



## Welcome

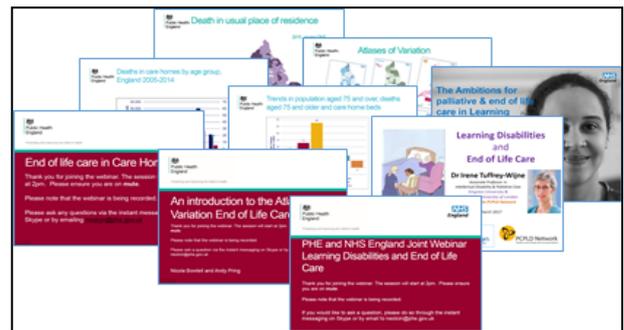
Welcome to the seventh issue of our NEoLCIN e-alert which shares the latest resources released by the NEoLCIN, recently published end of life care reports, and forthcoming events.

## Update from NEoLCIN

### End of life care webinar slide packs and recordings published in June

The NEoLCIN have recently hosted a webinar series with other colleagues in PHE. Three of the webinars from this series had a special focus on end of life care topics:

- An introduction to the new Atlas of Variation for End of Life Care
- A focus on End of Life Care in Care Homes
- PHE and NHS England Joint Webinar Learning Disabilities and End of Life Care



Over 400 of you joined us for these dynamic presentations, and we have received positive feedback. We are also aware that many

colleagues wanted to join us but were unable to. We have therefore now [published the slide packs and the recordings](#) for each of these webinars.

### Future end of life care webinars

We are pleased to announce that the NEoLCIN will host a number of End of Life Care (EoLC) webinars throughout 2017/18 with our colleagues in NHS England. Our first webinar 'Using EoLC profiles and other data from the NEoLCIN, including the new EoLC economics tool' will be on 12 July 2017. Register [here](#) or contact [ENGLAND.endoflifecare@nhs.net](mailto:ENGLAND.endoflifecare@nhs.net).

There will also be four other joint webinars hosted by NEoLCIN and NHS England and these will be:

- Electronic Palliative Care Co-ordination Systems Evaluation (October 2017)
- Atlas of Variation EoLC (January 2018)
- Compassionate Communities (February 2018)
- EoLC and Older People/Care homes (March 2018)

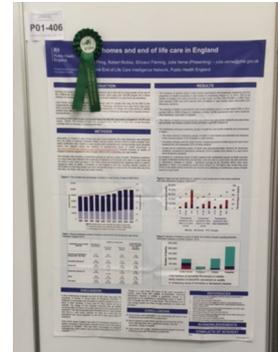
We will provide further information on these webinars in future editions of our e-alert.

## Update from the NEOLCIN continued...

### 15th World Congress of the European Association for Palliative Care (EAPC)

Professor Julia Verne attended the EAPC conference in Madrid in May. She gave an oral presentation — ‘The Effect of Planned Care on End-of-Life Outcomes and Costs in Liver Disease Patients with Diuretic Resistant Ascites. A Retrospective Cohort Study of Deaths in England’. The NEOLCIN also gave 6 poster presentations:

- Care homes and end of life care in England
- Atlas of Variation in End of Life Care for England—largest of its kind in the world
- Variation in place of death for leading causes of death, England (2015)
- Variation in number and lengths of hospital admissions in the last 90 days of life by local health administration geographies across England
- Palliative care for people with intellectual disabilities in England: How much happens, how much is needed?
- Delivering supportive and palliative care in advanced liver disease across the UK. A mixed methods study of Hepatologists’ perceptions, current service provision and future challenge



These can all be downloaded from the [NEoLCIN website](#). Our poster ‘Care homes and end of life care in England’ won a Rosset for Best in Class.

### New data added to End of Life Care Profile: Temporary care home indicator

New data has been added to our [End of Life Care Profiles](#). Our indicator on temporary resident care home deaths now has data for the calendar year 2015. You can find this indicator in our domain —‘Care home use at End of Life’.

