. It supports identification of appropriate workforce structures and when used with the cohort model it will also help determine end of life care costs.
- *The Cohort Model*
  A simulation tool that provides an insight into the impact of early recognition and reduced hospital admissions for a population over time, considering patterns for a key range of disease trajectories.

It is hoped these tools will provide a bridge between policy and service redesign through analytical support. They should also give commissioners and planners a better understanding of the local need for end of life care services. And they will give an indication of workforce and cost implications.

The NEoLCP developed the tools in partnership with NHS East Midlands, the Whole System Partnership, Skills for Health, NHS Yorkshire and the Humber, Kings College London and the Department of Health.

MORE INFORMATION

To find out more about the modelling tools see the NEoLCIN website

1. COHORT MODEL: PRINCIPIA AND NEWARK & SHERWOOD CCGs

Adopting the cohort modelling tool has allowed us to develop a commissioning plan for end of life care from scratch. It has also raised our awareness of the end of life care needs of the frail elderly and greatly increased partnership working with our neighbouring CCG as well as helping to share resources and information. In addition it will lead to new commissioning and has already resulted in the appointment of a community geriatrician.

Principia and Newark & Sherwood are two CCGs with a population of around 228,000, roughly a third of the county of Nottinghamshire. The team leader had already identified end of life care as one of three priority areas, along with long-term conditions and elderly care. The initial invitation to become an early adopter was therefore very timely. The opportunity for a partnership arrangement that would help the team understand local health needs and give access to information that would influence priorities was also very attractive.

The team, including GPs, chose the cohort model because it seemed to be accessible and easily understood by busy non-IT people. Its potential impact and value was clear.

As a result of adopting the new model the CCGs are already beginning to commission more respite and end of life care beds. The team is also talking to providers about their plans and has now set up a multi-partner End of Life Care Delivery Group. None of this requires additional funding since it is seen as part of our core business. Having such robust intelligence is seen as an advantage in terms of future costing plans.

The CCGs now have specific quantified goals for improving choice of place of death and end of life care outcomes for the 'frail elderly' group. They plan to set up rapid prevention services as well as integrated care teams.

The intelligence gained will also be used to show we are producing "clear and credible plans" and "working in collaboration" since using the model has required close working with GPs and supports commissioning decisions.

The team feels that being an early adopter of the cohort model has been of great benefit. Being able to analyse *local* data, rather than using someone else's data and trying to make it "fit" the local district, has led to confident and detailed commissioning. The team would like to have access to similar models in other areas such as long-term conditions.

CONTACT DETAILS

Lisa Green, Assistant Chief Operating Officer.
Newark and Sherwood CCG.
- lisa.green2@nottspct.nhs.uk
- 01636 594823

2. THE SKILLS FOR HEALTH FUNCTIONAL ANALYSIS MODEL: NORTH TYNESIDE CCG

North Tyneside CCG was selected as an early adopter for the functional analysis model. It was interested in using the tool to support its work on the feasibility of commissioning a hospice at home service in the North of Tyne area.

The group participated in two workshops following the master class to look at the functional analysis tool and to consider putting it to use in the North Tyneside, Northumberland and Newcastle areas.

This involved applying the functional analysis tool to the local area and aligning it with the cohort model, which had been calibrated to the local demographics, and then a second session with CCG members. The group was particularly interested in using the tool to better understand what was needed for a hospice at home model in terms of resources and staff competences. Our main focus was on initial discussions with people approaching the end of life and for assessment and care planning.

The benefit of the tool for us was that it could provide evidence to support the business case for a new service. We believed it would help us commission services efficiently and effectively and achieve our goal of keeping people in their preferred place of care and death.

Unfortunately, we have been delayed in taking this forward because we did not have the manpower needed for data input and analysis. In addition the requirement for varied input from our clinical and social teams was hard to justify at the time.

However, the tool has already given us a very helpful insight into what is needed to implement a hospice at home service and we have benefited from very good joint working with other groups, including service providers, commissioners and the analytical support team. This shared experience has underpinned other areas of joint working within end of life care such as service provision for care homes and the use of inpatient specialist beds.

Very recently it has been agreed we can continue to look at the hospice at home idea and we may be able to use the functional analysis tool to help with this.

✉ CONTACT DETAILS

Dr Kathryn Hall, End of Life Clinical Lead for North Tyneside CCG, Collingwood surgery, Hawkeys Lane, North Shields, North Tyneside, NE29 0SF.
- kathryn.hall@nhs.net
- 0191 257 1779

3. YORKSHIRE AND THE HUMBER CO-DESIGN MODEL: LANCASTER, MORECAMBE, CARNFORTH & GARSTANG CCC

Being an early adopter of the YH Co-Design Model has enabled the Lancaster, Morecambe, Carnforth & Garstang Clinical Commissioning Consortium (CCC) to understand more clearly how we currently treat our frail elderly population in the last year of life. It also means we have increased partnership working with the local hospital and developed service and financial plans, owned by clinicians, to support agreed priorities for patients.