### Updated Death in Usual Place of Residence Statistics

An update of [place of death statistics](#) has been released. This data is produced by the Office of National Statistics and includes the key indicator Death in Usual Place of Residence (DiUPR), and place of occurrence data (hospital, home, care home, hospice or elsewhere) each of which are available for various geographies including Local Authorities (LA) and Clinical Commissioning Groups (CCG). The latest figures are for financial period Q4 2015/16 to Q3 2016/17.

### Significant Reduction in Deaths in Hospital Over a Decade in an Increasingly Elderly Population Dying From Pelvic Cancer in England: A Population Based Study

The NEOLCIN team alongside Gloucestershire Hospitals have published a [paper](#) looking at pelvic cancer and end of life care.

## In the news

### NCPC publish new information for commissioners

NCPC have published '[Best Practice in care coordination for palliative and end of life care services: information for commissioners](#)'. This is an information resource to support commissioners in designing and contracting optimal care coordination system for their local areas.

### National Council for Palliative Care and Hospice UK agree merger

On Wednesday 29th March, the trustee boards of both Hospice UK and the National Council for Palliative Care (NCPC) agreed to [work towards the merger of the two organisations](#). The process of due diligence and formal merger agreement is now being taken forward.

Tracey Bleakley, Chief Executive of Hospice UK, will become the Acting CEO of NCPC from May 31st during the interim period before a merger is agreed. Hospice UK also announced that Claire Henry MBE, current Chief Executive of NCPC, will be joining the Hospice UK team as Director of Improvement and Transformation in June this year.

### Shining a spotlight on inequality—Nicola Spencer and Professor Bee Wee

In February, NHS England's End of Life Care team hosted a webinar on the topic of Health Inequalities in Palliative and End of Life Care. Unsurprisingly, given the high levels of interest in this topic, the webinar was heavily oversubscribed.

Nicola Spencer, Programme Support Manager for End of Life Care and Professor Bee Wee, National Clinical Director for End of Life Care have co-written a follow-up [blog](#) on the subject of health inequalities in palliative and end of life care, which also contains a link to the webinar recording. For more information, please contact [england.endoflifecare@nhs.net](mailto:england.endoflifecare@nhs.net)

### Palliative care development currency

NHS England has worked with providers and commissioners to undertake qualitative and quantitative testing of the [Specialist Palliative Care Currencies for Adults and Children](#). They have published a report on the outcomes of this testing and are making the currencies available to use from April 2017. They have also produced two guidance documents to help organisations who wish to use the currencies to support commissioning of these services.

### Cancer Registration Statistics, England: First Release 2015

PHE and the Office for National Statistics have published [cancer diagnoses and age-standardised incidence rates for England](#), for all cancer sites by age and sex. The results show that cancer incidence is increasing on the whole, with breast, prostate, lung and bowel cancer being the most common types.

## In the news continued...

### Government must keep pushing on with National Commitment on End of Life Care

National Council for Palliative Care's Board of Trustees chair, Baroness Ilora Finlay, [calls on the Government](#) to keep moving forward with the National Commitment on End of Life Care. [The National Commitment](#) was launched in June 2016 following a consultation.

### NCPC publish new edition of Good Decision Making

The National Council for Palliative Care have published the new edition of '[Good Decision Making: What you need to know about the Mental Capacity Act and end of life care](#)'.

### How do we support GPs providing end of life care?

The University of Bristol have written a blog '[How do we support GPs providing end of life care?](#)' It is written by Dr Lucy Selman.

### Hospice UK and NCPC publish 'No painful compromise'

A new report has been published '[No painful compromise: A guide for commissioners and providers to improve pain management for dying people at home](#)'.

### Marie Curie call for applications

Marie Curie, in partnership with Chief Scientist Office (CSO) in Scotland, the Motor Neurone Disease (MND) Association and The Brain Tumour Charity, is making over £1.5 million available this year through the [Marie Curie Research Grants Scheme](#). The deadline is 7 July 2017.

### Nurses say they don't have enough time to care for dying patients

Marie Curie has worked with Nursing Standard to [survey](#) 996 registered nurses and healthcare assistants from across the UK about the care they provide for people in the final months, weeks and days of their lives. The survey has revealed that over two-thirds of UK nurses feel they don't have sufficient time to provide high quality care for patients who are dying.

### Shifting the balance of care: Great expectations

Nuffield Trust have published [new research](#) which draws on an extensive literature review to assess the realism of the narrative that moving care out of hospital will save money. It explores five key areas: elective care, urgent and emergency care, admission avoidance and easier discharge, at risk populations, and self-care.

## In the news continued...

### Total transformation of care and support

The Social Care Institute for Excellence (SCIE) have published their ebulletin. This leads on a new paper on [Total Transformation](#) and looks at the potential of scaling up small, community-based preventative services.

### LGBT people face discrimination as they die

[Marie Curie](#) have published their findings of a new report '[Hiding who I am: Exposing the reality of end of life care for LGBT people](#)'.

### Palliative care from diagnosis to death

The British Medical Journal have published an article written by Scott Murray and colleagues on [Palliative care from diagnosis to death](#).

### The state of care in NHS acute hospitals

The Care Quality Commission (CQC) have published [The state of care in NHS acute hospitals 2014 to 2016](#). This presents findings from their programme of NHS acute comprehensive inspections.

### End of Life Care Core Skills Education and Training Framework

The new [End of Life Care Core Skills Education and Training Framework](#) has been launched – developed in partnership by Health Education England, Skills for Health and Skills for Care and supports the provision of high-quality, person centred care for individuals approaching the end of their life, and their family. The framework aims to improve the quality and consistency of end of life care training by outlining the required key skills and knowledge - ranging from general end of life care awareness to the in-depth knowledge required by specialists.

### What's behind delayed transfers of care?

Nigel Edwards, Chief Executive of Nuffield Trust explores what the data tells us about [delayed transfers of care](#) and busts some myths about how to prevent them.

### Compassion in dying launch a new and improved Advance Decision Form

Following the launch of Compassion in Dying's [Make It Your Decision](#) campaign earlier this year, a new and improved [Advance Decision form](#) has been launched - making it easier and simpler than ever for people to plan and ahead for free, and record their future care and treatment wishes in case of a later loss of capacity.

## In the news continued...

### An update from e-ELCA (End of Life Care for All)

Five new sessions have been announced by e-ELCA team:

- 1. Writing an advance decision to refuse treatment.** A [new session \(01\\_06b\)](#) complements sessions 01\_05 Advance Decision to Refuse Treatment Principles and 01\_06a Advance Decisions to Refuse Treatment in Practice.
- 2. “I’m not loveable anymore”.** [Session 03\\_28 "I'm not loveable anymore" - discussing intimacy in end of life care](#) has been significantly updated.
- 3. Intrathecal drug delivery.** This [new session \(10\\_01\)](#) provides an overview of intrathecal drug delivery (ITDD) for the management of cancer pain.
- 4. Motor Neurone Disease Learning Path.** A specific learning path: [ELCA Motor Neurone Disease Learning Path](#) has been developed and includes a number of sessions that will support professionals in caring for people living with Motor Neurone Disease (MND).
- 5. New End of Life Care Framework.** A new framework to personalise services for end of life care patients and their families has been released. Health Education England commissioned Skills for Health and Skills for Care to develop the [End of Life Care Core Skills Education and Training Framework](#), which is set to standardise training for health and social care professionals working with patients needing end of life care.