The CCC is located in the North West of England. It has around 120 local GPs with a registered population of around 160,000. Our strategic aim is to reduce the number of expected deaths in hospitals and, while we have had some impact on this in recent years, we anticipate that capacity in community provision will become an increasing problem. We are also aware that our palliative care services do not extend adequately over 24 hours.

We chose the YH Co-Design Model because it is focused on practical issues. These included increasing the number of people dying in their usual place of residence, communication across providers, 24/7 care in the community and rapid discharge.

The model takes Office of National Statistics and Secondary Use Services data over one financial year for the given population. The focus is on establishing how many people who died in an acute hospital could reasonably have ended their days in an alternative care setting. It identifies these alternative pathways of care as well as the costs of that alternative. It then calculates acute bed days saved by the change.

We analysed data for the year to August 2011. This showed that 450 patients aged 75 and over had died in hospital in that period. We also learnt there had been 899 hospital admissions for that patient group in the six months before their deaths.

Commissioners developed an overarching service specification based on the findings from the workshops. Existing providers were then asked to consider how they could redesign services to be better co-ordinated and managed while adding capacity. We told them about the additional patients that the model suggested could benefit from 24-hour palliative care services in the community and asked them to offer potential solutions.

We recognise that redesign and investment in new services may not save our consortium money in the first instance. However, we are committed to ensuring that patients are transferred to hospital only when they need to be. We cannot change the landscape of provision without making an investment to change our community services.

Our chief measures of success will be increasing the proportion of people who die in their preferred place of care or appropriate surroundings and reducing unplanned hospital attendances by more effective working together.

✉ CONTACT DETAILS

- helen.mcconville@northlancs.nhs.uk

Two teams with an award-winning message

St Luke’s palliative care team and Suffolk’s ACP team have both made their mark in the last year – and been recognised for it at the *International Journal of Palliative Nursing* awards. Here they describe their work

ROYAL SURREY COUNTY HOSPITAL MULTIDISCIPLINARY TEAM

In the past year the multidisciplinary palliative care team at St Luke’s Cancer Centre (Royal Surrey County Hospital) – which won this year’s *IJPN* award – has taken a number of initiatives to improve people’s experience of end of life care. And, according to Lead Consultant Andrew Davies, they are starting to make a difference.

The initiatives include the introduction of seven-day working, a triage bleep system to speed up reviews of patients with pain or other symptoms and a review of all patients on the Liverpool Care Pathway in the Royal Surrey County Hospital Trust.

The changes, which were accompanied by an expansion of a team that now consists of three consultants, six clinical nurse specialists, four researchers and three administrative staff, were the results of recognising that the hospital needed to alter its strategy to meet growing demand, says Andrew.

“We are now much more proactive in identifying patients with needs,” he says. The team regularly visits the medical and surgical assessment units to ensure patients are not admitted unnecessarily and that where admissions are essential they remain as brief as possible.

So, for instance, its new triage system means that if there’s an urgent admission or an end of life care issue, staff can call in a member of the team to provide help at a moment’s notice.

The team is also seeing every patient on the LCP at least every other day and accompanying this with targeted education for ward staff. “When [the LCP] was first introduced it was taken up very widely and positively but as time goes by people lose a bit of that initial enthusiasm,” explains Andrew. “I think this has made a difference.”

The Royal Surrey County Hospital is one of the pilot sites for the NEoLCP’s *route to success* acute care implementation guide and currently boasts the lowest hospital death rate of all participating trusts. Over the next year it is hoping to cut hospital deaths by a further 10% while increasing home deaths by the same proportion.

Andrew already sees signs of progress. “We seem to be getting more appropriate referrals and the process is much more streamlined. Anybody with symptoms is seen the same day. And our nurses are not only sorting out people’s acute problems, they are thinking ahead and liaising with the discharge team at an earlier stage.”

CONTACT

Dr Andrew Davies
Lead Consultant in Palliative Medicine and End of Life Care, St. Luke’s Cancer Centre, Royal Surrey County Hospital, Egerton Road, Guildford, Surrey GU2 7XX

- adavies12@nhs.net
- 01483 464885

SUFFOLK’S ADVANCE CARE PLANNING TEAM

The Suffolk Advance Care Planning team, which picked up the runners-up prize at the *IJPN* awards, has set itself a demanding task – to provide education and training on end of life care and the use of new standardised ACP documentation to health and care staff across Suffolk.

That means getting its message to a very wide constituency: 62 GP surgeries, 44 district nurse teams, 88 residential homes, 46 nursing homes and 53 domiciliary care providers as well as the ambulance service, out of hours staff, rapid response teams, CNSs, community matrons and many more.

The team consists of four multidisciplinary clinical staff from two independent hospices, a Suffolk Family Carers’ trainer and an administrator. Over the past 12 months it has helped to increase quality of care and choice for people at the end of life and reduce the number of people dying in hospital.

The main vehicle for this transformation has been a training package – covering topics such as ACP, LCP, verification of expected death and communications skills - which provides a consistent approach to end of life education across all settings and can be rolled out to a large number of recipients in a short space of time. A range of full-day workshops, half-day work-based sessions and presentations is complemented by on-going individualised support through link facilitators. This has enabled the team to be flexible to the learning needs of recipients and to be responsive to the challenges and issues they encounter.

The team has also linked with a higher education provider to offer the QCF Skills for Care level 3 accredited training *Supporting Individuals at the End of Life*.

The team has helped GPs and staff from the care homes they serve to forge closer working relationships for the benefit of residents and engaged with staff who have been unwilling or unable to prioritise end of life care.

Data gathered throughout the project has shown the far-reaching impact the team has had on the skills and confidence of professionals and the experience of patients and their families at end of life. As a result more people are living and dying as they wish and in the place of their choosing.

CONTACT

Annette Villis
Lead Facilitator Suffolk ACP Project, Suffolk PCT, Papermill Lane, Bramford, Ipswich IP12 2TP

- avgsf@stelizabethhospice.org.uk

The undergraduate perspective on end of life care

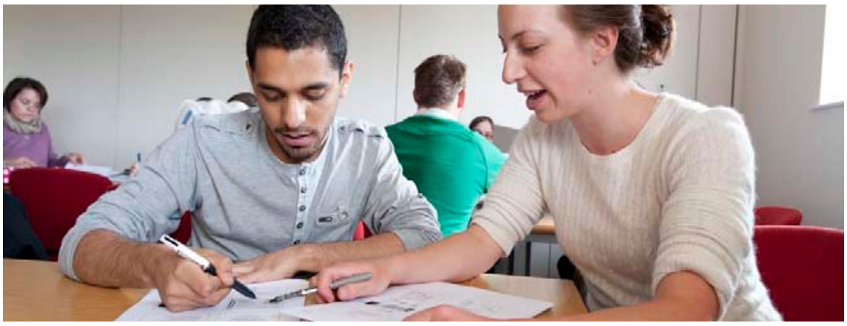
Medical, nursing and social work students at Warwick and Coventry Universities have come together to learn more about end of life care. Ann Jackson and Patricia Bluteau report on the many benefits of a multidisciplinary approach

All the evidence suggests that high quality end of life care is achieved when health and social care is co-ordinated and professionals are working collaboratively. Yet most undergraduate health and social care courses not only focus on delivering care within acute settings but also tend to consist of uni-professional learning activities.

Opportunities for students to learn with, from and about each other are limited and this could impact on their knowledge and understanding when working in inter-professional teams after qualification.

With this in mind health professionals from the University of Warwick and Coventry University, with funding from NHS West Midlands (now NHS Midlands and East), have joined forces to develop, deliver and evaluate an end of life learning resource for health and social care undergraduates.

The resource aims to generate an understanding of the importance of collaboration and team working between community-based health and social care professionals involved in delivering end of life care.



Undergraduates appreciated the chance to learn across professional boundaries

Students from three professions - medicine (3rd year graduate entry), nursing (2nd and 3rd year) and social work (1st year MA) - were invited to participate in an educational intervention designed to raise awareness of treating, delivering care, and supporting patients and relatives in their own homes as they approached the end of life.

Students met face to face for one three-hour session, which included two scenario videos (see panel), and worked in small groups of eight to 10. Groups were facilitated by trained representatives from these three professional groups.

Some of the topics covered over the day included rapport with people as they approached end of life, the GSF, Mental Capacity Act, assessing needs and preferences of both patients and carers, advance care planning, communication with other professions, identifying the dying phase, symptom management and carer needs after the death of a loved one.

To date, two inter-professional learning sessions have been completed involving 155 students (64 medical, 41 nursing and 50 social work). Students were asked to complete pre- and post-session questionnaires to evaluate the sessions.

PLANNING MRS KING'S CARE

Students watched a video featuring a fictional patient Mrs King and her son John. Mrs King, a frail 90-year-old lady with complex co-morbidities, was being discharged from hospital. The video focused on her history and needs and provided comments from each of the three participating professions who considered her to be in need of palliative care.

Students were provided with discharge letters identical to those used in practice. They were asked to consider what their professional role and responsibilities would be at the home visit following hospital discharge and to discuss these with members of their group.

In the second scenario Mrs King has deteriorated and her son offers his perspective, concerns and anxieties. Students were asked to explore how they would care for Mrs King and her son in the community, who they would need to refer to and what would be needed to enable Mrs King to remain at home until the end of her life. Finally students heard what various experienced professionals would have offered Mrs King and her son.