For more information on e-ELCA, please visit: <http://www.e-lfh.org.uk/programmes/end-of-life-care/>

## Events

### Transforming End of Life Care in Acute Hospitals

**Wednesday 12 July 2017**, Manchester Conference Centre, Manchester

This conference focuses on improving end of life care for people in hospital. Through national updates and learning from the NHS Transform Programme, and case studies demonstrating improvement in practice the conference will support you to meet the six national ambitions for end of life care within hospital, and improve care and outcomes for patients and their families.

For further information visit [Healthcare Conferences\\*](#).

### Cancer Survivorship Summit: Improving outcomes for people living with and beyond cancer

**Monday 25 September 2017**, De Vere West One Conference Centre, London

This national annual summit takes a practical approach to improving practice and outcomes for those living with and beyond cancer, moving from surviving to thriving. Through national updates and practical case studies the conference aims to support you to deliver on the above priorities outlined by NHS England and develop effective cancer survivorship support and services.

For further information and to book your place visit [Healthcare Conferences\\*](#).

### Non-Medical Prescribing for Pain

**Friday 29 September 2017**, De Vere West one Conference Centre, London

This important national conference provides an essential update for current and aspiring non medical prescribers on prescribing for pain. Pain is a growing area of non medical prescribing and one of the most common areas, in a survey of the Association for Prescribers members 50% of members prescribed for pain (Karen Stenner, University of Surrey). This makes it essential that non medical prescribers maintain the competence and skills to prescribe for pain in an effective way, working with patients to improve pain outcomes.

For further information and to book your place visit [Healthcare Conferences\\*](#)

### Effective Non-Medical Prescribing in End of Life Care

**Friday 6 October 2017**, De Vere West One Conference Centre, London

This important national conference provides an essential update for current and aspiring non medical prescribers on prescribing at the end of life. It is widely recognized that pain and symptom control at the end of life is not always optimal, the development of non medical prescribing has a key role in improving pain and symptom control for patients at the end of life.

For further information and to book your place visit [Healthcare Conferences\\*](#)

\*A 20% discount offer is available by quoting ref: **HCUK20NEOLIN** when booking. (Cannot be used in conjunction with any other offer. Full T&Cs available upon request.)

## Events continued

### Marie Curie Palliative Care Research Conference 2017

**Friday 6 October 2017**, Royal Society of Medicine, London

Marie Curie jointly hosts an annual research conference with the Palliative Care Section of the Royal Society of Medicine. The event is open to healthcare professionals, academics, Marie Curie staff and anyone with an interest in palliative care research.

For further information visit [Marie Curie](#).

### Rennie Grove Hospice Care Annual Conference

**Wednesday 18 October 2017**, The Clare Charity Centre, Saunderton

Rennie Grove Hospice Care's annual conference takes a slightly different perspective this year, broadening its scope to discuss issues around 'Loss, Grief and Bereavement'. Rennie Grove's education team has brought together experts in and beyond the field of palliative care, alongside people willing to share their own personal journeys, to offer delegates a thought-provoking insight into something that affects everyone.

For further information visit [www.renniegrove.org/conference](http://www.renniegrove.org/conference)

### The Mental Capacity Act & Advance Care Planning Training

**Tuesday 28 November 2017**, London

National Council for Palliative Care are running a workshop which is split into two halves, The Mental Capacity Act and Advance Care Planning. It is aimed at staff who are in a role which includes supporting people with long term and life limiting conditions in any setting including General Practitioners and District Nurses; Health or social care staff working with people with long term conditions including dementia; Any staff who wish to reflect on, develop and/or, add to existing skills and knowledge in this area of care; Commissioners, including leaders of CCGs and Health & Well Being Boards, NHS Trusts, social care and primary care, and voluntary and independent sectors; People managing services associated with long-term conditions or end of life care.

For further information visit the NCPCC [website](#).

**Suggestions for news items, updates, or events to be included in future issues please email [neolcin@phe.gov.uk](mailto:neolcin@phe.gov.uk). To join our mailing list, sign up to [e-alerts](#).**