When students were asked to indicate how useful these two scenarios - meeting Mrs King and future planning - had been for their professional development, over 90% of responses were positive.

Overall feedback from the first learning session indicated that their confidence in all aspects of end of life care appeared to increase. They also appreciated the chance to learn across professional boundaries. As one medical student commented: "It was very useful to have a discussion with the nursing students and social workers - we all had different areas of expertise." A nursing student said it was a "great opportunity to liaise with other professionals and see their point of view and what input they would have on the patients' care".

And a facilitator noted: "I was very happy with the session I facilitated. From the moment the students entered the room they were interacting with one another which continued throughout the afternoon."

It is intended to analyse the data statistically to establish the specific benefits of the resource and continue these sessions so that future students have the opportunity to participate in an inter-professional face-to-face activity which is relevant to professional practice around end of life care.

It is envisaged that the process will be embedded within the medical student GP placement at Warwick Medical School and that other professional groups will be invited to participate. The learning resource can be delivered to undergraduate and postgraduate students.

ABOUT THE AUTHORS

Ann Jackson
Associate Professor
Interprofessional Education.
Educational development and Research, Warwick Medical School, University of Warwick.
judith.jackson@warwick.ac.uk

Patricia Bluteau
Health and Social Care
Unit, Coventry University.
p.bluteau@coventry.ac.uk

News in Brief

Long-term conditions

Early implementers are being invited to apply to test a potential new way of funding long-term conditions care. The deadline for applications is Friday 25 May 2012. For more information click here.

Dementia nurse success

An evaluation of Housing 21's two year pilot of its Dementia Voice Nurse project in Westminster shows the value of employing a dementia specialist end of life nurse in a housing and care organisation. It is estimated that the DVN service wholly or partly contributed to cost savings of more than £314,000 over the two years.

ACP study

The National Institute for Health Research is funding a new study by the University of Nottingham into the initiation of advance care planning (ACP) for those entering end of life care.

Lung cancer stats

Lung cancer is continuing to rise among women, according to the latest figures from Cancer Research UK. Almost 35,000 people in the UK died from lung cancer in 2010, 19,410 men and 15,449 women.

TSL's strategic plan

Together for Short Lives has published its strategic plan for 2012–2015, based on feedback from special events and consultation with members.

Integrated working

The Social Care Institute for Excellence (SCIE) has produced a briefing on the factors that promote and hinder joint and integrated working between health and social services.

Marie Curie research

Marie Curie Cancer Care has extended its end of life care research programme, investing a further £3 million over the next three years.

Partnership scheme

Cancer Research UK has set up a five-year partnership programme with the Royal College of GPs with the aim of improving cancer diagnosis and care. A clinical lead for cancer has been appointed to oversee the programme.

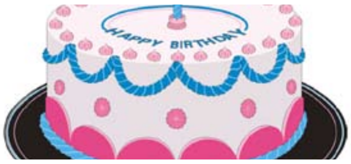
Social Care Bill

The government is to produce a draft Bill to modernise adult care and support in England, outlining what support and action people could expect from government and to help them make informed choices about their care.

Dementia ideas

The European Association for Palliative Care (EAPC) has produced a draft set of recommendations on palliative care in dementia. Following an evaluation, the EAPC hopes to publish the recommendations in a white paper between 2012 and 2013.

Anniversary issue



The Housing Learning and Improvement Network (LIN) has published an anniversary issue of its newsletter *Housing with Care Matters*. To download the newsletter click here.

Well-being boards

Health and well-being boards could be the catalyst for delivering integrated care, according to a new report, *Health and well-being boards: System leaders or talking shops?* from The King's Fund.

Dementia priorities

End of life care has been added to the list of priorities for the Dementia Challenge, the government-led programme to deliver major improvements in dementia care by 2015.

COMING EVENTS

Young adults day

The NCPC and Marie Curie Cancer Care are staging a special joint event on 28 June focusing on young adults with life-limiting conditions. Entitled *High Visibility* the event is at the Oval Cricket Ground, London SE11. If you would like to attend, please register by 31 May by clicking here, emailing publicserviceworks@gmail.com or phoning 020 8123 6954.

World Hospice Day

The theme for World Hospice and Palliative Care Day 2012 is *Living to the end – palliative care for an ageing population*. You can find out more, and register your event, on the World Hospice and Palliative Care Day website.

Draft code events

Skills for Health and Skills for Care is running a series of consultation events in June to allow people to comment on a draft code of conduct and standards for healthcare support workers and adult social care workers in England. To book for one of the joint health and social care events click here. To book for the health-only consultation events click here.

Nursing Times awards

Applications are being invited for the Nursing Times Awards 2012, which will be held in London on 31 October. To register your details click here. Deadline for submissions is 29 June.